University of Alberta

Role of Caregiver Beliefs About Alzheimer Disease in the Social Creation of Dependency Among Persons With Alzheimer Disease

by

Tiana B. Rust

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Abstract

It is estimated that over 1.1 million people in Canada will have dementia by 2038 (Alzheimer Society of Canada, 2010). In the caregiving context it is important that independence be maintained for as long as possible. Previous research has shown that caregivers can inadvertently create excess dependency (Baltes, Burgess, & Stewart, 1980) and use talk that is patronizing when their interactions with nursing home residents are guided by age-stereotypical beliefs. Social creation of dependency has not been studied in the care of persons with Alzheimer disease (AD). This study (a) assessed professional caregivers' attitudes toward aging using the Implicit Association Test and beliefs about aging and AD in the social, physical, and cognitive domains using the Beliefs about Aging and AD questionnaire (B-AD; Rust & Kwong See, 2010); (b) observed interactions between caregivers and persons with AD to find evidence for the social creation of dependency and patronizing speech; (c) explored the relationship between attitudes and beliefs and caregiver behaviours; and (d) using semistructured interviews, additionally probed caregivers' beliefs about AD, views on caregiving, and communication with persons with AD.

Caregiver attitudes toward aging were negative. Caregivers' beliefs about AD were found to be the most negative in the cognitive domain, less negative in the social domain, and the least negative in the physical domain. The observational data showed that residents' dependent behaviour secured caregivers' dependence-supportive behaviour, the dominant script that has been found among cognitively intact older adults and their caregivers (Baltes et al., 1980), and that caregivers displayed some aspects of patronizing speech in their interactions with residents. Associating AD with increased risk of injury and resistance to help is related to the dependence-support script. Caregivers' beliefs about poor long-term memory and resistance to help are related to greater use of patronizing speech. In the semistructured interviews caregivers' strategies to communicate effectively with residents with AD did not always coincide with what experimental evidence suggests is effective. Three themes emerged with regard to caregivers' goals for interactions with residents: ensuring that residents have a good day, showing residents respect, and promoting residents' independence. The implications of the study results for caregiver training to maintain independence are discussed.

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CHAPTER I:

INTRODUCTION

Dependency has been conceptualized in many ways (Baltes & Wahl, 1992; Kalish, 1969; Phillipson, Bernard, & Strang, 1986). Baltes (1996) defined dependency as a sense of helplessness and powerlessness because of the need to depend on other people to help one to do what one cannot do for oneself. Dependency can also be conceptualized as the opposite of independence (Sixsmith, 1986). People's beliefs, attitudes, and stereotypes about aging contribute to the social creation of dependency among older adults. The social creation of dependency, dependency that is created by the social environment, has been studied with participants who are alert and oriented to person, place, and time and not specifically with persons with Alzheimer disease (AD). The current study addressed this gap in the literature.

It is estimated that more than 35 million people in the world have AD or a related dementia; projections are that by 2050, the number of persons affected by these diseases will be more than 115 million (Alzheimer's Disease International, 2010). In Canada it is estimated that over 1.1 million people will have dementia by 2038 (Alzheimer Society of Canada, 2010). Nonprofessional caregivers care for persons with AD, but in large measure professional caregivers in institutions also provide care. The Canadian data show that almost half (45.4%) of those with dementia in 2008 were in long-term care (Alzheimer Society of Canada, 2010). The focus of this study is the social creation of dependency by professional caregivers in institutions. In the absence of any cure for dementia, treatment and care to improve the quality of life for persons with AD is essential. Reducing dependency that is not the result of aging and disease, but of the social environment, could lead to improvements in the quality of life for residents with AD. The main goal of this study was to provide insight into the factors that impact interactions between persons with AD and their caregivers who foster dependent behaviour.

The literature review will cover how dependency is conceptualized in old age, the role of age stereotyping, and attitudes in dependency; in particular, socially created dependency in old age. Because it is the focus of this study, I will then briefly review the characteristics of AD and dependency with AD and conclude with a review of caregivers' beliefs about AD, their perspectives on caregiving, and communication with persons with AD.

The objectives of this study were (a) to assess caregivers' implicit attitudes toward aging in general and beliefs about aging and AD specifically in the social, physical, and cognitive domains; (b) to observe interactions between caregivers and persons with AD for evidence of the social creation of dependency in behaviour and the talk addressed to persons with AD; (c) to examine the relationship between caregivers' attitudes and beliefs and dependence-supportive behaviour and talk; and (d) using a semistructured interview methodology, to acquire a greater understanding of AD caregivers' beliefs about AD and their views on caring for and communicating with persons with AD.

An examination of the social creation of dependency is important because it suggests that although intervention might not be possible for dependency that results from the inevitable age-related biological changes and disease-related changes, socially created dependency might be reduced to some degree with changes to the social environment. Therefore, research on dependency with AD in institutional care settings is important.

CHAPTER II:

LITERATURE REVIEW

The objectives of this study were (a) to assess caregivers' implicit attitudes toward aging in general and beliefs about aging and AD specifically in the social, physical, and cognitive domains; (b) to observe interactions between caregivers and persons with AD for evidence of the social creation of dependency in behaviour and the talk addressed to persons with AD; (c) to examine the relationship between caregivers' attitudes and beliefs and dependence-supportive behaviour and talk; and (d) using a semistructured interview methodology, to acquire a greater understanding of caregivers' beliefs about AD, views on caring for persons with AD, and communicating with persons with AD.

The literature review will begin by covering the different ways that dependency is conceptualized in old age. This will be followed by a review of the role of age stereotyping, age-based beliefs and attitudes, and their role in the social creation of dependency in old age. Because the social creation of dependency with AD has not been examined, a brief overview of AD and the beliefs about and attitudes toward AD will follow. I will also review the little that is known about caregivers' beliefs about AD and their perspectives on caregiving and communication with persons with AD and, finally, address communication with persons with AD.

Conceptualizations of Dependency in Old Age

Dependency has been conceptualized in many ways: lifecycle dependency, economic dependency, physical and mental dependency, dependency as the opposite of independence, and dependency as a positive gain. On a very broad level, dependency has been quantified with a dependency ratio. Lifecycle dependency considers the ratio of the number of people who are younger than 15 or older than 64 to the remaining population. The dependency ratio considers dependency to be nonparticipation in the labour force and views dependency as a social burden.

Economic dependency refers to dependence on others for income and financial support. This includes reliance on government financial support such as old age pension/social security or dependence on support from family members (Cantor, 1991; Walker, 1982).

Physical and mental dependency are the result of declines in health and cognition for which one cannot compensate and therefore that impede the ability to function. Epidemiological studies that have assessed the prevalence of dependency have operationalized it in various ways. However, these studies have all included some measure of self care, ability to carry out household activities, and mobility; and most also include measures of hearing and vision.

Dependency has also been conceptualized as the opposite of independence. Sixsmith (1986) interviewed 60 community-dwelling older adults on the meaning and importance of independence. The participants viewed independence as not being dependent on others, not being obligated to others, and as the “capacity for self-direction” (p. 341). The participants in this study placed great value on independence.

Dependency is usually conceptualized negatively; however, some view it as gain. Baltes and her colleagues (e.g., Baltes & Wahl, 1992, 1996) found that the dependent behaviour of older adults secures social contact with caregivers. Silva-Smith and Kovach (2006) argued that the dependent behaviour of some older adults (e.g., allowing health care professional to determine the best treatment for the patient) in their interactions with health professionals can be beneficial in terms of positive health outcomes.

Sometimes dependency is socially created and not solely the result of inevitable biological decline. The cultural, social, and physical environment; health status (physical, cognitive, and mental); and socioeconomic status are all contributors to dependency in old age (Berkman et al., 1993; Stuck et al., 1999). The social environment can lead to dependency when it is guided by age stereotypes. This socially created dependency can be the result of noncontingent environments (learned helplessness; Seligman, 1975), contingent environments (learned dependency; Baltes & Reisenzein, 1986), social policies and structures (structural dependency; Townsend, 1986), or exposure to age stereotypes (ageist dependency when it is the result of other people's beliefs; Alliance for Aging Research, 2003; or self-stereotype activation dependency when it is the result of the activation of older adults' internalized age self-stereotypes; Levy, 2003).

Dependency has detrimental effects; it can even affect one's desire to live. Seale and Addington-Hall (1994) conducted a study to determine the type of suffering that is most likely to influence the desire to die earlier. This desire is operationalized as people's requests for euthanasia or telling family members or friends that they want to die sooner. The family members or close friends of 3,696 people who died in 20 health authorities in England in 1990 were interviewed to determine the factors that influenced their wishes to die sooner. For the people who did not die of cancer, their high levels of dependency on others for assistance with the activities of daily living increased the odds of their wanting to die sooner by a factor of 2.6. Dependency was found to be an even greater contributor to the desire to die sooner than was pain.

Some risk factors for dependency, such as cognitive (e.g., Stuck et al., 1999) and physical health (e.g., Reuben, Mui, Damesyn, Moore, & Greendale, 1999), appear to lead to true dependency, which is purely the result of inevitable biological changes that occur with age. Others, such as socioeconomic status (e.g., Berkman et al., 1993) and the cultural, social, and physical environment, point to social causes of dependency. When dependency is the result of social/ environmental causes and is therefore not solely a result of the inevitable biological declines, there might be opportunities to reduce the excess dependency. Socially created dependency in older adults appears to be mediated by ageism and age stereotyping.

Socially Created Dependency

Age stereotyping and attitudes. Butler coined the term *ageism* in 1969 to refer to prejudice and discrimination against older persons. Negative attitudes toward older adults and discriminatory behaviour toward people based on age both reflect ageism. References to older adults frequently take the form of generalizations despite the fact that the older population is characterized by its heterogeneity (Palmore, 1990). People hold clear stereotypic beliefs that differentiate older and younger adults (Cuddy & Fiske, 2002; Hummert, 2011).

Stereotypes are rigid and oversimplified beliefs that are applied to all members of a group or category of people. By representing the typical characteristics of a group or category of people, stereotypes help to understand new individuals in terms of old beliefs, thus providing a great deal of information with a minimum amount of cognitive effort. These sets of beliefs offer insight into how others are likely to behave and how we ourselves should behave in social encounters. The difficulty is that these sets of beliefs are often overgeneralized, which helps individuals to cope with the complexity of day-to-day life but might also result in behaviours that are not appropriate when the stereotypic beliefs do not fit the situation.

Numerous stereotypes regarding aging exist in North American society (see Hummert, 2011, for a review), and the most prevalent link aging with disease, disability, dependence, incompetence, and demise (Barrett & Cantwell, 2007; Levin & Levin, 1980; Palmore, 1990; Rowe & Kahn, 1998). Although positive stereotypes of older adults (e.g., older adults are kind, wise, affluent, powerful, dependable, and happy) exist in our society (Lee, Carpenter, & Meyers, 2007; Palmore, 1990), the negative stereotypes of and attitudes toward aging are the most common (Kite & Johnson, 1988; Kite, Stockdale, Whitley, & Johnson, 2005; Stones & Stones, 1997).

A common age stereotype is that older adults are dependent on other people (Baltes, 1996; Kite et al., 2005; Stone, 2003). Baltes (1996) defined dependency as a sense of helplessness and powerlessness because of the need to depend on other people to help one do what one cannot do for oneself. Adams-Price and Morse (2009) examined people’s perceptions of older adults as recipients of help and explored how these perceptions relate to the age stereotypes of dependency. The participants rated vignettes in which either old or young people provided the same type of help to either old or young people. The helpers and help recipients were rated according to the level of considerateness and dependence. The old help recipients were rated more dependent than the young help recipients, the young helpers were rated more considerate than the old helpers, and, finally, the helpers of old adults were rated as more considerate than the helpers of young adults. This study suggests that older adults are seen to fit the dependency stereotype and appear to be dependent.

There is evidence that age stereotypes are held by children as young as two years of age (Gilbert & Ricketts, 2008; Kwong See & Nicoladis, 2010; Kwong See, Rasmussen, & Pertman, 2012; Montepare & Zebrowitz, 2002), university students (Rust & Kwong See, 2010), middle-aged adults, and older adults themselves (Hummert, Garstka, Shaner, & Strahm, 1995). Stereotypes are the cognitive component of ageism.

Attitudes, the affective components of ageism, are positive or negative evaluations of people that often predispose one to feel and behave positively or negatively toward them. In meta-analyses of the literature, Gordon and Arvey (2004), Kite et al. (2005), and Kite and Johnson (1988) found that the attitudes toward older people are more negative than those toward young adults. Attitudes toward aging have also been measured implicitly with the Implicit Association Test ([IAT] Greenwald, McGhee, & Schwartz, 1998). The logic behind the IAT is that sorting objects into one of four possible categories using only two response keys is easier and therefore faster when categories that are congruent (e.g., old and unpleasant) are paired than when categories that are incongruent (e.g., old and pleasant) are paired. The IAT effect is an overall measure that is calculated and takes into account differing reaction times and errors made between the incongruent and congruent pairings. Larger IAT effects reflect more negative associations with the target group.

Nosek, Banaji, and Greenwald (2002) investigated implicit age attitudes using an online version of the IAT through which they collected more than 600,000 responses from the general public. They found an automatic preference for younger people than for older people in the direct and indirect measures. The effect on the direct measure (explicit preference of young over old on a 5-point Likert rating scale) was much smaller than the effect size obtained from the IAT, which suggests that the IAT has the ability to resist self-presentation effects and demand characteristics. Nosek et al. (2007) found that of the 17 topics (e.g., gender, race) on which IAT data were collected, the IAT effect for age was the greatest. Only 6% of the participants showed an implicit preference for older people over younger people, and more than 80% of the respondents showed an implicit preference for younger people over older people.

Negative attitudes can lead to discrimination; that is, behaviour directed at people because of their membership in a group (e.g., Kwong See & Heller, 2004; Kwong See, Hoffman, & Wood, 2001; Kwong See & Ryan, 1999). Ajzen and Fishbein's (1980) theory of reasoned action suggests that attitudes affect behaviours in certain directions. People with negative attitudes toward a specific object most likely have unfavourable beliefs, feelings, and behaviours toward that object. Similarly, people with positive attitudes most likely have favourable beliefs, feelings, and behaviours toward such objects.

A number of characteristics have been found to predict attitudes toward older adults. These include the respondent's age, knowledge, and education on aging; contact with grandparents; contact with older adults; exposure to frail and ill older adults; and the dimensions on which the attitudes are assessed.

Respondent age. Most studies on age stereotypes have looked at young adults' attitudes toward older adults. Studies with a focus on older adults' attitudes toward older adults have shown less negative attitudes (e.g., Chasteen, 2005; Erber, Szuchman, & Rothberg, 1990; O'Hanlon, Camp, & Osofsky, 1993). For example, Rothbaum (1983, study 3) found that older participants rated the characteristics associated with elderly people more positively than did younger participants. Also, O'Hanlon et al. found that middle-aged and older students had less negative attitudes toward older adults than did younger students. Hummert et al. (1995) suggested that it is possible that older age is associated with more opportunities for learning about different kinds of older people, which thus provides more opportunity for stereotype disconfirmation.

Knowledge and education about aging. Research on the relationship between knowledge about aging and beliefs about aging has been mixed. Brooks (1993) found a negative relationship between knowledge about aging and attitudes toward aging: The more knowledgeable the participants, the more negative their attitudes. Harris and Dollinger (2001) found a benefit of formal education on knowledge of and attitudes toward older adults. Also, students in an undergraduate level course on aging displayed greater knowledge and more positive attitudes on the Aging Semantic Differential (Rosencranz & McNevin, 1969) than did students who had not taken a course on aging.

Contact with grandparents. Similarly to the findings of research on the relationship between knowledge about aging and attitudes, the findings on the relationship between contact with grandparents and attitudes toward older adults have been mixed. Whereas some studies have found that positive attitudes are related to positive contact with grandparents (Knox, Gekoski, & Johnson, 1986; Silverstein & Parrott, 1997), others have found no relation between contact with grandparents and attitudes (Caspi, 1984).

Contact with older adults. As with contact with grandparents, the findings on the relationship between contact with older adults in general and attitudes toward older adults have been mixed. Knox et al. (1986) and Schwartz and Simmons (2001) suggested that the mixed findings might be the result of measuring the quantity of contact rather than the quality of the contact. In fact, these researchers have found that the quality of the contact is a better predictor of attitudes than is quantity. Nevertheless, positive relationships have been found between the quantity of experience with older persons and more positive attitudes (Hawkins, 1996).

Exposure to frail and unhealthy older adults. The results of many studies have shown that health care personnel have negative attitudes toward older adults. For example, this was the case with medical, nursing, and radiology staff at a cancer centre (Kearney, Miller, Paul, & Smith, 2000), rehabilitation professionals (Kvitek, Shaver, Blood, & Shepard, 1986; Roberto & Carmichael-Schwab, 1995), nursing students and staff (Campbell, 1971; Lookinland & Anson, 1995; Slevin, 1991), medical students (Carmel, 1998), and staff in contact with residents at a long term care facility (Huber, Reno, & McKenney, 1992).

It has been suggested that health care personnel have negative attitudes toward older adults because they are frequently exposed to older adults who are frail and ill, and for this reason health care personnel might be particularly susceptible to negative attitudes, more so than those who do not work in the industry (Kearney et al., 2000; Palmore, 1998; Stevens & Crouch, 1995).

Dimensions on which attitudes are assessed. Most researchers assess attitudes on a global level, rather than on multiple dimensions. Stereotypes have been found to differ across contexts and life domains (Kornadt & Rothermund, 2011). Davis and Friedrich (2010) found that age bias in a group of 40-95 year olds was more negative in the physical domain than the social or psychological domains. In their meta analysis of 43 studies, Kite and Johnson (1988) found that differences in attitudes toward younger and older adults were minimized when the studies focused on personality rather than competency, which indicates that attitudes can be more or less negative, depending on the dimension being assessed.

Role of Age Stereotypes and Attitudes in Socially Created Dependency

There are five types of socially created dependency: ageist dependency, self-stereotype activation dependency, structured dependency, learned helplessness, and learned dependency. Age-based stereotyping plays a role in the creation of each type of dependency. Although I discuss the types separately for explanatory purposes, they are not necessarily mutually exclusive.

Ageist dependency. Age stereotypes can lead to what I will call *ageist dependency*—situations in which people treat older adults differently based on stereotypes of what older adults should be like. This can lead to excess dependency in a number of situations, such as when the potentially treatable symptoms of an older adult are attributed to the ‘inevitable’ results of aging.

In a randomized controlled trial, Learman, Avorn, Everitt, and Rosenthal (1990) found that depression among nursing home residents could be reduced by raising the caregivers’ expectations for the residents, which demonstrates that caregivers’ expectations can have consequences for the health of the residents for whom they care.

Ageism in health care is evidenced by reduced preventative care, reduced screening for disease and health problems, and reduced application of proven medical interventions for older adults than for younger adults, all of which can lead to premature loss of independence (Alliance for Aging Research, 2003). For example, deficits in hearing have been found to be associated with functional decline, which can result in loss of independence (LaForge, Spector, & Sternberg, 1992; Reuben et al., 1999). Treatments exist that can reverse some causes of hearing loss, and hearing aids have been shown to improve hearing ability. Despite this, the majority of older adults are neither assessed nor treated for hearing loss (Yueh, Shapiro, MacLean, & Shekelle, 2003).

The belief that old age is inextricably linked to disease and disability can result in therapeutic nihilism. Uncapher and Arean (2000) suggested that physicians' willingness to treat older adults' depression is affected by the belief that depression and suicidal thoughts are normal parts of aging, which they are not. Similarly, incontinence, despite its psychosocial costs, is sometimes not treated because it is considered a normal part of aging (Chiverton, Wells, Brink, & Mayer, 1996; Palmer, 1994). Although many older adults have physical limitations, some have few health issues (Ory, Hoffman, Hawkins, Sanner, & Mockenhaupt, 2003).

It has been implied that healthcare professionals are susceptible to ageist stereotyping because they frequently interact with unhealthy, frail, and dependent older adults. When health professionals accept these stereotypes, they can influence their behaviour (Donahue & Allegood, 1995). Health professionals who hold these stereotypic beliefs might attribute the real, potentially treatable symptoms of an older adult to the 'inevitable' results of aging and overlook the existing physical and psychiatric problems (Herrick, Pearcey, & Ross, 1997; Scheel Gavan, 2003).

Another way that age stereotyping can create ageist dependency is through the communication process. Negative expectations of the ability of older adults to communicate can be a barrier to successful communication (Caporael, 1981; Kwong See & Heller, 2004; Kwong See & Ryan, 1999). Examining stereotypes about older people's language competence, Ryan, Kwong See, Meneer, and Trovato (1992) found that both younger and older adults expected 75-year-olds to have more problems with both expressive and receptive language than 25-year-olds.

The negative stereotypes, attitudes, and beliefs about older adults of society in general and health care professionals specifically can have detrimental consequences for the ability of older adults to age healthfully. People can be influenced by negative implicit age stereotypes regardless of their explicit views on aging (Kwong See et al., 2001; Levy, Hausdorff, Hencke, & Wei, 2000). This means that individuals, unaware that a negative stereotype has been triggered, might attribute their ageist behaviours to other factors to protect their self-image. This is implicit ageism, in which one's beliefs, attitudes, and behaviours toward older adults operate without conscious awareness or control.

Many studies have shown that one person's expectations for the behaviour of another person can actually affect the other person's behaviour through the operation of covert communication processes. Hummert (2011) contended that patronizing speech is one way that age stereotypes can operate implicitly to exert an unconscious influence on behaviour.

Patronizing speech (see Draper, 2005, and Giles & Gasiorek, 2011, for reviews) is also known as baby talk (Caporael, 1981), accommodative speech (Brown & Draper, 2003), and elderspeak (Williams, Kemper, & Hummert, 2005). Patronizing speech has both verbal and nonverbal features. Williams, Kemper, and Hummert (2005) identified the following characteristic verbal features of patronizing speech:

> Diminutives: inappropriately intimate (e.g., honey, sweetie) and childish references (e.g., good girl); Inappropriate collective pronouns: addressing the older person as 'we' instead of 'you' (e.g., Are we all done our lunch?); Verbal Fluency: Speaking more slowly and using shorter sentences; Elevated pitch and volume of speech; Exaggerated intonation; Use of tag questions; Touch: pat on head, pat on hand, arm, shoulder. (p. 16)

Research has demonstrated that people are more likely to be the recipients of patronizing speech in certain situations. For example, it is prevalent in caregiving situations (LaTourette & Meeks, 2001; Ryan, Merideth, MacLean, & Orange, 1995; Salari, 2006). Persons with obvious disabilities (including cognitive disabilities) (Hummert, 1994; Kemper, Finter-Urczyk, Ferrell, Harden, & Billington, 1998) and those who live in institutions (Hummert, Shaner, Garstka, & Henry, 1998) are more likely to be the recipients of patronizing speech than are persons who do not have obvious disabilities or who dwell in the community. Salari interviewed older adults at adult day centres and found that they resented patronizing speech.

There is some evidence that caregivers' use of patronizing speech is not specific to the individual needs or abilities of the older adults for whom they care; rather, their use of patronizing speech reflects their beliefs/stereotypes about older adults. Caporeal (1981) did not find support for an association between caregivers' ratings of older adults' care abilities and their use of patronizing speech. Caporael, Lukaszewski, and Culbertson (1983), however, found that caregivers' composite ratings of several elderly listeners predicted the caregivers' beliefs about the appropriateness of patronizing speech.

Some older adults require speech accommodations for successful communication, but the result of overaccommodating speech is negative. Fifty-eight percent of older adults reported that they felt patronized, whereas less than 8% felt cared for following encounters with patronizing speech (Giles, Fox, & Smith, 1993). Kemper and Harden (1999) showed that the recipients of patronizing speech evaluate themselves as less competent. Hummert and Ryan (2001) and Savundranayagam, Ryan, Anas, and Orange (2007) showed that others also view the recipients of patronizing speech as less competent.

The communication predicament of aging model ([CPAM] Ryan, Giles, Bartolucci, & Henwood, 1986) explains how aging stereotypes and patronizing talk as a result of the overgeneralization of stereotypes can affect social interactions. This socioecological approach emphasizes the complex transactions between persons, groups, and their environments. It operates on the tenets of reciprocal determinism. Because the social and physical environment sets limits on the behaviours that can occur within it, the changing aspects of the environment result in the modification of behaviour. The CPAM is a framework for research on the occurrence and impact of negative social interactions. It suggests that age stereotype schemas, which affect one's perception of an older person and interactions with that person, are elicited when one perceives cues that are associated with old age (e.g., cane, grey hair; Ryan, Hummert, & Boich, 1995). These schemas of frailty and dependence result in patronizing speech (exaggerated tone, pitch, nonwords, and simplified structure, e.g., Ryan, Hamilton, & Kwong See, 1994) and actions that support dependence (Caporeal, 1981; Kemper, 1990). The modified speech and actions then constrain opportunities for satisfying communication and reinforce age-stereotype behaviours (Baltes, Neumann, & Zank, 1994; Whitbourne & Wills, 1993). Persons who are frequently exposed to this predicament can withdraw from activities and lose control and self-esteem (Baltes & Wahl, 1996; Kemper & Harden, 1999), which results in behaviours and characteristics consistent with the stereotypes (e.g., dependency), creates a negative feedback loop (Kemper, Vandeputte, Rice, Cheung, & Gubarchuk, 1995; O'Connor & Rigby, 1996), and becomes a self-fulfilling prophecy.

Self-stereotype activation dependency. The second kind of socially created dependency is self-stereotype activation dependency. Levy and colleagues (e.g., Levy, Slade, & Gill, 2006) conducted research that has shown that people act in accordance with stereotypes through mechanisms such as the failure to seek medical attention (Levy & Myers, 2004). Levy (2003) suggested that stereotypes are learned in childhood and reinforced and internalized through exposure to the predominantly negative stereotypes in North American culture over time. According to Levy, aging stereotypes become aging self-stereotypes once individuals reach old age. Both positive and negative aging stereotypes are learned throughout life, and both become aging self-stereotypes. There is evidence that the activation of these self-stereotypes affects older adults' functioning and can lead to dependency (see Levy, 2003, 2009, for reviews).

Levy (2000) demonstrated that priming older adults with age-stereotypes influences handwriting (an indicator of physical ability). Levy primed older adults with positive or negative age stereotypes. The handwriting style of the participants in the negative-stereotype priming group deteriorated more than that of the participants in the positive priming group. Similarly, Levy et al. (2000) found that negative age-stereotype priming increases older adults' cardiovascular stress in response to both verbal and arithmetic challenges. Research has also shown that persons who hold negative stereotypes about older adults when they were younger are more likely to suffer from serious cardiovascular disease, heart attack, and stroke when they are older (Levy, Zonderman, Slade, & Ferucci, 2009).

Levy, Slade, and Gill (2006) suggested that age stereotypes influence older adults' sensory perceptions. They found that community-dwelling older adults who hold relatively more negative age stereotypes and more stereotypes related to physical appearance at baseline had poorer screened hearing 36 months later (baseline-screened hearing, age, and other relevant variables were controlled for). Levy, Slade, and Gill (2006) suggested that this might be because people who hold more negative stereotypes and expectations about physical decline believe that hearing loss is an inevitable result of aging. Such negative expectations and beliefs can lead to their failure to seek intervention, which can therefore become a self-fulfilling prophecy.

Mock and Eibach (2011) found that middle aged and older adults' attitudes towards aging moderate the effect of subjective age on psychological wellbeing. Feeling older than one's chronological age predicts worse wellbeing among persons with more negative attitudes towards aging but not among persons with more positive aging attitudes.

The belief that older adults cannot benefit from exercise can be detrimental to independence (Rowe & Kahn, 1987). Exercise has been shown to combat age-related functional and cognitive declines. Although aging is associated with changes in physiology, there is evidence that diet and exercise can minimize the effects of some age-related disease processes (e.g., blood pressure, diabetes, respiratory functioning) and functional decline (Gill et al., 2002; Rowe & Kahn, 1987, 1998). Exercise has been shown to slow the rate of some age-related cognitive losses and the onset of dementia (Abbott et al., 2004; Laurin, Verreault, Lindsay, MacPherson, & Rockwood, 2001; Weuve et al., 2004). If older adults believe that decline is inevitable, they might not make an effort to slow the decline.

Slowed gait is frequently determined to be inevitable with increased age and indicates the general slowing related to increasing age. Gait speed is also an index of functional status (Guralnik, Ferrucci, Simonsick, Salive, & Wallace, 1995). The activation of stereotypes has been shown to affect physical capacity in the form of walking speed and gait. Hausdorff, Levy, and Wei (1999) exposed older adults to either positive or negative age stereotypes and found that the group that was subliminally primed with positive stereotypes walked faster compared to their baseline than did the group that was primed with negative stereotypes, which suggests that exposure to positive views of aging might help them to remain more independent because positive views likely intervene with age-related general slowing.

Loss of memory can lead to dependency; therefore, it is important to examine the role of cultural beliefs in memory loss. Levy and Langer (1994) assessed the attitudes toward aging and memory performance of old and young Chinese hearing, American deaf, and American hearing people. They hypothesized that because Chinese hearing and American deaf participants would have less exposure to negative aging stereotypes than American hearing participants would, they would hold more positive views about aging. They also hypothesized that older participants with more positive views about aging (Chinese hearing and American deaf) would outperform those with more negative views (American hearing) on the memory tasks. Both of their hypotheses were supported: They found that cultural beliefs about aging affect the extent of older adults' memory loss.

Levy (1996) was the first researcher to demonstrate the effects of age-stereotype priming on older adults' memory. Positive age-stereotype primes improved memory, whereas negative primes had deleterious effects. In another study Hess, Hinson, and Statham (2004) assessed the effects of beliefs on memory performance and found that the memory performance of older adults was poorer when the participants were primed with negative stereotypes than with positive stereotypes. Those primed with positive stereotypes performed at almost identical levels to those of young adults in some situations.

Dependency can also result when older adults choose not to use preventative health services. An association has been found between the belief that health problems are inevitable and the failure to seek medical care. Community-dwelling older adults who associated normal aging with cognitive and physical health problems were less likely to discuss cognitive and physical health problems with their physician than were the older adults who did not make the association (Sarkisian, Hays, & Mangione, 2002). Levy and Myers (2004) found that community-dwelling older adults with more positive self-perceptions of aging were not only more likely to seek medical care, but also more likely to report more preventative health behaviours (e.g., diet, exercise, medication compliance, and tobacco and alcohol avoidance). Cowan, Fitzpatrick, Roberts, and While (2004) demonstrated that age stereotypes can influence health perception and help-seeking behaviour. The participants primed with negative age stereotypes demonstrated more help-seeking behaviours than did those who were primed with positive age stereotypes, whereas the participants primed with negative stereotypes were more likely to show deteriorated health than were those primed with positive stereotypes. More negative aging self-stereotypes have been linked to less rapid recovery from health problems among older adults (Levy, 2003; Levy, Slade, May, & Caracciolo, 2006).

Coudin and Alexopoulos (2010) demonstrated that activating older adults' negative stereotypes has consequences for functioning that are reminiscent of helplessness and dependency. Activation of negative stereotypes led to less risk taking and lower reported subjective health and extraversion. Activation of negative stereotypes also led to more loneliness and help-seeking behaviour. These effects could increase dependency among older adults.

Ageist dependency and self-stereotype activation dependency both demonstrate that physical and mental dependency can be socially created when age stereotypes are internalized. When ageism is institutionalized, the result is structured dependency, the third kind of socially created dependency.

Structured dependency. Structured dependency is shaped by social policy and social structures. Nelson (2002) and Townsend (1986) argued that ageism has been institutionalized and woven into the social fabric, which results in dependency among older adults. Institutions that reflect ageism include retirement, pensions, and residential and community care (Townsend, 1986).

The power structure of society and social control can also lead to dependency among older adults. The social institution of retirement that uproots older adults from the workforce, often against their preference, can result in economic hardships, loss of status, and loss of the satisfaction of working, all of which can contribute to dependency. Mandatory retirement requires that employees cease working once they reach a specified age, usually 65. Until 2009 the human rights legislation in some Canadian provinces protected only workers between the ages of 18 and 65 from discrimination on the basis of age, which thus allowed employers to implement mandatory retirement policies. This has since been abolished in Canada.

Another example of structured dependency includes institutionalization. According to Statistics Canada (2002), 9.2% of women and 4.9% of men over the age of 65 resided in institutions in 2001. This number is far greater for those 85 years and older, and in 2005, 38% of women and 24% of men lived in an institution (Statistics Canada, 2005). Townsend (1986) argued that residence in an institution implies more dependency, and the individual characteristics/abilities of residents are not always considered. The structures of institutions can result in limited personal control, as can the structures of community care when the services are not aligned with clients' needs.

Beck, Heacock, Mercer, Walton, and Shook (1991) found that when caregivers do not encourage or allow persons with dementia to perform the activities of daily living to the full extent of their abilities, these persons' activities of daily living skills deteriorate more rapidly than their cognitive decline warrants. This results in less independence in performing the activities of daily living and a decreased quality of life.

Agich (1990), in an ethical analysis of autonomy in long term care, reported that true autonomy is found in the ordinary decisions of daily living rather than in monumental life-and-death decisions. To be truly autonomous, residents have to be permitted to be who they are and to make meaningful decisions about their day that allow them to express their identity. He also noted that the abilities to “perform . . . normal functions of daily living define the individual’s own sense of self-worth and identity” (p. 15).

Structured dependency can lead to economic dependency when the structure of pensions legitimizes the exclusion of older adults from other, more lucrative sources of income (i.e., employment). Structured dependency can also lead to political (restricted freedom/powerlessness) and physical dependency as a result of the structure of institutionalization or residential care. Fennell (1986) suggested that structured dependency “is the sociological counterpart to the psychological concept of learned helplessness” (p. 59).

Learned helplessness. Learned helplessness is the fourth kind of socially created dependency. Learned helplessness (Seligman, 1975; Peterson, Maier, & Seligman, 1993) is a situation in which one learns that one is helpless as a result of exposure to unpredictable and uncontrollable events. It has three components: contingency (uncontrollability: the relationship between one’s actions and their consequences must be random), cognition (an expectation of helplessness in the future), and behaviour (passive behaviour: failure to initiate actions that might result in control of a situation). According to Peterson et al., older adults can experience a loss of control because of an increasing number of uncontrollable events such as loss of employment, loss of income, and death of friends or relatives or when others respond to them in terms of old-age stereotypes rather than in a manner that is contingent on the older adult’s behaviour.

In a classic experiment, Schulz (1976) demonstrated that designing predictable or controllable significant positive events for older adults can slow or reverse the decline in physical and psychological status. The older adults in

Schulz’s study participated in one of the following conditions: *control* condition, in which they controlled the frequency and duration of visits; *predict* condition, in which they were told in advance when and how long the visits would be but could not control the frequency or duration; *random* condition, in which they were visited randomly; or *comparison* condition, in which they did not receive visits. The predict and control conditions had positive effects on the physical and psychological status of the older adults.

Rodin and Langer (1977) provided institutionalized older adults with either an intervention that increased their sense of choice and control (choosing a plant to take care of or on which of two nights to go to a movie) or one that did not (receiving a plant that a nurse would take care of and being told which of two nights to go to a movie). Soon after this intervention, the group that had a choice and control was more active and happier. Eighteen months after the intervention, these participants were also more likely to be alive and in better health.

Because of age stereotypes, people might assist older adults with tasks that they are capable of performing independently. Avorn and Langer (1982) revealed evidence that overhelping can facilitate dependency. In a randomized, controlled trial, they found that nursing home residents who were encouraged to do a jigsaw puzzle on their own were more capable than were those who received help to do the puzzle. Not only did the residents who received help perform more poorly, but they were also less confident in their ability to complete a similar puzzle and rated the task as more difficult than did the residents who were encouraged and completed the puzzle on their own, which demonstrates that overhelping can undermine older adults’ sense of control and their performance.

The passive behaviour that results from learned helplessness can lead to economic, physical, and mental dependency. Learned helplessness is caused by dependency that results from exposure to unpredictable and uncontrollable events (i.e., noncontingency); dependency that results from contingency is learned dependency.

Learned dependency. Learned dependency is the fifth and last form of socially created dependency that I will discuss. This form and the first, ageist dependency, are the focus of this research. There is evidence of a dependence-support script among institutionalized older adults in that dependent behaviour initiates social contact. Learned dependency differs from learned helplessness in that a contingent environment creates it, whereas a noncontingent environment creates learned helplessness.

Baltes, Burgess, and Stewart (1980), Baltes, Honn, Barton, Orzech, and Lago (1983), Baltes, Kindermann, Reisenzein, and Schmid-Furstoss (1987), Barton, Baltes, and Orzech (1980), and Lester and Baltes (1978) have shown that the behaviours of the staff in long term care facilities and of family caregivers (Baltes & Wahl, 1992) encourage the dependent behaviours of those for whom they are caring, thereby creating barriers to independence by creating dependency.

Rose and Pruchno (1999) compared the behaviour sequences of residents and caregivers in a nursing home and an assisted living facility. Although the stated philosophy of the assisted living facility was to support the independence of its residents, whereas the philosophy of the nursing home did not mention independence, the setting did not affect the behavioural interaction sequences.

To determine whether the dependence-support, independence-ignore script is a consequence of institutionalization or age-differentiated treatment, Baltes and Reisenzein (1986) compared the interactions of caregivers and institutionalized children to those of caregivers and nursing home residents and concluded that the dependence-support script is not the effect of institutionalization but, rather, the effect of age-differentiated treatment of residents of nursing homes by their social partners. The independent behaviour of the institutionalized children and the dependent behaviour of the nursing home residents were most likely to be reinforced.

To gain insight into the relationship between the expectations of competency and dependence-supportive behaviour, Kindermann (1993) adapted Baltes et al.’s (1987) observational coding scheme and applied it to the observation of parent-child interactions before, during, and after the children gained competence in developmental tasks (learning to walk, eat, and dress). They recorded the independent and dependent behaviours of the children and the independence-supportive and dependence-supportive behaviours of the parents. Before the children gained competence in the tasks, the parent-child interactions were nurturing, and the parents demonstrated dependence-supportive behaviour. While the children were gaining competence in the tasks, the parent-child interactions complemented each other: The parents supported both independent and dependent behaviour. After the children gained competency in the task, the parents rarely showed contingent support when the children were performing the tasks. The dependence-support script for institutionalized older adults appears similar to nurturing parent-child interactions, which suggests that older adults are not expected to be competent.

In a study to determine why the behaviours of the staff of long term care facilities encourage the dependent behaviours of those for whom they care, Wahl (1991) interviewed staff caregivers and older adults who were receiving care in the community and in an institution to elicit their causal explanations of dependent and independent self-care behaviours. The older adults described themselves as competent more often than the staff did and attributed a lack of competence predominantly to the staff. The staff attributed the older adults' lack of competence more often to the characteristics of the older adults than did the older adults themselves. Also, the staff attributed the older adults' competent self-care behaviour to the staff themselves. Wahl argued that the causal explanation style of staff regarding the lack of competence is important because if professional caregivers blame residents for not demonstrating their competence, the caregivers will see no reason to change the way that they currently administer care.

Learned dependency stands apart from the other forms of socially created dependency because dependency is considered a loss and a gain, whereas all other forms consider dependency only a loss (Baltes, 1996). With learned dependency the older adult is able to gain control over the social environment. As evidenced in the dependence-support script, dependent behaviour is instrumental in securing social contact (Baltes, 1996). Although our culture values independence and many older adults fear becoming dependent, learned dependency serves a purpose. However, it would be ideal to secure social contact without risking excess disability.

Excess dependency can be reversed (Baltes & Wahl, 1996; see Flora, 2004, for a review) and can have an impact on self-esteem. Blair (1999) demonstrated that a group of cognitively intact nursing home residents whose caregivers were trained to promote independence could perform more of the activities of daily living and had higher self-esteem than did a group whose caregivers did not receive training.

Most of the work conducted in the area of learned dependency was generated in the 1980s and 1990s. The early work documented the phenomenon in nursing homes (e.g., Lester & Baltes, 1978), later work documented it in different settings (Baltes & Wahl, 1992; Rose & Pruchno, 1999), and the most recent studies have focused on reversing learned dependency (see Flora, 2004, for a review).

Socially Created Dependency in AD

Learned dependency has been studied in nursing homes with older adults who are oriented to person, time, and place, but not with persons with AD. This important gap in the research needs to be addressed. In the absence of a cure for AD, maintaining the quality of life for persons with AD for as long as possible is essential. Reducing dependency that is not the result of aging and disease but, rather, the result of the social environment, could improve the quality of life of residents with AD.

Characteristics of AD. AD is characterized by progressive memory loss, and other symptoms can include coordination problems, loss of cognition (person, place, time), impairment of judgment, behaviour changes, personality changes, physical changes, and the inability to perform normal activities of daily living (Albert, 2008). Although the progression of the disease is generally very gradual and symptoms are slow to appear, the rate and nature of the progression can vary tremendously from one individual to another. Symptoms can occur at different times for different individuals, and not everyone will experience every symptom. Because of this variability from individual to individual, an individualized approach is necessary to provide quality care that helps individuals to maintain their remaining abilities and dignity as the disease progresses (Rader, 1995). Beard, Fetterman, Wu, and Bryant (2009) conducted focus groups with persons with mild cognitive impairment and AD and their family caregivers. One of the themes that emerged was aging well. The affected individuals and their caregivers indicated that independence and not having to depend on others are related to aging well.

Persons with AD have both expressive and receptive communication difficulties. The ability of caregivers to communicate effectively with residents with AD is important to meet their physical and social needs (Hopper, Bayles, Harris, & Holland, 2001), which thus minimizes their dependency. Studies have shown that the quality of life of persons with dementia can be improved when caregivers are trained in and use effective communication strategies (McCallion, Toseland, Lacey, & Banks, 1999; McCallion, Toseland, & Freeman, 1999). Ripich (1994) identified the characteristics of communication for persons with AD (Table 1). The greatest difficulties are in the pragmatics and semantics of communication (Bayles, 1982).

Table 1

Characteristics of Communication in AD

Stage	Pragmatics	Semantics	Syntax	Phonology
Early	• Some difficulty with storytelling and giving instructions • Many requests for clarification and confirmation • Some problems with pronominal referencing	• Compromised word fluency and word finding • Comprehension of abstract or complex concepts	• No errors	• No errors

Middle	• Difficulty with topic maintenance • Difficulty with pronominal referencing	• Use of circumlocutions and empty speech • Poor word fluency	• Some grammatical errors • Some difficulty with complex structures	• No errors
Late	• Not coherent, mute in final stage, prosody intact	• Echolalia, palilalia, paraphasia, poor comprehension	• Grammar generally preserved • Poor comprehension of grammatical structures	• Occasional errors

The communicative difficulties that caregivers encounter with residents with AD should be the result of the characteristics in Table 1.

Strategies from the FOCUSED approach to communication with persons with AD (Ripich, 1994) include (a) face to face: maintaining the attention of and eye contact with the person with AD; (b) orientation: repeating key words and sentences and giving the person with AD enough time to comprehend what has been said; (c) continuity: maintaining a topic of conversation for as long as possible and preparing the person with AD for a new topic; (d) unsticking: suggesting words when a patient with AD searches for a word or repeating the sentence with the word on which he or she is stuck; (e) structure: asking questions that can be answered with a yes or no response or offering only two options; (f) exchange: asking questions that the person with AD can easily answer; bringing up pleasant, normal topics; and maintaining a normal exchange of ideas; and (g) direct: keeping sentences short, direct, and simple; using aids such as pictures and body language/gesture; and using nouns instead of pronouns.

Training in the FOCUSED approach and knowledge about communicating with persons with AD have improved the communication between caregivers and persons with AD (Ripich, 1994), which suggests that, without training, caregivers are either not aware of all of the strategies or are aware of but are not using the strategies to the extent that they could. Learning more about what caregivers consider useful strategies, which ones they employ, and how they might be similar to or different from the literature's suggestions is of interest, as are the difficulties that caregivers face in communicating with residents with AD.

Tuohy (2003) observed nursing students' interactions with older adults who were receiving long-term or respite care and interviewed the students with the goal of understanding how student nurses communicate with older people. Tuohy found that nursing students found it difficult to communicate with cognitively impaired persons. The following quotation highlights a difficulty and the student's way of coping with it: "She has absolutely no concept of where she is or the time or who we are. . . . That's very, very difficult and I find it hard to communicate with her. . . . I try to smile and keep everything positive" (p. 23). The student nurses in this study believed that it is important to show older adults respect in communicating with them to maintain their well-being. Tuohy found that the student nurses held some beliefs about older adults that might have affected the way that they communicated with older adults. These

> ranged from believing that older people love to talk, were lonely, demotivated, lacked autonomy, and the notion that older people could be demanding and manipulative. Some of the students felt that older people had no control over their lives and that this affected their desire and/or ability to communicate. (p. 23)

A deeper understanding of caregivers' stated beliefs about AD and how these beliefs relate to their views on caring for people with AD would add to the literature.

Cunningham and Williams (2007) reported an association between patronizing communication and disruptive behaviours (e.g., crying, pulling away) among persons with dementia. Williams, Herman, Gajewski, and Wilson (2009) found that residents of an Alzheimer care centre were more likely to resist care or behave disruptively when they were addressed in a patronizing manner than in a nonpatronizing manner. Nevertheless, patronizing communication with cognitively impaired older adults has been deemed more acceptable than with cognitively alert older adults, as well as with institutionalized older adults than with community-dwelling older adults (LaTourette & Meeks, 2001; Ryan & Cole, 1990).

Staff who use patronizing speech might reinforce the dependency and increase the social isolation of the residents for whom they care, which can precipitate physical, cognitive, and functional declines (Ryan et al., 1986). Small, Gutman, Makela, and Hillhouse (2003) demonstrated that slowing down speech, one aspect of patronizing speech, is not effective in communicating with persons with AD. However, whether other aspects of patronizing speech have a negative effect on residents with AD is largely unknown. It is also not known whether persons with AD have the same insight as healthy older adults do into the inappropriateness of patronizing speech. If not, it might not become a self-fulfilling prophesy. Younger adults who believe that older adults are less benevolent and vital have reported avoiding communication with older adults (Giles, Dailey, Sarkar, & Makoni, 2007; McCann, Dailey Giles, & Ota, 2005); whether caregivers with this belief are more likely to use patronizing speech in interacting with persons with AD is unknown. Examining caregivers' patronizing speech in caring for persons with AD and the role of beliefs about AD in the use of patronizing speech is a first step.

Because it has been argued that age-based beliefs (stereotypes) and attitudes mediate the social creation of dependency in cognitively intact elders, beliefs about and attitudes toward AD are assumed to mediate dependency in the AD context. Compared to the large body of literature on age-based beliefs in the absence of disease, beliefs about and attitudes toward AD have been largely overlooked:

> The adverse effects of negative self-stereotyping and stereotype threat with regard to ageing in physically healthy people have been well documented, but there has been lamentable little attention to, and research concerning, the effects of these processes on people with AD. (Scholl & Sabat, 2008, p. 104)

Attitudes toward persons with AD. Kahana and Kahana (1996) explored attitudes toward persons with AD by comparing the attitudes of nursing home employees toward the well elderly, the physically ill elderly, and persons with AD. They used a sample of items from Rosencranz and McNevin's (1969) semantic differential scale as a measure of attitudes. These items included good, optimistic, warm, pleasant, wise, generous, friendly, cooperative, acceptable, and profit from help. The respondents indicated their degree of agreement with 10 pairs of attributes on a 4-point scale for each of the three target groups. The results indicate that the overall evaluations of the three groups were the most positive for the well elderly, more negative for the physically ill elderly, and the most negative for the persons with AD. Kahana et al. observed this pattern for all of the items except for optimistic. They predicted more positive evaluations of the AD target from the participants' perceived self-efficacy in dealing with persons with AD, as measured by a three-item scale (how competent, effective, useful).

Beliefs about AD. Only a few researchers have assessed beliefs about AD. Blair, Berry, and Lee (2009) found that both young and old adults had differential perceptions of normal and pathological aging (AD). The participants rated the main character in a vignette (either a healthy older adult or a person with AD) on activities of daily living, instrumental activities of daily living, and memory ability. The ratings were higher for the older adult than for the person with AD.

The B-AD, a tool to measure beliefs about aging and AD in the cognitive, social, and physical domains has been developed (Rust & Kwong See, 2010). The B-AD is similar in structure to the Language in Adulthood Questionnaire (Ryan et al., 1992), which assesses the perceptions of and beliefs about the language abilities of young and old adults. The participants rate their beliefs about typical 25-year-olds (young targets), typical 75-year-olds (old targets), and typical institutionalized persons with AD (AD targets) on 46 statements (12 cognitive, 12 physical, and 22 social). Examples of the items/statements used include "Have good memory for events that happened to them long ago" (cognitive); "Are physically active people" (physical); and "Are kind people" (social). The items are presented in the same random order for all target conditions, and the participants indicate their degree of agreement with each statement on a 7-point Likert scale ranging from 1 (*strong disagreement*) to 7 (*strong agreement*). The questionnaire responses are recoded so that the higher scores (7) always represent the more positive beliefs on each item and the lower scores (1) always represent the more negative beliefs. For example, *Strongly Agree* (7) on the item “Are benevolent people” indicates a positive belief, so this item would not need to be recoded. Alternatively, *Strongly Agree* (7) on the item “Are stubborn people” indicates a negative belief, so the participants’ responses on this item would be recoded so that 7 would be recoded to 1, 6 to 2, and so on. Thus a high score always indicates a positive belief in each domain. Rust and Kwong See’s reliability estimates (Cronbach’s alpha) for the cognitive, social, and physical domains were .78, .87, .77, respectively, for the young targets; .79, .85, .86, respectively, for the old targets; and .68, .85, .83, respectively, for the AD targets.

Rust (2005) used the B-AD to compare the beliefs of 53 caregivers of persons with AD with those of 53 noncaregivers (students). Both groups’ beliefs about aging were the most negative in the physical domain, less negative in the cognitive domain, and the least negative in the social domain. Generally, the cognitive beliefs about AD were the most negative, the social beliefs were somewhat less negative, and the physical beliefs were the least negative (and positive for students). Because these results were the foundation for the current study, I will explain the beliefs in each domain.

Beliefs about AD in the social domain. Overall, both caregivers and noncaregivers had more negative beliefs about persons with AD than about typical 75-year-olds in the social domain (Rust, 2005). The degree to which the caregivers’ and noncaregivers’ beliefs about AD in the social domain were negative did not differ; however, the pattern of beliefs did. The noncaregivers’ beliefs were more negative for all social constructs for AD, whereas the caregivers saw no difference between persons with AD and typical 75-year-olds in terms of benevolence or social interaction. This suggests that working with people with AD leads to the belief that people with AD are favourable to social interaction, whereas those who do not work with people with AD believe that people with AD withdraw.

Beliefs about AD in the physical domain. Overall, the caregivers' and noncaregivers' beliefs about AD in the physical domain differed markedly (Rust, 2005). The caregivers had more negative beliefs about persons with AD than about typical 75-year-olds, whereas the noncaregivers had more positive beliefs about persons with AD than about typical 75-year-olds. The pattern of beliefs also differed greatly between the caregivers and noncaregivers in that the caregivers did not see any difference in physical abilities between typical 75-year-olds and persons with AD, except that persons with AD are at greater risk for physical injury. The noncaregivers, on the other hand, believed that persons with AD demonstrate a higher level of activity and better sensory functioning than do typical 75-year-olds (except for taste, in which they believed that there is no difference). The noncaregivers also believed that persons with AD were no more likely than typical 75-year-olds to be at risk for injury.

Beliefs about AD in the cognitive domain. Both the caregivers' and the students' beliefs about typical 75-year-olds were more positive than their beliefs about persons with AD on the items in the cognitive domain. The patterns of response on all cognitive constructs were the same for both caregivers and noncaregivers, which suggests that they see changes in the cognition of persons with AD in the same way (as declining).

The Current Study

Objective 1 and predictions. The first objective of this study was to quantitatively assess caregivers' beliefs about AD and aging in the social, physical, and cognitive domains and their attitudes toward aging. I assessed the attitudes toward aging by using the IAT (Greenwald et al., 1998), which I administered in a standard way; although it does not ask specifically about AD, persons with AD are also typically old. I predicted that the caregivers' attitudes toward aging would be negative because they are frequently exposed to impaired older adults (Kearney et al., 2000; Palmore, 1998; Stevens & Crouch, 1995).

I assessed the stereotypical beliefs by using the B-AD measure that Rust (2005; see also Rust & Kwong See, 2010) developed and predicted that the caregivers' beliefs about AD would follow the same pattern of results that Rust obtained.

Objective 2 and predictions. The second objective of this study was to observe caregivers and persons with AD to document the social creation of dependency for institutionalized persons with AD. I observed caregivers and residents with AD during a meal-preparation task and captured and coded the behavioural repertoire. I predicted that I would also find the dependence-support script that is evident in older adults who are oriented to person, time, and place and their caregivers in nursing homes, homes for the chronically ill, and at home (Baltes et al., 1980; Baltes et al., 1983; Baltes et al., 1987; Barton et al., 1980; Lester & Baltes, 1978) in persons with AD and their caregivers in Alzheimer care centres.

I also captured the verbal interactions to document the presence of patronizing speech directed at persons with AD. The features of patronizing talk that I coded included diminutives, tag questions, and utterance length. Kemper (1990) and Williams, Kemper and Hummert (2003) found that these features are modifiable with training, and for applied relevance I coded these particular features of patronizing talk. As is evident in the talk between caregivers and care recipients, I expected that the caregivers in their interactions with residents would demonstrate the features of patronizing speech.

Objective 3 and predictions. The third objective of this study was to examine the relationship between caregivers' attitudes and beliefs and the interactions between caregivers and persons with AD. I followed Rust and Kwong See's (2010) beliefs about aging and AD in the cognitive, social, and physical domains as predictors and then examined selected individual beliefs (constructs) that are intuitively thought to be predictors. I predicted that the caregivers' attitudes toward aging, beliefs about aging and AD, and characteristics that are related to attitudes toward aging would be related to the interaction patterns that support dependency and that caregivers with more negative beliefs about AD and more negative attitudes toward aging would use more patronizing speech.

Objective 4 and predictions. The caregivers who spend the most time with the residents of continuing care facilities/nursing homes with AD are resident companions, health care aides, nurse aides, nursing assistants, and nursing attendants. The role of these caregivers involves providing personal assistance and support services to residents under the supervision of a nurse or heath professional. These caregivers offer physical, social, and emotional support to residents, and their duties include assisting residents with grooming, bathing, dressing, toileting, personal hygiene, and therapeutic activities. Caregivers communicate with residents and observe and report on their condition (Government of Alberta, 2011). Some caregivers receive on-the-job training, and others have taken a course. Alberta Health and Wellness has developed a standard curriculum for health care aide training that takes 15 to 27 weeks at various postsecondary institutions.

Little is known about the stated beliefs of caregivers of persons with AD about AD and their views on caring for and communicating with these persons. In a small pilot study Beach and Kramer (1999) investigated caregivers' perspectives on communication with persons with AD in residential facilities. Gaining residents' compliance and learning the language were the themes that emerged from their study.

The fourth study objective was to describe and acquire a greater understanding of the stated beliefs of caregivers of persons with AD about AD and caregiving. Using a semistructured interview approach, I probed caregivers' philosophy on caring for persons with AD and communication with persons with AD. I then compared their caregiving philosophy with the observed behaviour sequences and their stated beliefs with the beliefs questionnaire (B-AD) and predicted that caregivers' stated beliefs about AD would correspond with the beliefs identified in the beliefs questionnaire.

Significance. Baltes et al. (1980), Baltes, Barton, et al., (1983), Baltes et al. (1987), Barton et al. (1980), Lester and Baltes (1978), and Baltes and Wahl (1992) examined the reinforcement of the dependency of elders who are not demented. The social creation of dependency when residents have dementia has not received a systematic focus. The goal of many continuing care facilities is to maximize the independence of their residents. Maximizing the abilities of persons with AD for as long as the disease allows is desired and can be accomplished by reducing the socially created dependency. Likewise, positive expectations can enhance communication. Therefore, understanding the stereotypes about aging and disease is of great importance.

CHAPTER III:

METHOD

Participants

I recruited resident companions (caregivers) and persons diagnosed with possible or probable AD (residents) from three Alzheimer care centres in Edmonton and surrounding area. Resident companions' duties are to help residents "to enjoy a lifestyle designed to encourage independence, dignity and maintenance of functional ability by providing support with activities of daily living, household chores and social needs" (CapitalCare, 2010, para. 1). These Alzheimer care centres are family-style living environments for people with AD. They include McConnell Place North, McConnell Place West, and Strathcona Alzheimer Care Centre. Each centre has 36 supportive-living beds and is organized into three "houses" of 12 residents each that have a kitchen, dining room, living room, and laundry room. Each centre has a common great room, a large outdoor area, a sitting area with fireplace, and a family dining room, which has a dining table that seats six, a fridge, a stove and oven, and a dishwasher. Families use the family dining room when they visit, and the centre also uses it for its activities. The residents of the three Alzheimer care centres can participate in activities that they might have done when they lived at home, such as laundry, gardening, cleaning, cooking, and baking. These centres emphasize the maintenance of their residents' independence and dignity.

Caregivers. The caregivers received a $25 honorarium for completing the beliefs questionnaire and the IAT and $115 ($30 honorarium and $85 for transportation; i.e., taxi, bus, personal vehicle, etc.) for participating in the observation and interview. Twenty-six institutional caregivers of persons with AD volunteered to participate in the study. According to their self-reports, the caregivers had worked with people with AD from 3 months to 30 years (*M* = 7.1 years, *SD* = 6.3) and with seniors from 3 months to 30 years (*M* = 11.2 years, *SD* = 8.7); they ranged in age from 18 to 57 years (*M* = 47.2 years, *SD* = 11.9) and were all female (the majority of caregivers in these centres are female). I correlated their experience with older adults and persons with AD with their age ($r = 0.46$, $p < 0.02$; $r = 0.50$, $p < 0.01$, respectively). All participants gave their consent prior to beginning the study.

Residents. I recruited 26 residents of the three Alzheimer care centres that CapitalCare operates in Edmonton and the surrounding area. They included only female residents with AD to control for differences in interactions that might be a result of the resident's gender, and I paired caregivers with residents whom they did not know to control for familiarity. All of the residents were diagnosed with possible or probable AD (as indicated in the residents' charts, based on the diagnosis of geriatricians or family physicians). The residents' guardians/ substitute decision makers signed informed consent forms, and I then sought the assent of the residents.

The Research Unit staff assess the residents' cognitive and functional abilities annually, and I collected them from the residents' charts within one and six months of when the assessments were done. I obtained the functional ability scores from the Functional Autonomy Measurement System ([SMAF] *Système de mesure de l'autonomie fonctionnelle*; Hébert, Guilbault, Desrosiers, & Dubuc, 2001), a clinically based instrument used to measure older people's disabilities and handicaps in the areas of activities of daily living, mobility, communication, mental functions, and instrumental activities of daily living. The more negative the score, the poorer the functional ability (-87 is the worst possible score; it indicates complete dependence in all activities. 0 is the best possible score; it indicates complete independence in all activities). SMAF scores correlate with nursing care time and the cost of care. I obtained the cognitive ability scores from the mini-mental state examination ([MMSE] Folstein, Folstein, & McHugh, 1975) and the modified mini-mental state examination ([3MS] Teng & Chui, 1987). The MMSE is a brief test used to screen for cognitive impairment. Scores on the MMSE range from 0 to 30. Scores ≥25 points are normal, scores of 21 to 24 indicate mild impairment, scores of 10 to 20 indicate moderate impairment, and scores of 0 to 9 indicate severe impairment (Mungas, 1991). The 3MS examination adds four items to the MMSE and allows partial scoring on some items. The scores range from 0 to 100; larger scores indicate greater impairment. I obtained the residents' age, MMSE, 3MS, and SMAF scores from their charts to describe the sample and to determine whether their characteristics (Table 2) play a role in their caregivers' use of patronizing speech.

Table 2

Characteristics of Residents

Characteristics	Minimum	Maximum	Mean	SD
Age	70	95	83.7	6.8
SMAF	-69	-22	-36.1	10.7
MMSE	0	23	12.1	7.4
3MS	3	78	36.2	20.7

Objective 1: To Assess Caregivers' Beliefs About Aging and AD and Their Attitudes Towards Aging

Materials and procedure. I administered the B-AD, a beliefs questionnaire (Rust & Kwong See, 2010) to measure the caregivers' beliefs about cognitive, physical, and social performance for four targets: first for self as a benchmark only, and then for typical 25-year-olds, typical 75-year-olds, and typical institutionalized persons with AD, in counterbalanced order. See Table 3 for the reliability statistics for the sample in the current study.

The participants rated the degree to which they agreed that each of 46 statements (Table 4) pertained to three target groups (typical 25-year-olds [young targets], typical 75-year- olds [old targets], and typical institutionalized persons with AD [AD targets]) using 7-point scales (1 for *strong disagreement* to 7 for *strong agreement*). For example, to rate the young targets, the item would read "Typical 25-year-olds are wise people," for the old targets the item would read "Typical 75-year-olds are wise people," and for the AD targets the item would read "Typical institutionalized persons with AD are wise people." The differences in ratings between the young and old targets reflect the participants' beliefs about the aging process. The differences in ratings between the old and

AD targets reflect their beliefs about persons with AD, over and above what is expected just because of old age.

Table 3

Reliability Estimates (Cronbach's Alpha) for the Cognitive, Social, and Physical Domains for Each Target for the Study Sample

	Target		
Domain	Young	Old	AD
Cognitive	0.61	0.81	0.71
Social	0.78	0.82	0.83
Physical	0.73	0.84	0.73

Table 4

Caregivers' Belief Scores on Questionnaire Items in the Social, Cognitive, and Physical Domains

Domain	Construct	Questionnaire items	Young *M* (*SD*)	Old *M* (*SD*)	AD *M* (*SD*)
Social	Storytelling	More and more find that people enjoy their storytelling	4.27 (1.00)	5.23 (0.95)	2.65 (1.33)
		Are good story tellers	5.00 (1.20)	5.46 (1.14)	4.85 (1.43)
		Do not tell good stories	4.85 (1.29)	5.42 (1.17)	5.04 (1.22)
	Happiness	Feel happy a lot of the time	5.73 (0.87)	4.77 (1.28)	4.19 (1.52)
		Enjoy life	5.96 (0.92)	5.12 (1.11)	4.69 (1.38)
	Social Interaction	Prefer to be with other people	6.12 (0.71)	5.12 (0.95)	5.27 (0.87)
		Seek social interaction	6.31 (0.55)	5.12 (1.11)	5.23 (1.34)
		Avoid social interaction	5.50 (1.18)	4.62 (1.20)	4.54 (1.21)
		Prefer to be by themselves rather than to be with other people	5.58 (1.10)	4.73 (1.25)	4.54 (1.24)

(table continues)

Domain	Construct	Questionnaire items	Young *M* (*SD*)	Old *M* (*SD*)	AD *M* (*SD*)
	Benevolence	Are caring people	5.31 (1.01)	5.58 (1.03)	5.58 (1.14)
		Are kind people	5.58 (0.95)	5.65 (0.89)	5.52 (1.05)
		Are friendly people	5.69 (1.01)	5.58 (0.95)	5.46 (0.95)
	Cantankerous	Are argumentative	3.42 (1.20)	4.35 (1.26)	3.73 (1.28)
		Are stubborn people	3.08 (1.55)	3.73 (1.43)	3.23 (1.11)
		Are not easily irritated	4.27 (1.15)	4.15 (1.05)	5.27 (1.51)
		Are not easily upset	3.88 (1.28)	3.92 (1.35)	2.96 (1.31)
		Easily grow impatient	3.54 (1.30)	3.96 (1.25)	2.68 (1.21)
	Suspicious	Do not trust other people	5.00 (0.98)	4.27 (1.34)	3.27 (1.34)
		Are suspicious of other people	4.81 (1.27)	3.85 (1.26)	2.65 (0.89)
	Help	Would be accepting of help	4.58 (1.39)	5.12 (0.90)	5.38 (0.85)
		Resist help	4.27 (1.28)	4.27 (0.96)	4.31 (1.46)
		Would appreciate help	4.68 (1.46)	5.35 (0.89)	5.65 (0.89)
Cognitive	Wisdom/ intelligence	Are smart people	5.88 (0.71)	5.58 (1.07)	5.15 (1.22)
		Are wise people	4.85 (1.08)	5.81 (0.85)	4.96 (1.34)
		Are intelligent people	5.65 (0.94)	5.84 (0.94)	5.08 (1.57)
		Are knowledgeable people	5.54 (0.91)	5.85 (0.93)	4.96 (1.61)
	Communication	Find it easier to understand when spoken to slowly	4.38 (1.60)	2.85 (1.67)	1.65 (0.75)
		Find it easier to understand a message when simple words are used	3.88 (1.68)	2.62 (1.39)	1.62 (1.02)
	Long-term memory	Have good memory for events from their childhood	6.27 (0.72)	5.58 (0.86)	5.35 (1.23)
		Have good memory	6.23 (0.51)	4.42 (1.20)	2.65 (1.60)
		Have good memory for events that happened to them long ago	6.00 (1.02)	5.81 (0.80)	5.42 (1.14)
	Recent memory	Have good memory for events that happened recently	6.38 (0.50)	4.23 (1.07)	2.12 (1.07)
	Distraction	Are easily distracted by random thoughts	4.50 (1.20)	3.48 (1.33)	1.92 (0.84)
		Find that their mind wanders to random thoughts	3.96 (1.18)	3.62 (1.27)	1.92 (0.84)

(table continues)

Domain	Construct	Questionnaire items	Young *M* (*SD*)	Old *M* (*SD*)	AD *M* (*SD*)
Physical	Active	Are physically strong people	6.08 (0.94)	3.73 (1.34)	4.04 (1.59)
		Are physically active people	6.19 (0.49)	4.46 (1.20)	4.19 (1.52)
		Have a lot of energy	6.27 (0.72)	4.19 (1.33)	3.69 (1.40)
	Injury risk	May drop a boiling pot of water	4.81 (1.20)	3.15 (1.08)	1.96 (0.87)
		May hurt themselves while chopping onions	4.72 (1.49)	3.19 (1.27)	2.35 (1.52)
		Would spill while pouring hot coffee	4.73 (1.28)	3.23 (1.07)	2.65 (1.32)
	Have difficulty seeing small print	Have difficulty seeing small print	5.88 (0.82)	2.53 (0.95)	2.15 (0.93)
	Find newspaper print too small to read	Find newspaper print too small to read	5.85 (1.01)	2.35 (0.98)	2.73 (1.89)
	Smell	Have a poor sense of smell	5.73 (1.12)	3.31 (0.88)	3.27 (1.40)
	Taste	Do not experience tastes strongly	5.35 (1.57)	3.46 (1.33)	3.31 (1.26)
	Find that people speak too softly to hear	Find that people speak too softly to hear	5.04 (1.61)	2.54 (0.95)	2.54 (1.14)
	Find it easy to hear faint sounds	Find it easy to hear faint sounds	5.54 (1.39)	3.15 (1.22)	3.00 (1.62)

The caregivers indicated their age, years of education, the number of years that they had worked with seniors, and the number of years that they had worked with persons with AD, and on a 7-point scale ranging from 1 (*not at all*) to 7 (*very much*) rated their level of contact with grandparents, seniors in general, and persons with AD and the degree to which that contact was positive. The participants also rated their perceived self-efficacy in dealing with persons with AD on a three-item scale (how competent, effective, useful) and their level of knowledge about AD ("How much knowledge do you have about Alzheimer disease?") on a 7-point scale ranging from 1 (*not at all*) to 7 (*very much*) (self-rated level of knowledge about AD). See Appendix A for the questionnaire booklet.

I used the IAT (Greenwald, 2009; Greenwald et al., 1998) to assess the participants' implicit attitudes toward aging. A minor change was made to the program to correspond to the improved IAT method (Nosek, Greenwald, & Banaji, 2005), which presents the stimuli for the second task twice as many times as for the first task to give the participants extra practice to learn the new sides of the target categories.

I used 12 words (paradise, gift, peace, happy, love, lucky, war, filth, murder, slime, poison, anger) that represent the evaluative categories of pleasant and unpleasant (Dasgupta & Greenwald, 2001; Greenwald et al., 1998). I also used stimuli that represent the target categories of old and young (Hummert, Garstka, Greenwald, Mellot, & O'Brien, 2002). The stimuli that I used in this study were pictures of old (three male and three female) and young (three male and three female) faces rated to represent ages 60-90 and 18-27, respectively, and perceived as moderately happy (Hummert et al., 2002). All of the stimuli in the evaluative and target categories are presented in Appendix B.

The participants categorized the pictures as young or old and the words as pleasant (paradise, gift, peace, happy, love, lucky) or unpleasant (war, filth, murder, slime, poison, anger). I presented the IAT tasks on a laptop with a color screen and set the display settings for the screen area at 800 x 600 pixels. The target items appeared in the center of the screen on a white background, and the category labels (e.g., young, old) appeared in the upper-left and -right corners of the screen. I instructed the participants to press the left (D) key if the target item belonged to the category indicated on the left and the right (K) key if the target item belonged to the category indicated on the right and to make these judgments as quickly but as accurately as possible. During the practice trials, if they pressed the incorrect key, a red X appeared at the center of the screen, and the next item would not appear until they pressed the correct key.

For each trial the computer recorded the reaction time from the appearance of the target to the correct response in milliseconds. The Inquisit computer program (Millisecond Software, 2000) controlled the presentation of the seven tasks, the order of the blocks, and the recording of the reaction times. The first task was discriminating between young and old (left key for old, right key for young) over 24 trials. The second task was discriminating between pleasant and unpleasant (left key unpleasant, right key pleasant) over 24 trials. The third task was a practice-congruent task (left key for old or unpleasant, right key for young and pleasant) over 24 trials. The fourth task was the test phase of the previous congruent task over 40 trials. The fifth task was a repeat of the first task, but the target categories on the screen were reversed from the way that they appeared in the first step (left key for young and right key for old) to familiarize the participants with these new positions of the target categories and eliminate this possible confound in the subsequent step. To correspond with the new IAT procedure (Nosek et al., 2005), the stimuli were presented twice as many times as the first task (48 trials) to give the participants extra practice to learn the new sides of the target categories. The sixth task was a practice-incongruent task (left key for young and unpleasant and right key for old and pleasant) over 24 trials. Finally, the seventh task was the test phase of the previous incongruent task over 40 trials. The IAT effect is based on the difference in the mean reaction times to the incongruent and congruent tasks and indicates the strength of the participants' implicit associations.

The caregivers completed the questionnaires and IAT individually at each of the Alzheimer care centres. I held the sessions before and after their shifts or at whatever time was convenient for them. It took the participants between 50 and 90 minutes to complete the questionnaire and the IAT.

Data preparation for the analysis of beliefs and attitudes. I recoded the questionnaire responses on the B-AD so that higher scores (7) always represented the more positive beliefs for each item and the lower scores (1) always represented the more negative beliefs. For example, *Strongly Agree* (7) on the item "Are good storytellers" indicates a positive belief, so I did not need to recode this item. Alternatively, *Strongly Agree* (7) on the item "Are argumentative" indicates a negative belief, so I recoded the participants' responses to this item; for example, I would recode 7 to 1, 6 to 2, and so on. Therefore, high scores always indicate positive beliefs.

I collapsed individual items to form constructs as Rust and Kwong See (2010) did previously and as Rust (2005) did previously with a larger sample through principal-components analysis. I obtained the composite score for each construct by averaging the responses on the items that comprised each construct (e.g., I averaged smart, wise, and intelligent to create the construct called *wisdom/intelligence*) for each target (typical 25-year-olds, typical 75-year-olds, and typical institutionalized persons with AD) separately. I then averaged the scores for all constructs in each of the domains to create a score for the beliefs about each target in each domain. The reliability statistics for each of the three domains (cognitive, physical and social) are reported in Table 3. These mean scores for each domain are not ideal because the patterns of beliefs for the constructs within the domains do not all show the same patterns (see Figures 1, 2, and 3). However, I did this because I had to reduce the data because of the small sample size.

I used repeated measures multivariate analysis of variance (MANOVA) in the statistical analysis. MANOVA determines whether mean differences exist on two or more dependent variables simultaneously. The statistic initially tests the null hypothesis that there are no mean differences among the various groups. I used Wilks’ lambda multivariate test statistic to test the null hypothesis that there were no mean differences across the targets. Wilks’ lambda is the product of the unexplained variances on each of the discriminant variates. Generally, smaller values of Wilks’ lambda lead to statistical significance and indicate a good model. If significant differences appear, post hoc tests are then conducted to further examine these group differences. In the current study I used three MANOVAs (one for each domain) to determine whether differences existed among the means of the domains (cognitive, social, physical) and the targets (young, old, AD). I conducted univariate statistics and planned comparisons to understand the multivariate effects. The planned comparisons compared the beliefs about typical 25-year-olds to those about typical 75-year-olds and beliefs about typical 75-year-olds to those about institutionalized persons with AD to assess the beliefs about

AD over and above what is expected in old age. The effect sizes are reported as partial eta squared (η_p^2).

I analyzed the IAT data from tasks 3, 4, 6, and 7 using Greenwald, Nosek, and Banaji's (2003) algorithm. Before the analysis, I discarded individual trial response latencies >10,000 ms and calculated the mean of the correct latencies for each block. I calculated one pooled *SD* for all trials in tasks 3 and 6 and one for tasks 4 and 7. I removed the error trials and replaced them with the mean for that performance block plus a penalty of 600 ms. I then averaged the resulting values for each of the four tasks. From these averages (average of task 6 minus average of task 3, and average of task 7 minus average of task 4), I computed two differences and divided each difference by its associated pooled *SD*. I averaged these two quotients, and this average is the IAT effect for each individual.

Objective 2: To Observe Interactions Between Caregivers and Persons With AD for Evidence of Socially Created Dependency and Patronizing Speech

Materials and procedure. I invited the residents to make lunch (juice from frozen concentrate and grilled cheese sandwiches) with a caregiver and to set the table, eat the meal, and clean up. I paired the caregivers with residents from a centre at which they did not work to ensure that they did not know these residents. This controlled for the caregivers' knowing the residents with whom they were being observed. I selected the task of preparing lunch because residents of the Alzheimer care centres should be capable of completing it and because the task has ecological validity. After I gained the assent of the residents, they and the caregivers made lunch in the family dining room of the centre in which the residents resided. A family dining room was available in each of the centres where the observations took place. I set up the dining rooms, which were similar at all of the centres, in the same manner for each of the resident-caregiver pairings. I used video cameras on tripods to capture the kitchens and dining areas.

From the residents' charts I collected information that included age, cognitive (MMSE, 3MS) and functional (SMAF) information, food allergies, and diagnosis. The interactions occurred between 10 minutes after the caregivers had completed the beliefs questionnaire and IAT to three months later, depending on their schedule and availability.

Data preparation for the analysis of interactive behaviours. I used a sequential observation methodology to document the sequence of overt observable behaviours that occurred when the caregivers interacted with the residents, and I adapted the observational coding system that Baltes et al. (1987) used extensively in their work to code the behavioural stream that I had captured on videotape.

The residents' behaviours that were of interest included dependent behaviour, such as requesting assistance or accepting assistance with tasks; independent behaviour, such as performing tasks without physical assistance; constructively engaged behaviour, such as socially appropriate behaviour that is not task related; and destructively engaged behaviour, such as socially inappropriate behaviour. The caregivers' behaviours that were of interest included independence-supportive behaviour, such as encouraging independent task-related behaviour or discouraging dependent task-related behaviour; dependence-supportive behaviour, such as encouraging dependent task-related behaviour or discouraging independent task-related behaviour; engagement-supportive behaviour, such as encouraging engagement; and nonengagement-supportive behaviour, such as not encouraging residents' engagement.

Data preparation for the analysis of patronizing speech. A research assistant transcribed the caregivers' utterances in the videotaped interactions between the caregivers and persons with AD, and I checked them. We considered an utterance to be a stretch of spoken language that was preceded by silence, or another person speaking and followed by silence or a change in the person who was speaking. A research assistant and I then coded all of the transcripts for elements of patronizing communication, including the use of diminutives (inappropriately intimate and childish references), tag questions (grammatical structures in which a declarative statement is turned into a question with the addition of an interrogative fragment), and the mean length of the utterance (number of words in an utterance). We did not disagree on the coding of the diminutives or tag questions. The following are examples of diminutives that the caregivers used:

- “Have you had breakfast yet, dear?”
- “Can you help me, darling?”
- “Good, my friend; good, good.”
- “Can you wipe the table, sweetheart?”
- “Right here, sweetie.”
- “I really appreciate your help, honey”

The following are examples of tag questions that the caregivers asked:

- “It is good juice, isn’t it?”
- “You have an English accent, right?”
- “You had a hard time keeping up to him, did you?”
- “Do you like sports? No?”
- “We don’t want to get too fat, do we?”

The research assistant and I agreed 96% of the time on what constituted an utterance in the transcripts that we both coded (one quarter of the total number). Diminutives and tag questions were coded and reported in per utterance counts. I used the Systematic Analysis of Language Transcript computer program (Miller & Chapman, 1984) to make the calculations.

Objective 3: To Examine the Relationship Between Caregivers’ Beliefs and Attitudes and Their Behaviours

Analysis strategy to predict interactive behaviour. To determine which resident behaviours were associated with which caregiver responses, I computed the sequential conditional probabilities to determine the dominant interaction pattern between the caregivers and the residents with AD. I computed Sackett’s binomial z-score to compare the conditional probabilities of the consequent events (caregiver behaviours) with their base probability (ratio of the observed frequency of specific caregiver behaviour to the sum of all observed caregiver behaviours). Statistically significant deviations of the conditional probability from the base probability indicated that a particular caregiver behaviour followed the antecedent resident behaviour with a probability that is greater than chance. In addition to computing the sequential probabilities, I used correspondence analysis (a statistical visualization method of displaying the associations between the levels of a two-way contingency table) as a means of displaying the categorical data in two-dimensional graphical form (a correspondence plot).

Because the sample size was insufficient for straightforward statistical inference, I used bootstrapping to determine which caregiver beliefs and characteristics might impact the way in which caregivers respond to residents' behaviours. The characteristics of interest included the caregiver's age; self-rating of competency in working with AD; attitudes toward aging (IAT); self-rating of self-efficacy in working with people with AD (effective, useful, confident); beliefs about aging and AD in the cognitive, social, and physical domains (B-AD; Rust & Kwong See's, 2010); self-rated knowledge about AD; self-rating of usefulness in working with people with AD; number of years of working with people with AD; and number of years of working with older adults.

Analysis strategy to predict patronizing talk. I performed a stepwise regression to determine which caregiver beliefs and attitudes would predict the three measures of patronizing speech expressed as a proportion (mean length of utterance, number of diminutives per utterance, number of tag questions per utterance). As predictors for this analysis, I decided to select items that should intuitively be predictors and for which there were significant differences in the ratings for the young target and the target with AD. I derived the belief score as the difference between ratings for the young target and the target with AD and created a score for each of the items: active, injury risk, help, social interaction, long-term memory, wisdom, communication, and happiness. Further predictors were attitudes toward aging (IAT) and resident characteristics (age of resident, MMSE score, SMAF score).

Objective 4: To Describe and Acquire a Greater Understanding of the Stated Beliefs About AD of Caregivers of Persons With AD, Their Views on Caring for Persons With AD, and Their Communication With Persons With AD

Materials and procedure. Semistructured interviews offered me the flexibility I required to probe for details or discuss issues (Patton, 1990). They are a good tool to capture what and how a person thinks about a particular domain and allow greater ease in synthesizing across the respondents than do unstructured interviews. See Appendix C for the guide that served as the framework for the interviews.

The first set of questions explored beliefs about AD in general and, more specifically, in the social, cognitive, and physical domains. I asked the caregivers, “What are people with Alzheimer disease like?” “Tell me about the cognitive aspects of Alzheimer disease. How are people who have Alzheimer disease different cognitively from typical older adults?” “Tell me about the physical aspects of Alzheimer disease. How are people who have Alzheimer disease different physically from typical older adults?” and “Tell me about the social aspects of Alzheimer disease. How are people who have Alzheimer disease different socially from typical older adults?”

Other questions explored caregivers’ philosophy, goals, and values in caring for residents with AD. I asked them, “What is your caregiving philosophy for people with Alzheimer disease?” “What are your values for interactions with residents with Alzheimer disease at work?” and “What are your specific goals when you interact with residents with Alzheimer disease at work?”

The last set of questions explored challenges and strategies for effective communication with persons with AD. I asked the caregivers, “What challenges do you face in communicating with residents with Alzheimer disease?” “What strategies do you use for effective communication with residents with Alzheimer disease?” and “How do you change the way that you communicate, verbally and nonverbally, when you communicate with residents with Alzheimer disease?”

I also used detail-oriented, elaboration, and clarification probes (Patton, 1990) to generate more data from the participants. The caregivers participated in the audio-recorded, semistructured interviews after interacting with the residents.

Data preparation for qualitative analysis. A research assistant transcribed the audiotapes, and another research assistant and I coded the transcripts of the interviews for themes using an inductive atheoretical approach. I used thematic analysis, a process in which the researcher seeks themes that are integral to the description of the phenomenon (Daly, Kellehear, & Gliksman, 1997), to identify the themes through “careful reading and re-reading of the data” (Rice & Ezzy, 1999, p. 258). Once I recognized recurrent patterns in the transcripts, the themes that emerged became the categories for analysis. I used NVivo to help me to organize the data and maintain an audit trail. NVivo is a qualitative data-analysis computer-software package that helps the user to organize and analyze text by sorting and arranging the information and easily link it back to the source. The analytic process began by preparing the data for analysis. I imported the transcripts of the interviews into NVivo. Then I gained a sense of the topics embedded in the transcripts through my initial reading of the text. I then reread the text closely, line by line, and entered preliminary codes in NVivo. I collated the codes into themes by organizing the items related to similar topics into categories and then reexamined the transcripts for relevant incidents of the text.

CHAPTER IV:

RESULTS

Objective 1: To Assess Caregivers' Beliefs About Aging and AD and Their Attitudes Toward Aging

The mean ratings of caregivers on each of the items on the beliefs questionnaire for each of the targets (young, old, and AD) are shown in Table 4. I conducted Cronbach's alpha for each domain for the evaluations of each target. Table 3 shows the reliability estimates for the questionnaire with this sample. The reliability was reasonable, generally above .70 (Nunnally & Bernstein, 1994).

The literature revealed that caregiver age and experience in working with older adults can impact the results, so I ran three MANCOVA analyses, one for each of the domains (cognitive, social, physical) of the B-AD. For each analysis, the target (young, old, AD) was a repeated measure, and the constructs within the domain were the dependent measures. I entered the caregiver's age and years of experience in working with older adults as covariates. None of the covariate*target interactions were significant, which indicates that each of the covariates behaved the same way across the three targets. Therefore, I no longer considered these variables covariates, and I ran three two way MANOVA analyses, one for each of the domains (cognitive, social, physical). For each analysis, the target (young, old, AD) was a repeated measure, and the constructs within the domain were the dependent measures. The results are shown in Table 5 for expedience, and I explicate them with follow-up univariate analyses.

Beliefs about aging and AD in the cognitive domain. I conducted a two way 3 (Target) x 5 (Cognitive) multivariate analysis of variance for the cognitive constructs that yielded a significant multivariate effect for Target $F(2,24) = 149.6$, $p < .001$, $\eta_p^2 = .93$, and a cognitive*target interaction $F(8,18) = 22.9$, $p < .001$, $\eta_p^2 = .91$. I then ran univariate contrasts to determine the nature of the interactions. Table 6 presents the univariate simple contrasts to compare the beliefs about aging (typical 75-year-olds vs. typical 25-year-olds), and AD (typical 75-year-olds vs. typical institutionalized persons with AD) in the cognitive domain.

Table 5

Multivariate Effects for the Cognitive, Social, and Physical Domains

Variable	Wilks' lambda	*F*	*df*	Error *df*	*p*	η_p^2
Cognitive	.099	50.0	4	22	.000	.901
Target	.074	149.6	2	24	.000	.926
Cognitive*target	.089	22.9	8	18	.000	.911
Social	.083	36.7	6	20	.000	.917
Target	.436	15.5	2	24	.000	.564
Social*target	.096	10.9	12	14	.000	.904
Physical	.190	11.6	7	19	.000	.810
Target	.099	108.6	2	24	.000	.901
Physical*target	.091	8.6	14	12	.000	.909

Table 6

Beliefs About Aging and AD in the Cognitive Domain

Belief	Young *M* (*SD*)	Old *M* (*SD*)	AD *M* (*SD*)	*F* values for target (2,24)	Old vs. young *F* values (1,25)	Old vs. AD *F* values (1,25)
Wisdom/ intelligence	5.69 (0.74)	5.76 (0.83)	5.06 (1.37)	5.8*	*ns*	12.1*
Communication	4.13 (1.47)	2.73 (1.33)	1.63 (0.71)	23.5**	14.6**	29.7**
Long-term memory	6.13 (0.66)	5.69 (0.72)	5.38 (1.06)	6.2*	5.4*	*ns*
Distraction	4.23 (0.99)	3.60 (1.25)	1.92 (0.74)	70.5**	67.5*	55.2**
Memory of recent events	6.38 (0.50)	4.73 (1.07)	2.12 (1.07)	127.7**	76.6**	45.0**

*p < .05; **p < .001. Higher scores indicate more positive beliefs for each construct.

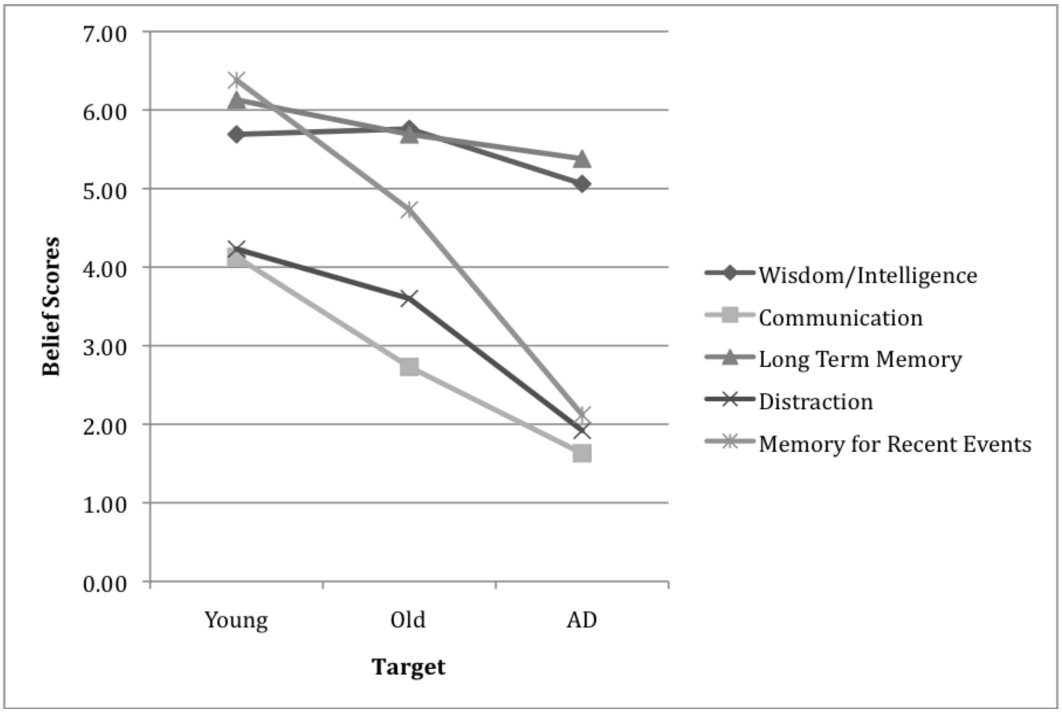


Figure 1. Beliefs about aging and AD in the cognitive domain by target.

I plotted the data in Table 6 in Figure 1 to better show the perceived decline in the cognitive constructs from young to old and old to AD. I acknowledge that such a line graph is more appropriate when the axes are continuous variables, however, it effectively creates a visual of the perceived declines in the cognitive domain.

The caregivers rated typical 25-year-olds the most positively, typical 75-year-olds less positively, and persons with AD the least positively on all constructs except for wisdom/intelligence and long-term memory. For wisdom/intelligence, they did not rate typical 75-year-olds differently from 25-year-olds, but they rated persons with AD more negatively than 75-year-olds. It is not clear whether the caregivers rated persons with AD more negatively than typical 25-year-olds on wisdom/intelligence, so to further explore this, I did a simple comparison to determine whether caregivers' beliefs about the wisdom/ intelligence of typical 25-year-olds and persons with AD differed. They considered persons with AD less wise/intelligent than typical 25-year-olds

F(1,25) = 12.09, $p < .01$. For long-term memory, they rated typical 75-year-olds more negatively than 25-year-olds, but their ratings for persons with AD did not significantly differ from the ratings for 75-year-olds.

Beliefs about aging and AD in the social domain. I conducted a two way 3 (Target) x 7 (Social) multivariate analysis of variance for the social items of the beliefs questionnaire, which yielded a significant multivariate effect for Target $F(2,24) = 15.5$, $p < .001$, $\eta_p^2 = .56$ and a social*target interaction $F(12,14) = 10.9$, $p < .001$, $\eta_p^2 = .90$. I conducted univariate contrasts to determine the nature of the interaction. Table 7 presents the univariate simple contrasts to compare caregivers' beliefs about aging (typical 75-year-olds vs. typical 25-year-olds) and AD (typical 75-year-olds vs. typical institutionalized persons with AD).

Table 7

Beliefs About Aging and AD in the Social Domain

Belief	Young *M* (*SD*)	Old *M* (*SD*)	AD *M* (*SD*)	*F* values for target (2,24)	Old vs. young *F* values (1,25)	Old vs. AD *F* values (1,25)
Storytelling	4.70 (0.91)	5.37 (0.92)	4.83 (1.10)	4.7**	8.28*	6.1*
Happiness	5.85 (0.72)	4.94 (0.89)	4.37 (1.25)	16.8**	15.6**	5.5*
Social interaction	6.00 (0.59)	4.99 (0.92)	5.01 (0.93)	26.1**	36.4**	*ns*
Benevolence	5.53 (0.91)	5.60 (0.87)	5.54 (0.92)	*ns*		
Cantankerous	3.59 (0.76)	4.08 (0.68)	4.08 (0.66)	5.1*	10.0*	*ns*
Suspicious	4.90 (1.03)	4.06 (1.09)	2.96 (0.86)	58.4**	19.0**	28.4**
Help	4.51 (0.96)	4.91 (0.69)	5.11 (0.78)	5.37*	4.65*	*ns*

*p < .05; **p < .001. Higher scores indicate more positive beliefs for each construct.

For suspiciousness and happiness, the caregivers rated typical 25-year-olds more positively than typical 75-year-olds and typical 75-year-olds more positively than typical institutionalized persons with AD. For social interaction, they rated typical 25-year-olds more positively than typical 75-year-olds, but their ratings for typical 75-year-olds and typical institutionalized persons with AD did not differ. For storytelling, the caregivers rated typical 75-year-olds more positively than the other target groups. For social interaction the caregivers' beliefs about typical 75-year-olds were more negative than about typical 25-year-olds, but they saw no difference between typical 75-year-olds and institutionalized persons with AD on this construct. For benevolence, their beliefs did not vary by target. For cantankerous, their beliefs were more positive beliefs about typical 75-year-olds than about typical 25-year-olds, whereas their ratings for typical 75-year-olds and typical institutionalized persons with AD did not differ. For help, the caregivers rated typical 75-year-olds as less amenable to help than typical 25-year-olds, but the ratings for typical 75-year-olds and typical institutionalized persons with AD did not differ.

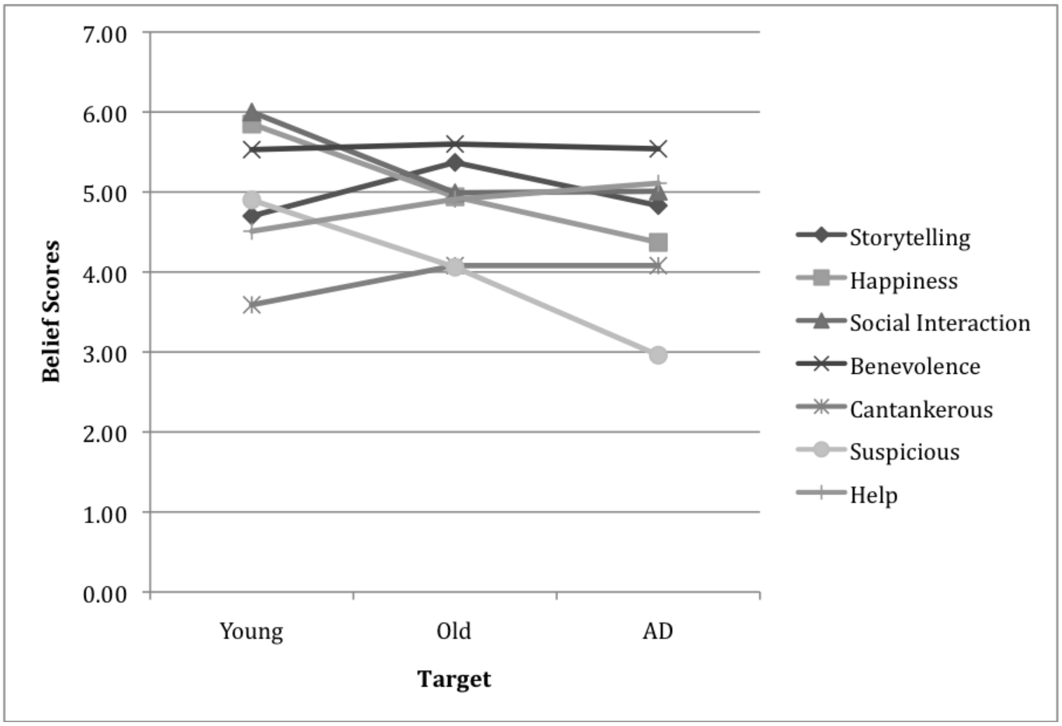


Figure 2. Beliefs about aging and AD in the social domain by target.

Beliefs about aging and AD in the physical domain. I conducted a two way 3 (Target) x 8 (Physical) multivariate analysis of variance for the physical items on the beliefs questionnaire; it yielded a significant multivariate effect for Target $F(2,24) = 108.64$, $p < .001$, $\eta_p^2 = .91$, and a Physical*Target interaction $F(14,12) = 8.6$, $p < .001$, $\eta_p^2 = .91$. Table 8 presents the univariate simple contrasts to compare beliefs about aging (typical 75-year-olds vs. typical 25-year-olds) and AD (typical 75-year-olds vs. typical institutionalized persons with AD).

Table 8

Beliefs About Aging and AD in the Physical Domain

Belief	Young *M* *SD*	Old *M* *SD*	AD *M* *SD*	*F* values for target (2, 50)	Old vs. Young *F* values (1,25)	Old vs. AD *F* values (1,25)
Active	6.17 (0.58)	4.13 (1.17)	3.97 (1.30)	47.1**	81.1**	*ns*
Injury risk	4.75 (1.11)	3.19 (1.01)	2.32 (1.04)	68.8**	53.7**	24.7**
Have difficulty seeing small print	5.88 (0.82)	2.50 (1.33)	2.15 (0.93)	94.6**	109.3**	*ns*
Find newspaper print too small to read	5.85 (1.01)	2.35 (0.98)	2.73 (1.89)	52.2**	218.2**	*ns*
Find that people speak too softly to hear	5.04 (1.61)	2.54 (0.95)	2.54 (1.14)	35.5**	49.2**	*ns*
Have a poor sense of smell	5.73 (1.12)	3.31 (0.89)	3.27 (1.40)	49.2**	86.1**	*ns*
Find it easy to hear faint sounds	5.54 (1.39)	3.15 (1.22)	3.00 (1.63)	22.4**	36.9**	*ns*
Do not experience tastes strongly	5.35 (1.57)	3.46 (1.33)	3.31 (1.26)	16.7**	20.9**	*ns*

*p < .05; **p < .001. Higher scores indicate more positive beliefs for each construct.

I plotted the data in Table 8 in Figure 3 to demonstrate the perceived declines with aging and the perceived stability with AD.

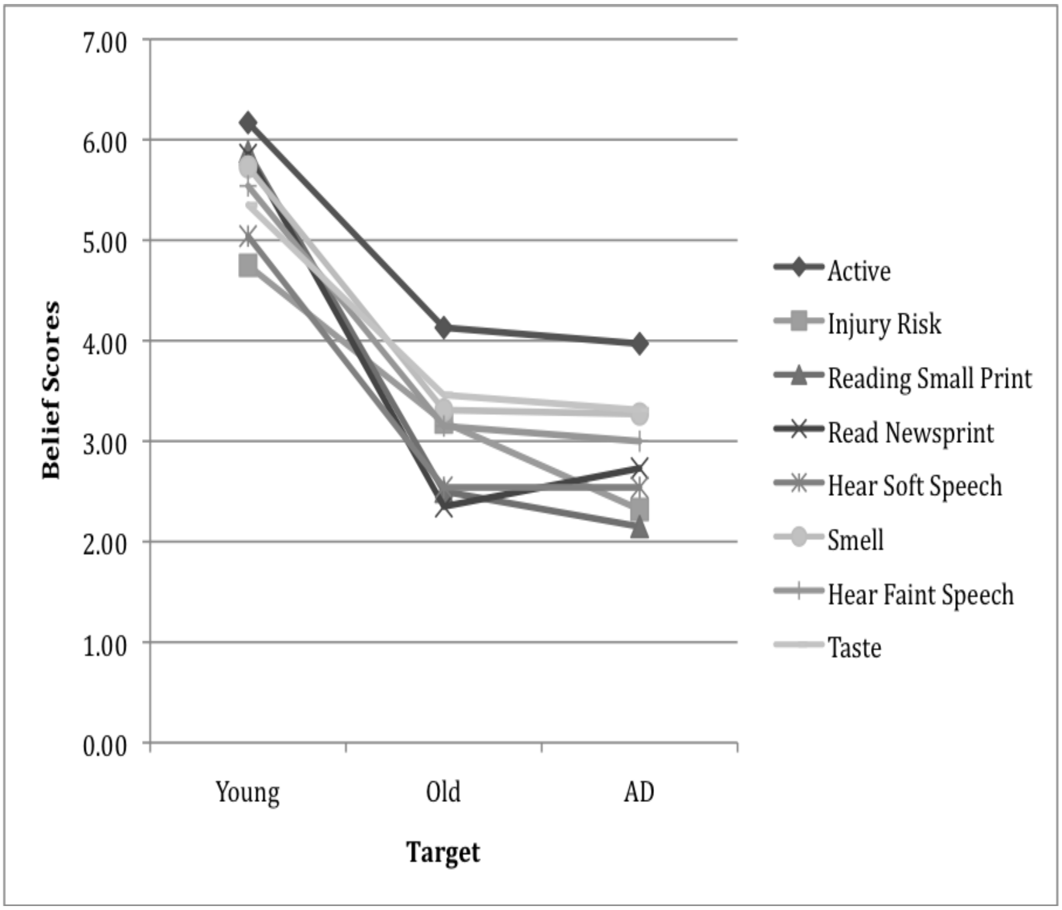


Figure 3. Beliefs about aging and AD in the physical domain by target.

The caregivers rated typical 75-year-olds more negatively than typical 25-year-olds on all constructs in the physical domain. Although they rated persons with AD as at more risk for injury than typical 75-year-olds, the ratings for those with AD and typical 75-year-olds did not differ on the other constructs.

Implicit association test. Because a greater cognitive effort is required to generate an appropriate response on incongruent trials than on congruent trials, incongruent trials take longer and are less accurate than congruent trials. An overall measure, based on the difference between the congruent and incongruent latencies, is referred to as the *IAT effect*. In this study a positive IAT effect indicates a negative bias toward older people. I analyzed the data by using

Greenwald et al.’s (2003) algorithm to obtain the most robust IAT effect. The results indicate a positive IAT effect of .951 (*SD* = .44) and ranged from -.027 to 1.63. Larger values indicate a greater association of old and unpleasant. I conducted a one-sample *t*-test using the IAT scores to test the hypothesis that the population’s mean IAT score is 0. The one-sample *t*-test indicated a significant association of old and unpleasant in this sample of caregivers $t(25) = 11.12$, $p < .001$.

Objective 2: To Observe Caregivers and Persons With AD for Evidence of Socially Created Dependency and Patronizing Speech

Interactive behaviours. I used the observational coding system that Baltes (e.g., Baltes, 1988) used extensively in her work to code the behavioural stream of interactions between the residents and caregivers that I had captured on videotape. Table 9 shows the behaviours of interest of the residents and caregivers. All categories of behaviours are based on Baltes, Barton, Orzech, and Lago’s (1983) behaviour mapping study. Whereas Baltes and her colleagues were interested in self-care behaviours, this study was concerned with task-related behaviour. I adapted the codes for this study, as Table 9 shows. I coded the behaviours every 5 seconds to create a behavioural profile of the interactions between the caregivers and residents as they prepared the meal and cleaned up. When their behaviours were simultaneous (e.g., they talked about family at the same time that they buttered bread), the research assistant and I coded the task-related behaviours in each 5-second time segment using the categories in Table 9. We assessed the interrater agreement on 20% of the observations as 92%.

Table 9

Resident and Caregiver Behaviours

Resident & caregiver behaviour	Behaviour code	Description of behaviour code	% total resident & caregiver behaviours
Resident behaviours	Dependent	Requesting assistance or accepting assistance with tasks. This code was used when caregiver was doing a task while resident was not doing the task; e.g., Resident not setting table, not preparing sandwiches or juice, while caregiver was doing task, or resident asking for assistance with task.	27.0
	Independent	Performing tasks without physical assistance. This code was used when the resident was independently performing a task, regardless of what caregiver was doing at the time. This code was also used if the resident was performing a task independently while talking to the caregiver; e.g., Resident setting table, buttering bread, stirring juice.	65.0
	Constructively engaged	Socially appropriate behaviour that is not task related behaviour. This code was used when residents were constructively engaged and NOT behaving independently or dependently at the same time; e.g., Conversation with caregiver.	8.0
	Sleeping	Sleeping during the interaction.	0.0
	Destructively engaged	Socially inappropriate behaviour; e.g., spitting or kicking.	0.0
	Non engaged	No involvement in any activity.	0.0
Caregiver behaviours	Independence - supportive	Encouraging independent task related behaviour, or discouraging dependent self care behaviour; e.g., Caregiver asking resident to get the bread, caregiver saying ‘good job’ for stirring the juice, caregiver asking the resident what they would like to help with next.	15.5

(table continues)

Resident & caregiver behaviour	Behaviour code	Description of behaviour code	% total resident & caregiver behaviours
	Dependence-supportive	Encouraging dependent task related behaviour, or discouraging independent task related behaviour; e.g., Caregiver gets bread out of bag, caregiver butters bread, caregiver makes juice, or caregiver says let me do that for you, caregiver takes over task from resident.	27.0
	Engagement-supportive	Encouraging engagement; e.g., Caregiver asks resident a question, caregiver in conversation with resident (not dependence supportive or independence supportive conversation). This code would not be used if caregiver is being dependence supportive and talking to resident at the same time.	46.0
	No response	No response; e.g., Caregiver is not being dependence-supportive, independence supportive, engagement supportive or nonengagement supportive	11.5
	Nonengagement-supportive	Encouraging nonengagement; e.g., caregiver not encouraging conversation by being abrupt.	0.0

The most common behaviour that the residents exhibited was independent (65%), followed by dependent (27%) and constructively engaged (8%). The most common behaviour of the caregivers was engagement-supportive (46%), followed by dependence-supportive (27%), independence-supportive (15.5%), and no response (11.5%). Table 10 shows the data from Table 9 in whole numbers. These data easily show the distribution of behaviours—the number of caregivers' behaviours that followed residents' behaviours. Dependence-supportive behaviour most frequently followed residents' dependent behaviour, independence-supportive behaviour most commonly followed residents' independent behaviour, engagement-supportive behaviour most frequently followed residents' independent behaviour, and no response most frequently followed residents' independent behaviour.

Table 10

Number of Caregiver Behaviours That Follow Resident Behaviours

	Caregiver dependence supportive	Caregiver independence supportive	Caregiver engagement supportive	Caregiver no response	Resident totals
Resident dependent	620	102	111	13	846
Resident independent	191	372	1,134	342	2,039
Resident constructively engaged	33	13	197	9	252
Caregiver totals	844	487	1,442	364	3,137

I computed the sequential conditional probabilities to determine the dominant interaction pattern (see Table 11). For Sackett's binomial z-score, I compared the conditional probabilities of the consequent events (caregiver behaviours) with their base probability (ratio of the observed frequency of a specific caregiver behaviour to the sum of all observed caregiver behaviours). Statistically significant deviations of the conditional probability from the base probability indicate that a particular behaviour follows the antecedent resident behaviour with a probability greater than chance. Figure 4 is a correspondence plot of these data. Similar to principal-components analysis, correspondence analysis reduces the dimensionality of the data in an attempt to represent the entire contingency table along a smaller number of axes. Figure 4 shows the results of this analysis in the form of a biplot (Greenacre, 2010), which shows the relationships of higher dimensional data in the 2D plane. In this asymmetric biplot (Gabriel & Odoroff, 1990) I plotted the rows (resident behaviours) in principal coordinates and the columns as standardised residuals from the principal components. Intuitively, the arrows indicate a measure of the correlation between that column and the principal component, and the arrows that point in the same direction as an axis have a strong relationship. The shaded points indicate inertia, which is related to the chi-square statistic that measures the deviations of the

Table 11

P(Caregiver Behaviour/Resident Behaviour)

Behaviour	Dependence supportive	Independence supportive	Engagement supportive	No response
Dependent	**.73****	.12**	.13**	.02**
Independent	.09**	**.18****	**.56****	**.17****
Constructively engaged	.13**	.05*	**.78****	.04*
Base rate probabilities	.27	.16	.46	.12

Note. Omnibus log likelihood-ratio chi-square test for testing overall effects. (*G*) = 1373.158, *X*-squared *df* = 6, p-value < 2.2e-16. Sackett's binomial z-score to test individual cells. * $p < 0.05$ ** $p < 0.001$. Bolded values are significantly greater than base rate probability.

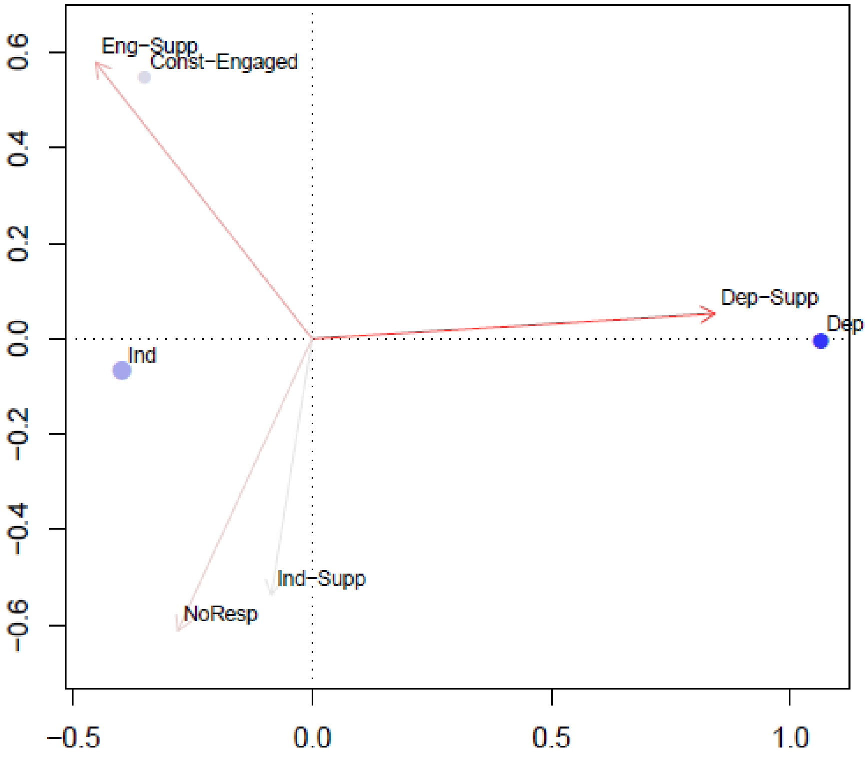


Figure 4. Correspondence plot of resident and caregiver behaviour.

observed table entries from expected values under independence; higher values of inertia (darker circles) indicate that the point accounts for more of the total chi-squared deviation. I performed the analysis in R (R Development Core Team, 2008) using the CA package. The results of the analysis indicate that the first axis accounted for 93.97% of the inertia and the second axis for 6.07% of the inertia. The first axis is dependence, and the second axis, though more difficult to interpret, appears to be an interaction of engagement-supportive versus independence-supportive and no response. Dependent behaviour secures dependence-supportive behaviour from caregivers, and constructively engaged behaviour intermittently secures engagement-supportive behaviour from caregivers, whereas independent behaviour secures independence-supportive, engagement-supportive, and no-response behaviours from caregivers.

Speech behaviours. Table 12 summarizes the caregivers' use of the three characteristics of patronizing speech.

Table 12

Caregivers' Use of Patronizing Speech

Patronizing speech	Min	Max	M	SD
Mean length of utterance	3.30	7.76	5.05	.96
No. of diminutives	.00	23.00	3.65	5.12
No. of diminutives per utterance	.00	.06	.009	.01
No. of tag questions	1.00	63.00	17.81	13.72
No. of tag questions per utterance	.00	.08	.037	.02

Objective 3: To Examine the Relationship Between Caregivers' Beliefs and Attitudes and Their Behaviours

To extend Baltes's (Baltes et al., 1980; Baltes et al., 1983; Baltes et al., 1987; Barton et al., 1980; Lester & Baltes, 1978) work by determining whether the caregivers' characteristics predicted the behavioural contingencies, I fit multinomial logistic regression models using the multinom package in R (R

Development Core Team, 2008). Because of the small sample sizes, it was not possible to rely on the central distribution, so I attempted to reduce the model to its most parsimonious form using nonparametric model selection. I exhaustively removed the variables from the model (for all possible combinations of variables) and calculated Akaike's (1974) information criterion (AIC) for each new model, by bootstrapping (based on N = 10000 replicates per model; Efron & Tibshirani, 1993); I then used the distribution of the resampled data to calculate the confidence intervals for the AICs. I adopted the model with the most improved AIC as the reduced model. If a log-likelihood test of significance showed a significant improvement in model fit based on the difference in AICs between the full and reduced model, I adopted the reduced model as the new full model and repeated the process until the removal of further variables resulted in no improvement.

The variables entered into the multinomial regression included caregiver age; self-rating of competency in working with AD; attitudes toward aging (IAT); self-rating of self-efficacy in working with people with AD (effective, useful, confident); beliefs about aging and AD in the cognitive, social, and physical domains (B-AD, Rust & Kwong See, 2010); self-rated knowledge about AD; self-rating of usefulness in working with people with AD; number of years of working with people with AD; and number of years of working with older adults. The model could not be reduced (log-likelihood test of significance did not show a significant improvement in model fit based on the difference in AICs between the full and reduced model). Therefore, the results of the multinomial logistic regression should be regarded as suggestive only and as indicators of areas for future study.

I have reported the results for the caregiver characteristics that increase or decrease the odds of their independence-supportive and engagement-supportive behaviour in comparison to their dependence-supportive behaviour following either resident independent or dependent behaviour. Because of the low frequency of occurrence of the resident constructively engaged behaviour, I have not reported the results of the caregiver behaviour following resident constructively engaged behaviour here.

The odds of caregivers’ independence-supportive behaviour (rather than dependence-supportive behaviour) following residents’ dependent behaviour were greater when the caregivers’ beliefs about AD in the cognitive domain were more positive (OR 2.86) and less when the caregivers’ beliefs were more positive about AD in the social domain (OR 0.12), which suggests that caregivers support the independence of residents more if they believe that people with AD are more cognitively capable and less if they believe that people with AD are only socially capable and pleasant.

The odds of caregivers’ engagement-supportive behaviour (rather than dependence-supportive behaviour) following residents’ dependent behaviour were greater when the caregivers’ attitudes toward aging were more negative implicit (larger IAT effect scores; OR 2.31) and less when their beliefs about AD in the social domain were more positive (OR 0.20) or they had worked with older adults longer (OR 0.92).

The odds of caregivers’ engagement-supportive behaviour (rather than dependence-supportive behaviour) following residents’ independent behaviour was greater when the caregivers rated themselves as more effective (higher effectiveness ratings; OR 1.63) and less when they had worked with older adults longer (OR 0.94).

In the previous analysis I used the caregivers’ scores on their beliefs about aging and AD in the social, cognitive, and physical domains. I also used these composite scores previously to reduce the number of variables in the analysis (Rust, 2005; Rust & Kwong See, 2010); however, not all constructs that compose the domains follow the same pattern. In an alternative analysis I included eight beliefs about the differences between typical 25-year-olds and institutionalized persons with AD rather than using the composite domain scores (physical, social, and cognitive). The eight constructs that I selected were active, injury risk, communication, happiness, help, social interaction, wisdom, and long-term memory. As with the previous bootstrapped analysis, I could not reduce the model (the log-likelihood test of significance did not show a significant improvement in model fit based on the difference in AICs between the full and reduced model). Table 13 presents the results of the logistic regression.

Table 13

Odds Ratios for Caregiver Independence Supportive Behaviour Compared to Dependence Supportive Behaviour Following Either Resident Dependent or Independent Behaviour

	Caregiver behaviour following resident dependent behaviour					Caregiver behaviour following resident independent behaviour				
Predictor	Estimate	*SE*	*z*	*p*	*OR*	Estimate	*SE*	*z*	*p*	*OR*
Intercept	-1.081	0.343	-3.156	0.002	N/A	0.931	0.278	3.353	0.000	N/A
Active	-0.121	0.094	-1.283	0.199	0.887	0.046	0.079	0.582	0.560	1.047
Injury risk	0.297	0.129	2.296	0.022	1.346*	0.155	0.090	1.727	0.084	1.168
Communication	0.109	0.074	1.472	0.141	1.115	0.016	0.061	0.263	0.792	1.016
Happiness	0.188	0.153	1.235	0.217	1.207	0.096	0.114	0.844	0.400	1.101
Help	0.360	0.122	2.942	0.003	1.433**	0.204	0.096	2.133	0.033	1.226*
Social interaction	-0.095	0.179	-.528	0.597	0.914	-0.156	0.136	-1.154	0.249	0.855
Wisdom	0.032	0.125	0.254	0.799	1.032	0.049	0.100	0.4889	0.625	1.050
Long-term memory	0.159	0.127	1.250	0.211	1.173	-0.137	0.099	-1.39	0.165	0.872

**p* < .05; ***p* < .01.

The odds of caregivers’ independence-supportive behaviour (rather than dependence-supportive behaviour) following residents’ dependent behaviour was greater when the caregivers believed that people with AD are less at risk for injury (OR 1.35) and persons with AD are more accepting of help (OR 1.43), which suggests that caregivers support the independence of residents more if they believe that people with AD are less at risk for injury and more willing to be helped (less resistive to being helped).

The odds of caregivers’ independence-supportive behaviour (rather than dependence-supportive behaviour) following residents’ independent behaviour was greater when the caregivers believed that people with AD are more accepting of help (OR 1.23), which suggests that caregivers support the independence of residents more if they believe that people with AD are more willing to be helped (less resistive to being helped).

I performed a regression to determine whether caregiver characteristics or resident characteristics predict the three measures of patronizing speech. Table 14 shows the variables entered in the stepwise regressions.

Table 14

The Criterion and Predictor Variables Entered in the Regressions to Examine Study Objective 3

Criterion variables	Predictor variables: caregiver beliefs	Predictor variables: resident characteristics
Mean length of utterance No. of diminutives per utterance No. of tag questions per utterance	Beliefs about the difference between young and AD in active, injury risk, help, social interaction, long-term memory, wisdom, communication, and happiness (B-AD, Rust & Kwong See, 2010) Attitudes toward aging (IAT)	MMSE score SMAF score Age of resident

Predictors of caregivers' use of diminutives. The caregivers' beliefs about the difference in long-term memory between 25-year-olds and persons with AD predicted their use of diminutives (β = -0.05, $p < 0.04$; their belief that the long-term memory of persons with AD is poorer resulted in a greater use of diminutives) and accounted for 16.9% of the variance in the caregivers' use of diminutives per utterance.

Predictors of caregivers' use of tag questions. None of the resident or caregiver characteristics predicted the caregivers' use of tag questions.

Predictors of caregivers' mean length of utterance. The caregivers' beliefs about the difference in accepting help between 25-year-olds and persons with AD predicted the mean length of their utterances (β = 0.40, $p < 0.02$; their belief that persons with AD are more resistant to help resulted in a shorter mean length of their utterances) and accounted for 21.5% of the variance in caregivers' use of diminutives per utterance.

Objective 4: To Describe and Acquire a Greater Understanding of the Stated Beliefs About AD of Caregivers of Persons With AD, Their Views on Caring for Persons with AD, and Their Communication With Persons With AD

A research assistant transcribed the audiotapes, and I coded the transcripts for themes by using thematic analysis. Another coder independently reviewed the quotations that comprise each of the themes, and the coder and I agreed 96% of the time that the quotations related to the themes. Discussion of the discrepancies resulted in 100% agreement.

Caregivers' values and goals in caring for persons with AD. The caregivers talked about their values and goals for their interactions with residents with AD. Figure 5 illustrates the caregivers' values and goals as well as representative quotations. Descriptions of the themes follow, with quotations from the caregivers that are verbatim to avoid losing their meaning by paraphrasing. See Appendix D for the complete quotations from the caregivers that support each of the themes.

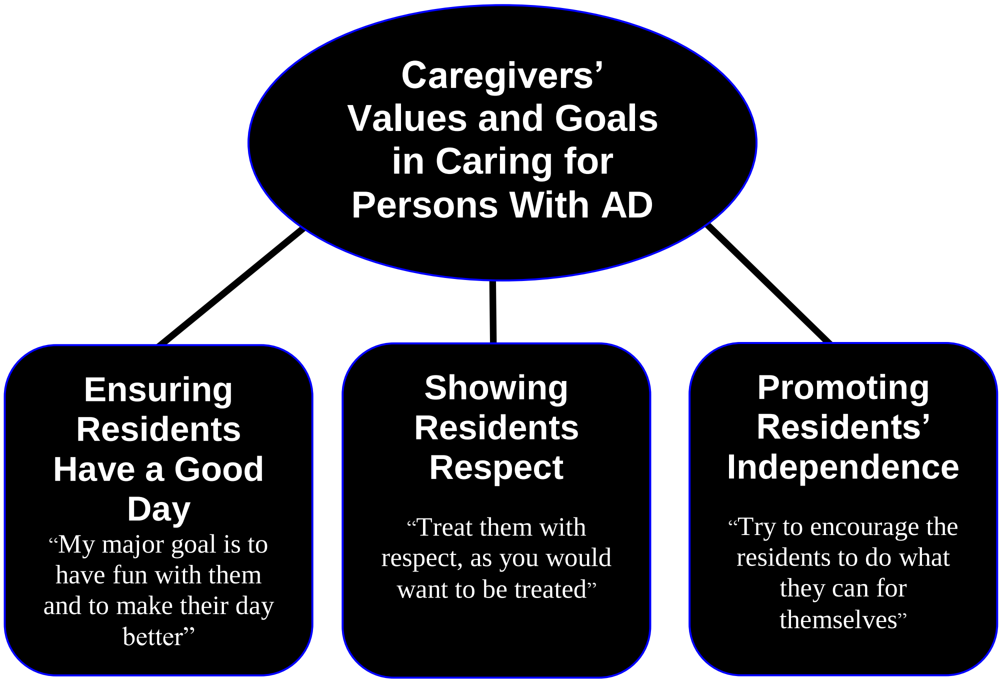


Figure 5. Caregivers' values and goals in interactions with residents with AD.

The questions about caregivers' values and goals for their interactions with residents with AD produced three themes: ensuring that residents have a good day, showing residents respect, and promoting residents' independence. The first theme involves making them smile, ensuring that they are satisfied, making them happy, comforting them, making them feel contented, making them laugh, and ensuring that they are not frustrated or afraid. One caregiver explained, "I want them to have a good day; that's what I want them to do. I'd like to see them smile and enjoy their day. That's what I go to work for"; another said, "For the Alzheimer person it's not just looking after their daily needs; it's making them smile, so they have a good day." The caregivers offered strategies to ensure that residents have a good day, including creating "a friendly atmosphere" and "making them feel important . . . by showing genuine interest in their . . . interests and in their life." They would "sing with them, . . . dance with them," "joke with them," have "music involved with interaction, . . . singing and humming; . . . make a funny face . . . to get someone laughing." Other caregivers would try to involve the residents "because I don't want them to be sitting by themselves."

The theme of showing residents respect includes issues of dignity, treating them as the caregivers wanted to be treated themselves, privacy, and taking time for the residents. Respect meant many things to the caregivers. Sometimes showing respect means going out of one's way:

> That's part of dignity, that it doesn't matter how convenient it is for me or one of the other staff members when it comes to whether we put on slacks or not. That's dignity, that's respect. She needs to be treated like anybody else, that she needs to have the right to her modesty.

Respect means protecting residents' privacy: "I make sure that the door is closed, and also I knock on the door before I enter. It is very important because that is their property, instead of being just intrusive." Respect means addressing the residents the way that they preferred to be addressed:

> If they want to be called by their name, I don't give them names like "Hey, Mr. Somebody!" or something like that. I address them the way they wanted to be called. That is…respect.

Respect means allowing residents to choose what they want to do:

> If they don't want to go to an activity, you don't force them. There are some residents that like to stay in their room and sleep. You ask them, you give them the choice, and if they want to want to attend [or] if they don't, that's their choice. If they want to sleep, let them sleep.

Respect means not doing everything for the residents, but allowing them to be independent: "And it's not to fully do everything for them, but it's just to encourage them and just help them with the minor details." Respect means treating residents "as normally as possible. You don't treat them different because they have Alzheimer's." Finally, respect means being patient with residents and listening to them:

> You have to have patience all the time. Respect for that person, and just listening to them, because I often see how frustrated they get, and I don't think there would be anything worse than being that frustrated and thinking that nobody cares or wants to take time to listen to you.

Another value and goal in interactions with persons with AD is to promote their independence: "My goal is to help them to stay as independent as they can, . . . to maintain that and do what they like to do as long as they can." Caregivers promote independence by doing *with* the resident instead of doing *for* the resident:

> I care with all my heart. . . . It's my commitment, . . . the reason why I took nursing, because I like caring for people, and I like to be with people. And I like doing things for people, not just doing them for them but doing with [them].

Caregivers also promote independence by finding activities that the residents can still do: "Do some puzzles, for example, in the centre, or trying to color, because these are the things which they on this level can do still in some way." Breaking up tasks that are too difficult for the residents into smaller components that they are capable of managing promotes independence. It is important to let the residents know that

> a full task may not always be able to be completed, and that it's okay to do part of it; that that's still an accomplishment, and that tomorrow maybe it's a different part that they're able to complete. Or maybe they can complete the whole thing. Just don't assume that because one day it can't

> be done— maybe they've been up all night, and they're just exhausted. Every day is different.

Promoting the independence of residents with AD involves cueing:

> Let them . . . have a feeling of self-worth that they can do as much as they can for themselves, even if it requires cueing. They don't remember, because they can maybe still do the task, but they just have to be reminded.

Promoting independence is important because it affects the residents' well-being and self-esteem: "But if they can still do something for themselves, why not involve them? And in a way it makes them independent, their sense of well-being [increases], and also you're boosting their self-esteem too." A sense of accomplishment also affects their self-esteem and well-being:

> If you can still do something that is very important, because that is a little accomplishment on their part, and I'm sure they're very proud that they can still do something. That is independence. Whenever I'm setting the table, I just don't do it myself. I can easily do it myself in just a short time, but that's not the purpose. The purpose is to make them independent and be able to do something. The involvement is very important.

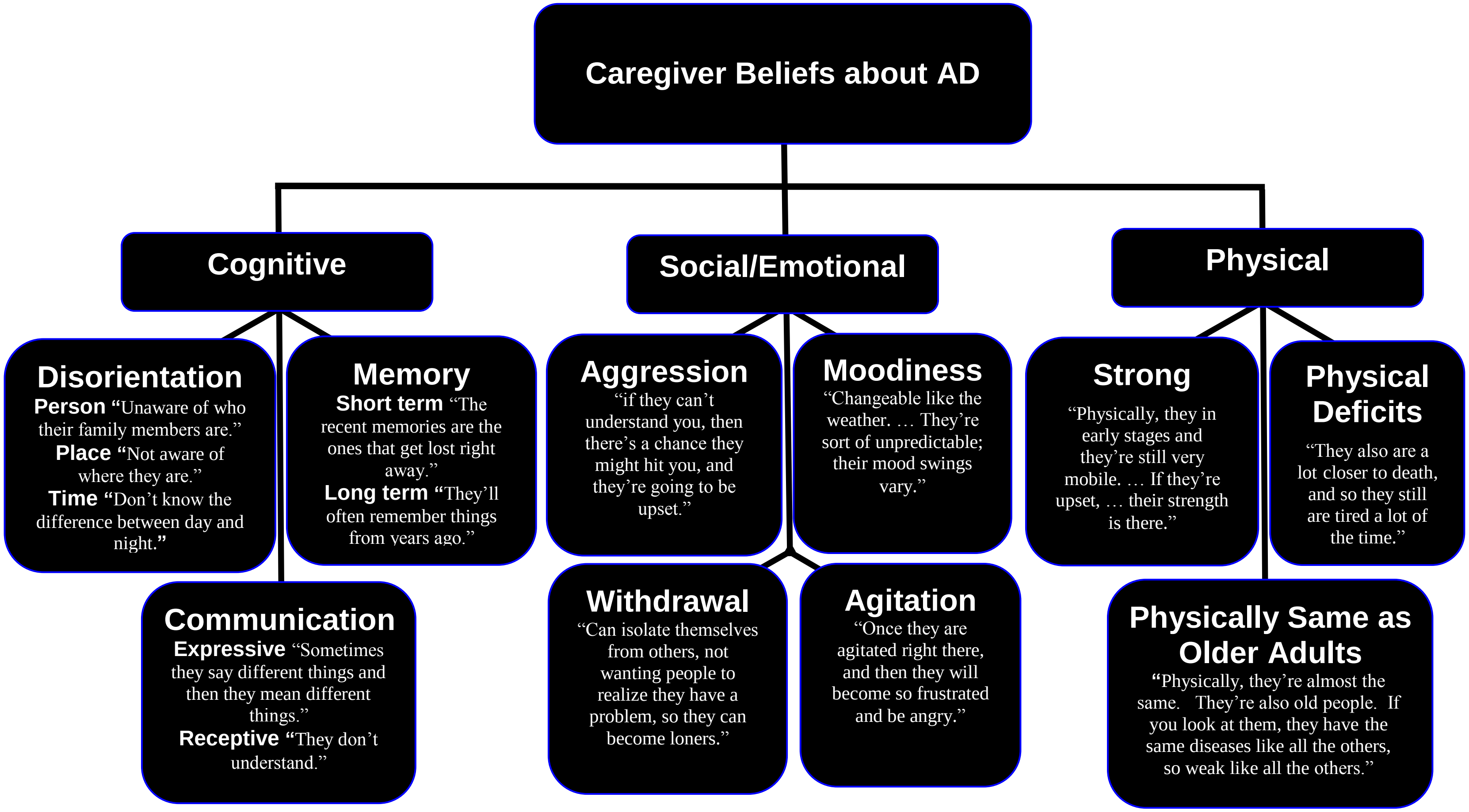
The caregivers indicated that doing *for* the resident is faster and easier than doing *with* the resident: "It's always easy to do stuff for everybody." But allowing the residents to participate in the activities of daily living is important because "if you don't use it, you lose it"; "I guess because they would lose their independency and they wouldn't be able to do anything if you wouldn't let them do anything"; "You cannot stop their memory loss, but at least if you let them do their task, they tend to remember more." Supporting independence is important because "it kind of determines who you are. Once you can't do anything … then your personal value is decreased."

Caregivers' stated beliefs about AD. The caregivers talked about the cognitive, social, and physical domains of people with AD. Figure 6 illustrates their beliefs about persons with AD and includes representative quotations. I discuss the themes below with quotations from the caregivers. See Appendix E for complete quotations that support each of the themes.

Themes in the cognitive domain. The themes that emerged in the cognitive domain included memory (short-term, long-term), communication (receptive, expressive), and disorientation (to time, to person, to place).

The caregivers mentioned the "poor memories" of persons with AD and that "they forget things easily." They distinguished between short-term and long-term memory with regard to residents' abilities. They believed that AD affects short-term memory, but long-term memory is somewhat spared until the late stages of the disease. Persons with AD "don't remember what happened just a few minutes ago" but will "often remember things from years ago."

Another theme was impairment in communication; the responses fell into two categories, expressive and receptive communication, and the caregivers reported that persons with AD have difficulty with aspects of both. In expressive communication the caregivers identified issues with aphasia and repetition. Persons with AD are not "able to express themselves the way they would like to"; "They'll forget what things are, or what they're for." The residents often lose the ability to recall or correctly voice the word they want to use. Sometimes "an object isn't the same for them any more. . . . The breadmaker sitting on the counter would be 'that white bucket.'" This inability to communicate effectively is frustrating for persons with AD themselves: "They know what they want, but they can't communicate, and so they get really frustrated."



Disorientation
Person "Unaware of who their family members are."
Place "Not aware of where they are."
Time "Don't know the difference between day and night."

Memory
Short term "The recent memories are the ones that get lost right away."
Long term "They'll often remember things from years ago."

Communication
Expressive "Sometimes they say different things and then they mean different things."
Receptive "They don't understand."

Aggression
"if they can't understand you, then there's a chance they might hit you, and they're going to be upset."

Moodiness
"Changeable like the weather. … They're sort of unpredictable; their mood swings vary."

Withdrawal
"Can isolate themselves from others, not wanting people to realize they have a problem, so they can become loners."

Agitation
"Once they are agitated right there, and then they will become so frustrated and be angry."

Strong
"Physically, they in early stages and they're still very mobile. … If they're upset, … their strength is there."

Physical Deficits
"They also are a lot closer to death, and so they still are tired a lot of the time."

Physically Same as Older Adults
"Physically, they're almost the same. They're also old people. If you look at them, they have the same diseases like all the others, so weak like all the others."

Figure 6. Caregiver beliefs about persons with AD.

Another aspect of expressive communication with which persons with AD struggle is repetition. The caregivers noted “repetition of words,” stories, and questions. Many attributed this repetition to residents’ “forget[ing] what they have said a few minutes or even a few seconds ago.” For one caregiver, “the repetition is the biggest challenge: how to continue a conversation when you’ve been down that road before. Just as an example, the lady I just spoke with, I heard the same story three or four times.”

Another theme in the cognitive domain is disorientation. The caregivers consider people with AD “generally . . . confused at times, disoriented to time, person, and place at times.” This “confusion really makes it so hard on [the persons with AD] and so hard for the caregivers.” It affects residents with AD: “Confusion is . . . something that really . . . agitates them.” Disorientation is difficult for the caregivers because it makes people with AD more difficult to care for.

People with AD are disoriented to person, place, and time. The caregivers described disorientation to person, the inability to recognize familiar individuals such as staff, friends, and family: “Over a period of time they don’t even recognize family members any more.” One caregiver gave an example of being mistaken for someone else: “And then sometimes [when] they come down the hallway, they will say, ‘Oh, there’s my mum.’ And I look behind me, and there’s nobody. I know they think I’m their mum.”

The caregivers also reported that disorientation is evident in terms of place or location. Residents’ inability to find their way around is common: They “can leave out of the door and say they’re going for a walk, but have no idea how to get back.” Disorientation to place can make residents feel “scared at times, not knowing where they are” and affects caregivers because the residents “need a lot of direction” and because it can lead to behaviours when the residents, “on awakening, [are] not aware of where they are, don’t know the difference between going to the kitchen table or going to eat somewhere else, not sure where the bathroom is, will void anywhere [that is] not a specific place.”

In addition to disorientation to person and place, the caregivers spoke of disorientation to time. Many residents have lost their sense of time, such as how long it has been since dinner, what time of the day it is, "the difference between day and night," what day of the week it is, or what year it is. They "don't even know the seasons any more" and can be

> confused in the sense they don't know what they're supposed to do next. That's something I hear quite a bit, is 'I don't know what I'm supposed to be doing now.' They don't know if that was breakfast they just had or supper they just had or whether they actually ate or didn't eat. They don't seem to know what to do next.

Sometimes

> residents refer back to their younger days as opposed to living in the present. . . . You might say, "It's your birthday today. You're eighty-seven," and they'll look at you and say, "No, I'm twenty-five." And you can't argue with them because, in their mind, that's where they're at. They go back to that spot. Some go way back, twenty-five, thirty, thirty-five, depending on where they want to be.

Themes in the social/emotional domain. The themes that emerged in the social/emotional domain included aggression, agitation, moodiness, and social withdrawal. Persons with AD can be aggressive. It is not always clear to their caregivers why, and it can happen very quickly:

> So one time I'm just by myself, and then that's the time he tried to corner me and tried to hit me, punch me, yeah, without saying anything. I'm just washing the dishes, and then all of a sudden he was behind me.

Other triggers are,

> if they can't understand you, then there's a chance they might hit you, and they're going to be upset. I think a lot of times it just depends on the day, where their medication is, or there's so many things that can be a factor. It could be somebody said something, and it just triggered it.

The caregivers are concerned about residents' aggressiveness because "they're very strong; . . . they're aggressive. They can beat you. It looks like they're so old, it looks like they're not really healthy any more, but once they're aggressive, oh, they're strong." The strategies that the caregivers use to deal with aggression include "leaving them for a while until the anger calms down" and

> car[ing] for them with lots of patience, lots of encouragement; you have to spend lots of time. You don't need to be in a hurry, because if you are in a hurry to them, then the more you're in trouble; they get upset. They might hit you. And also whatever you want to do with them, you have to explain to them what you're doing. That's the most important, because if you just go there without saying anything, for sure they're going to hit you without asking. Because even the doctor, they hit the doctor on their face when the doctor just introduced himself.

Further, they "can use distraction and talk in a calm voice, don't get angry or anything. That doesn't do any good." Finally, "first thing you have to do is give them a smile, make the day run smoothly, do something better, and they will do things better for you."

Another theme in the social/emotional domain is agitation. The caregivers reported that residents become agitated for a variety of reasons, such as the social environment. They become agitated if their caregivers take control away from them and are pushy: "Some people were controlling type of people to start with, and if you take that control away from them, they become irritated and unmanageable"; "If you push her on what she doesn't want to do, then it's not good because she's going to be upset. Then you'll be upset too." Residents can also become agitated when they are exposed to lower-functioning residents, when the room is noisy, or when the caregivers yell: "If you have a highly functional [person], early stages of Alzheimer's, and you put them at a table with somebody who's more down the road of Alzheimer's and they try to talk, I think they get frustrated"; "The noise level, the talking, the kids screaming. . . . It becomes very agitating actually"; "If the resident can't hear really good and you yell at her, then you won't be satisfied with your work because they're going to be upset with you."

Residents' cognitive difficulties also lead to frustration: "I think it agitates them too if they can't answer your questions or don't know how to answer your questions"; "The confusion, that is something that really . . . agitates them"; "They're very frustrated, and they know what they want, but they can't communicate, and so they get really frustrated."

Another theme in the social domain is the social withdrawal of persons with AD. The caregivers discussed the variability in the residents' social interactions. Some

> kind of draw back and aren't quite as sociable, but they may not have been, if they didn't have Alzheimer's. And some are very social, and they like to be around people all the time. They like lots of social interactions.

However, more often the caregivers reported that persons with AD withdraw socially: "With the disease process they can isolate themselves from others, not wanting people to realize they have a problem. So they can become loners, depressed." The caregivers have to encourage and coax the residents to participate in social activities:

> And there's quite a few that just, especially as their disease progresses, to have a conversation. It just doesn't happen; it's just gone. And they don't want to come out and do activities, and you feel like you're really coaxing them to be involved in things.

Another theme was moodiness. Mood swings are common among persons with AD: "They can flip on a switch and turn that switch off in a matter of two minutes apart. They could be happy one minute and throwing something at you the next."

> With Alzheimer's you have to be cautious what you say, because anything can set them off. Even if you're saying it nicely, it can set them off. They can take it differently than other adults, so you have to be cautious with what you say and how you say it to them.

Persons with AD can be

> changeable like the weather. . . . They're sort of unpredictable, their mood swings vary. You can say, . . . "I want to give you your pills now"; they'll refuse to take them. You come back later, and they'll take them. Or "we're going to have a bath, we'll get washed up," or "so brush your teeth," but one time they're adamant and stubborn they won't want to do it, and then when you leave them alone for a little bit, they'll come around.

Themes in the physical domain. The themes that emerged in the physical domain with regard to people with AD were physical strength, physical deficits, and a lack of difference physically from other older adults. The caregivers reported a great deal of variability in the physical abilities of persons with AD:

> Physically, there could be nothing wrong with them, no different than any other older adult …And for other ones, they actually go through the different stages where they lose their bladder control, become incontinent, eventually forgetting how to eat and walk. And so it's [that] each person and the stages they go through are different. Some are never incontinent, or suddenly they wake up one morning, and they're unable to do anything basically.

The caregivers described some residents as physically strong, which one attributed to aggression and cognitive deficits:

> So physically, in early stages, they're still very mobile, and if they're upset or angry, their strength is there; whereas maybe the average senior, may be weaker. But for some reason, I don't know, someone who's confused and whatever and thinks they have to get out that door, I mean, if you're holding it shut, there's a lot of power there when they want to go. Physically, yeah, they probably don't realize their limitations, I guess, so that doesn't stop them. Like forgetting that they have a sore knee or they broke their arm or whatever.

The caregivers gave examples of strong residents; for example, "A very agile eighty-year-old man . . . jumped the fence. He jumped the fence, and what he did was, he was walking home, and that was it. So the police found him, brought him back." Another caregiver noted that "maybe it's just that that's who we have in our centres, but a lot of them seem to be better physically than a lot of other ninety-year-olds."

Some caregivers noted that persons with AD have more physical deficits than other older adults do: "A lot of them though, my experiences of working with them is, they also are a lot closer to death, and so they still are tired a lot of the time"; "People with Alzheimer's, I think, sit around more perhaps than other seniors that I know [who] go to the mall and mall walk-and understand that it's important to have physical exercise; whereas Alzheimer's, they couldn't care less." Some of the caregivers attributed these physical deficits to the residents' cognitive deficiencies: "They're forgetful. Sometimes their cognition impairs them with walking and talking. The ability to do things, they can't quite do what a regular seventy-five-year-old person could do"; and

> They would have maybe some of the body functions slowing down or inability to control body functions. So a lot of people will become incontinent and not able to distinguish when they need to go or where they need to go to go, that sort of thing: "Where's the bathroom?"

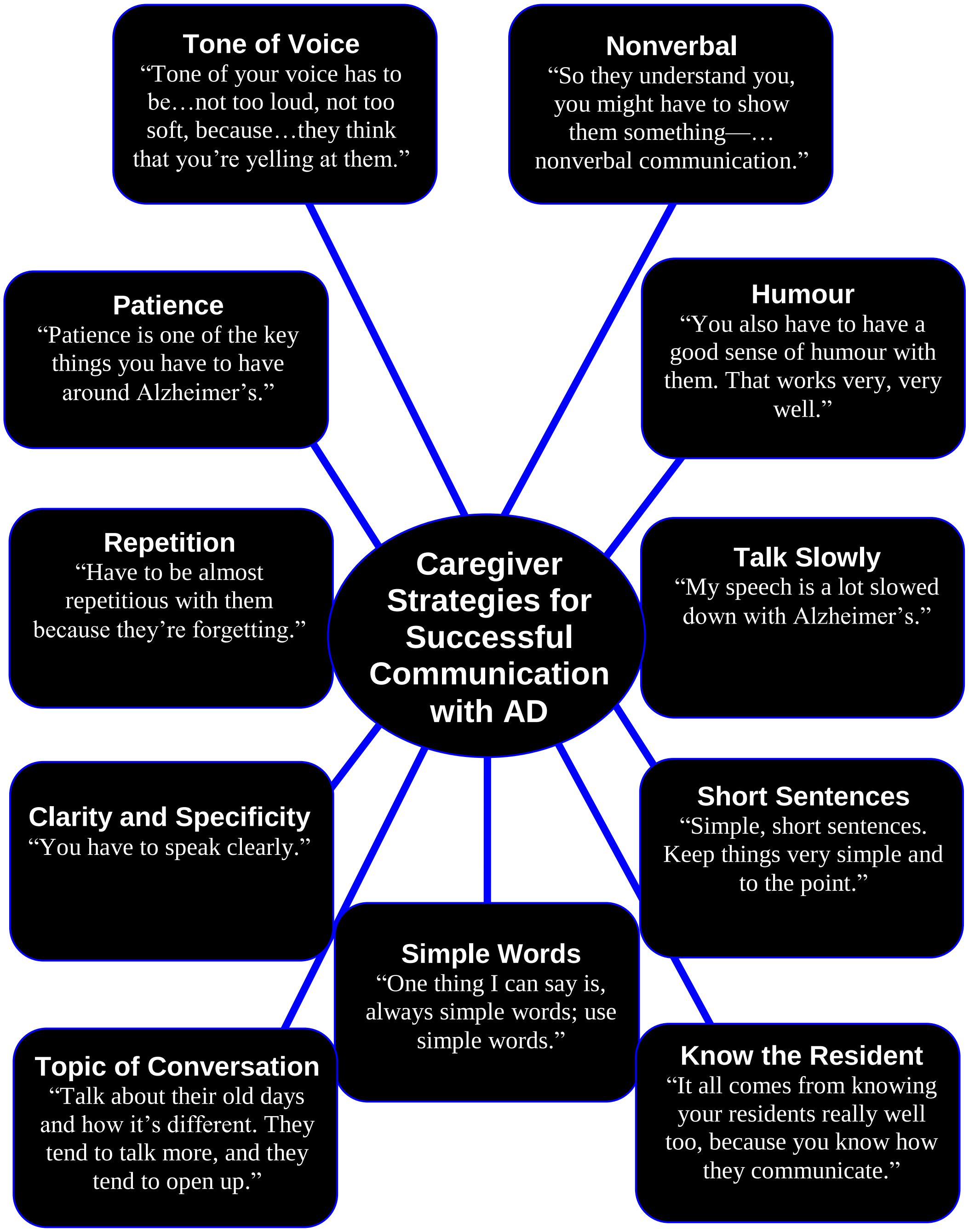
The most commonly stated belief about the physical domain was that persons with AD are physically the same as older adults without AD. The following quotations from the caregivers support this theme:

> They're a lot the same as older adults; it's just some of them with memory loss. And sometimes you get that with older people as well. They can be a bit more shaky or unstable, but that's older people in general.

Others added, "If you keep them active there's no reason why they should go downhill any more than any other senior because it's the brain that's going; it's not their body"; "I think, physically, they're almost the same. They're also old people. If you look at them, they have the same diseases like all the others, so weak like all the others"; "I think that those kinds of things [senses] deteriorate with age. It doesn't necessarily mean that it's with Alzheimer's."

Caregiver strategies to maintain and enhance communication. Communication with residents with AD can be challenging because of the language degeneration that is associated with the disease. The caregivers identified many strategies (verbal, nonverbal, and paraverbal) to maintain and enhance communication with residents with AD. Figure 7 is an overview of the caregivers' strategies to maximize the effectiveness of communicative with residents with AD. I have included some quotations from the caregivers in the themes, but all of their quotations in support of the themes are found in Appendix F.

Tone of voice. Tone of voice is an important part of communication, because the way that people say things can override the words that they actually



Caregiver Strategies for Successful Communication with AD

Tone of Voice
"Tone of your voice has to be…not too loud, not too soft, because…they think that you're yelling at them."

Nonverbal
"So they understand you, you might have to show them something—… nonverbal communication."

Patience
"Patience is one of the key things you have to have around Alzheimer's."

Humour
"You also have to have a good sense of humour with them. That works very, very well."

Repetition
"Have to be almost repetitious with them because they're forgetting."

Talk Slowly
"My speech is a lot slowed down with Alzheimer's."

Clarity and Specificity
"You have to speak clearly."

Short Sentences
"Simple, short sentences. Keep things very simple and to the point."

Simple Words
"One thing I can say is, always simple words; use simple words."

Topic of Conversation
"Talk about their old days and how it's different. They tend to talk more, and they tend to open up."

Know the Resident
"It all comes from knowing your residents really well too, because you know how they communicate."

Figure 7. Caregivers' strategies to maximize the effectiveness of communication with residents with AD.

speak. The caregivers identified using a soft, calm voice with a nice tone that is not “loud or boisterous” as a strategy to communicate with residents with AD to avoid startling them and sounding angry. “The tone of . . . voice has to be . . . not too loud, not too soft, because sometimes they can’t hear you, and sometimes too loud, they think . . . that you’re yelling at them, you’re screaming at them.” One caregiver commented that “if you’re sarcastic or have an attitude in your voice, that can really affect the way [residents with AD] communicate with you.” They use these strategies when a resident is aggressive, to prevent a resident from becoming upset, when a resident is hard of hearing, and to avoid causing distress. See Appendix F for quotations from the caregivers related to this theme.

Patience. Another theme that emerged was patience. The caregivers stressed the importance of taking the time to listen: “You have to be very patient with them and try to understand what they’re trying to say, because sometimes they say different things, and then they mean different things.” It is also important to give the residents extra processing time for them to be able to understand and formulate verbal responses—“time to be able to think about what they want to say”—or they can become confused or frustrated. One caregiver noted the difficulty of

> [their] not being able to express themselves the way they would like to and [their] knowing that they’re not getting that across. There are times—I can think of a lady in particular, and she would know that, “No, that’s not it, that’s not it,” but [she] gets very frustrated. And so it’s having the time to say, “It’s okay. Think about it for a few minutes or whatever; it will come.” We all have moments like that where that word is just sitting right there and it doesn’t come out. So it’s giving people the time to be able to think about what they want to say.

Patience is also required when residents “ask questions over and over . . . every five minutes they ask you the same thing,” because verbal perseverations are common with AD. A lack of patience with residents or rushing can upset them, and they can become aggressive and less satisfied with the interaction. “If you are in a hurry to them, then the more you’re in trouble, they get upset. They might hit you.” Patience also communicates caring:

> You have to have patience all the time, respect for that person, and just listening to them, because I often see how frustrated they get, and I . . . don't think there would be anything worse than being that frustrated and thinking that nobody cares or wants to take time to listen to you.

Being patient and encouraging residents' attempts to express themselves rather than rushing them can enhance communication. See Appendix F for quotations from the caregivers related to this theme.

Repetition. A recurring theme was the need for caregivers to repeat themselves to aid communication with residents with AD. They identified two reasons, memory and hearing deficits: "You might have to be a little more repetitive to get your point across so they understand you." Some residents require several repetitions before they are able to understand a question or instruction: "Sometimes they don't understand what you are doing when it's just a repeated task of the day, and so you just have to repeat it to them, sometimes slower, sometimes rewording it." The caregivers also suggested rephrasing or gesturing rather than repeating themselves. See Appendix F for quotations from the caregiver related to this theme.

Clarity and specificity. Being clear and specific in communicating with residents is another strategy that the caregivers use to facilitate communication. It is important to annunciate, and "make sure it's clear [so] that they can understand well." One caregiver stressed the need to be specific and avoid being vague to facilitate understanding:

> The difficult part is when you try to explain to some of them what they have to do. . . . "Go to the bathroom," and some of them, when they go in the bathroom, they don't even know what is this. This is the hard part. So here you have to be very, very specific and slow with them.

See Appendix F for quotations from the caregivers related to this theme.

Topic of conversation. Ensuring that conversations with residents with AD flow can be difficult. Topics of conversation with which the caregivers have found success fall into the categories of the present and reminiscences about the far past. One caregiver explained in detail:

> Oh, just even reminiscing, talking about their past as far as their family or their children. Most people are pretty receptive to family conversations or children conversation; if the cat walked by or something and you're talking about animals. Our centres are so great about having pictures and other cueing things, so you can, if you're walking by a picture, just talk about the farm scene or the airplane or whatever. Just those regular social conversations about "Oh, what did you do for a living?" or "Did you ever fly a plane?" The same as we would if we're out in public, right? Yeah, just cues around the centre or I guess, things that they would bring up. Trying to get more explanation into things that interest them or whatever they show interest in.

One caregiver mentioned the use of *Reminiscence Magazine* as a successful way of starting a conversation:

> The magazines, to reminisce, because they can relate to the story. And once I start reading something, all of a sudden one will come out with a story, and then another one will come out with a story, and there it goes in circle.

The caregivers did not suggest the future or recent past as topics, likely because "their memory is good from the past. So go based on the past, because that's what they know best, and it's easier to communicate with them using the past."

Another approach is "just basic: Talk about the day" rather than "more detailed conversations about things happening in the world [that one would have] with regular seniors."

Another strategy is to compliment the residents. For example, when residents are "just getting their hair done, brush their hair, and you compliment them: 'Oh, my goodness, you look so lovely. You still look sixteen years old. Oh, I love that'—just compliments all the time, and that that helps them." See Appendix F for quotations from the caregivers related to this theme.

Simple words. The caregivers recommended the use of simple words, because the disease reduces residents' ability to understand the meaning of some words: "Simple words, one thing at a time, because they will be confused." They also recommended avoiding "complicat[ing] anything with big words, because they probably have no idea what those words are any more," and refraining from using uncommon vocabulary and slang to ensure that the residents are familiar with the words that they use. Furthermore, to get a point across,

> if they don't understand one thing you talk to them about, then you change your wording or you say it differently or simplify it more or whatever, because eventually the simple words they can understand. It's just the difference as they go down.

See Appendix F for quotations from the caregivers related to this theme.

Getting to know the residents. Another strategy for effective communication is to get to know the residents to tailor strategies to each individual and the specific interaction, because success "depends on the person, and what works with one doesn't work with the other." The caregivers' strategies to get to know the residents included the following: "To learn their past., . . . get to know them and you learn, and then you read also their . . . chart, and then you get to know this person, what their likes and dislikes [are]." Other strategies are to talk to other caregivers or the family about 'how they handle things'" to "kind of learn from other staff what works in their experience"; to spend time with the residents, because "by being with someone all the time you kind of . . . tune into them"; and "When the resident is new, I'm trying to talk to the resident so that I can see if she can hear good or if she can understand you more in action. Then that's what I do."

Becoming familiar with the residents informs the caregivers of effective strategies in multiple domains; the caregivers specifically mentioned humour, eye contact, willingness to talk about their past, and gaining their compliance: "You can laugh and be goofy but that comes from knowing them too, who you can do that with and who you can't." Similarly, it is important to know about eye contact: "Some of them don't like eye contact. Once again, it's getting to know them."

One caregiver reported that, once one knows the residents and their capabilities, "the most important thing is to adjust into their level" to make the communication effective. However, another caregiver that that adjusting to a resident's level can be a challenge:

> I think you've got to reach each person at their own level, so that can be the challenge. Saying to one person "Do you want to watch [TV]?" Or the radio even: "Do you want this type of music on?" They might be able to tell you what they like, whether it's country or blues or something, where another might tell you they don't know what music is until you put it on, and then they can tell you if they like something. And some just like the sound or don't like the noise, so each person's different. So I think it's finding out what triggers them, and then once you know that, communicating with them is second nature.

Simple sentences. Using simple sentences and stating thoughts or questions more simply is also a strategy to enhance the effectiveness of communication. Some caregivers recommended using short sentences to ensure that the residents understand what they are saying: "Don't use anything like big huge sentences, because they won't be able to catch what you're saying. Just use simple words, simple sentences." Another also recommended "very short sentences. Don't go into a long explanation, because you've lost them right off the hop." A third caregiver suggested that the use of simple sentences decreases the demands on residents and can prevent them from becoming flustered: "Simplify the questions . . . so that you're not demanding too much of them at once. That's the big thing, because that just gets them flustered."

Many caregivers pointed out the need to use multiple short sentences—one thought or concept at a time:

> Just simple sentences, . . . simple words, one thing at a time, because they will be confused. They're already confused. But if you will say, "Oh, let's put this in the garbage, and then after that . . . ." That is very confusing. So it's one sentence, three or four words at a time.

In the same vein, another caregiver indicated the importance of "simple directions and instructions so that it's easy for them to understand as opposed to a big, long story of how to put your stockings on in the morning." Another caregiver illustrated this concept nicely:

> "We're going to make our bed." We're not going to sit there and say, "Okay, today we're going to make our bed and we're going to get dressed and we're going to do this and we're going to do that." We do one thing at a time, and so just keeping the tasks little. Or if you're going to ask them a question about how they are and what they are doing and blah blah

> blah, don’t give them three questions all at once. Give them one question. Simple. And then the next question. And then wait for them to respond.

Talking slowly. Another strategy was “to slow your words down”: “Keep it simple and slow, . . . not boring slow, but . . . some people really talk really, really fast, and then [the residents respond] ‘What?’” Although many caregivers mentioned the need to talk slowly to people with AD, only one caregiver elaborated:

> The speed at which you speak really makes a difference. If you blah blah blah blah blah blah a whole bunch of instructions, then they’re lost. Or if you talk too fast, they’re lost. But if you give them one part of the instruction at a time and speak slowly and face them try not to have your head in the drawer looking for socks when you’re trying to tell them to do something or ask them to do something, because they have no idea what you’re trying to communicate to them.

Some caregivers find that slowing down and maintaining a slow pace is “not always the easiest thing to do.”

Humour. Another strategy is to use humour: “You also have to have a good sense of humour with them. That works very, very well.” Caregivers often laugh, have fun, tease, and joke to communicate better with residents and make them laugh. One caregiver uses humour to gain residents’ attention in addition to making them laugh:

> I try to play like a kid. I’m dancing, or I’m pretending I’m singing, or I’m doing exercise. Yeah, just to get their attention. Then once I’ve got their attention, for sure then they’re going to smile at me or they’re going to laugh at what I’m doing.

Residents with AD seem to maintain their sense of humour: “I find they’re very easy to joke around with. They have great senses of humour”; and

> If you’re singing and humming and whatever, it just makes looking after them that much better. If you’ve got to make a funny face or whatever to get someone laughing so be it. . . . I think if people outside of my work saw me: “How old are you?” But . . . it’s all about making the residents’ day.

However, the caregivers cautioned that not all residents appreciate humour, so it is important to be aware of the personality of those with whom they interact: "I think of the residents that I work with, and you can laugh and be goofy, but that comes from knowing them too," who will appreciate humour. See Appendix F for quotations from the caregivers related to this theme.

Nonverbal. Residents might be better able to understand something that they cannot comprehend verbally with the use of body language or a combination of the two. The caregivers' nonverbal strategies to communicate and understand the residents included facial expressions, eye contact, gestures, and touch. For example, they look "for the physical clues of what [the residents are] trying to tell you." Facial expression, specifically smiling, is a common strategy because the residents are attuned to it: "Smile all the time, because . . . they know that everything's good. You need . . . a happy approach, because they can read you pretty good. If you're sad or upset, they'll be able to read that"; and

> You know how you come up to a person and speak to them, and you're smiling at them? Like we say, we read their body language, but they also read yours, and I think that's very important. And even if they can't find the words to say, they know if you're smiling and you say "Hi." . . . They're happy as you are happy, and I think it makes their day.

One caregiver mentioned winking: "sometimes it's as simple as walking past somebody that you've gotten a relationship with or something and winking or whistling, and they get the big smile, and they're happy and they're content again for twenty minutes." A caregiver explained why smiling is important in communication with residents: "Isn't it nicer to see a smiling face than a grumpy face? And if it's a face you don't know, it's the smiling face that gets the candy. Let's put it that way." Smiling is a means of gaining compliance and making residents happy.

The caregivers use facial expressions not only for expressive communication, but also for receptive communication. Being attuned to residents' facial expressions helps the caregivers to determine the best way to interact with the residents:

> If they're looking happy or they're looking sad and you're trying to make them laugh and they're not wanting to, . . . sometimes it's very important, the expression of the face, because whenever you see the expression and

> see that they’re not happy, you know you’d better just also leave them for a while until the anger calms down.

Another nonverbal communication strategy is to make eye contact: “Eye contact is very important. If you look at them face to face and your facial expressions say everything to them.” Eye contact informs the residents that you are trying to communicate with them and increases the likelihood that they will read your body language and facial expressions.

The caregivers use gestures to communicate with residents when words by themselves are not effective: “Sometimes if they’re not very verbal, that can be a challenge too, to communicate what you want them to do, usually by actions and that and gestures, and they’ll do it”; and

> To show them as you do it, to show as you speak. You don’t say, “go over there and wash your hands”; you say, “Come with me. Let’s wash our hands and do it together,” and show them what you want them to do. And that applies to just about everything: Have some actions with your words, some demonstration.

Examples of gestures that the caregivers use are in the area of self-care:

> Action is the best, like going to the bathroom, let’s say. To sit down I show [them how] like to sit down. And to eat, I’m showing “Let’s sit down, and we’re going to eat” with action. Sometimes it helps.

In addition, “Nonverbally, it would be cues, like ‘Brush your hair,’ using your hand movements to get them to brush their teeth.” The caregivers use gestures not only to assist residents with their self-care, but also to ask them to move from one location to another:

> Sometimes I motion them to come, or I motion them to do something, because sometimes you say, come here and they don’t know how to, so you go like this to them [motioned with hand to come]. Or you’ll say “Sit,” and you pat. I don’t know if it’s [that] they don’t understand that you mean sit and she doesn’t know what to sit is any more, so you just go like this [pats the chair]; then they get it.

The caregivers use gestures to communicate their messages as well as to understand what the residents are trying to communicate. For example, a caregiver described her strategy to determine which outfit a resident would wear:

You take two things and then get them to try to choose what they want. The best way to do [it] is, get them to come and show you. Take their hands and let them show what they're trying to say.

Proximity to residents in communicating with them is important not only because it is easier for the residents to observe the caregivers' facial expressions and gestures and vice versa, but also because it facilitates communicating by touch. Physical contact can convey warmth and affection to the residents to make them feel supported. Examples of touch include hugging them, holding hands, kissing them, rubbing [a hand or an arm], and putting an arm around them. Caregivers use touch to communicate that they care and are not angry and to show friendship, love, and trust. Touch also makes the residents feel safe and calm down when they are upset:

> But there's not an elder around that does not like to be hugged, not like to be talked to. When you guide a person, you hold their hand so they can feel safe, because it's a real scary disease. They're scared an awful lot because they just don't know any more.

The caregivers affirmed that they must use touch cautiously, gently, to avoid frightening the residents. Although they asserted that most residents with AD benefit from and enjoy touch, they also warned that not all residents do. The rules for touching seem to different between residents with AD and the average adult. One caregiver observed that, compared to her use of touch with AD residents, "with an average adult I'd have to get to know them a lot better first." Similarly, another caregiver indicated that a resident "who is quite cognitively impaired and a child may be at the same level in a lot of ways, so [the way that one would communicate with those two groups is] not going to change. But if you're suddenly going to working with teenagers or adults obviously winking at them would be inappropriately taken. Or touching them, like hugging." See Appendix F for quotations from the caregivers related to this theme.

CHAPTER V:

DISCUSSION

The objectives of this study were (a) to assess caregivers' implicit attitudes toward aging in general and beliefs about aging and AD specifically in the social, physical, and cognitive domains; (b) to observe interactions between caregivers and persons with AD for evidence of the social creation of dependency in behaviour and talk addressed to persons with AD; (c) to examine the relationship between caregivers' attitudes and beliefs and dependence-supportive behaviour and talk; and (d) using a semistructured interview methodology, to acquire a greater understanding of caregivers' beliefs about AD, views on caring for persons with AD, and communication with persons with AD.

To address these objectives, I asked the caregivers of persons with AD from three residential Alzheimer care centres to complete an explicit measure of their beliefs about aging and AD in the social, cognitive, and physical domains and an implicit measure of their attitudes toward aging (age IAT). I then observed these caregivers interacting with residents of the Alzheimer care centres as they prepared a meal together. I coded the videotaped interactions that demonstrated the caregivers' use of patronizing speech, dependency, independence, and engagement-supportive behaviours and the residents' dependent, independent, and engaged behaviours. Subsequently, I interviewed the caregivers on their beliefs about AD, caregiving philosophy, and communication with persons with AD. I compared their stated beliefs about AD with the results of the beliefs questionnaire and compared and contrasted their caregiving philosophies with their behaviour. The next section compares the caregivers' strategies to communicate with people with AD with the recommendations from the literature.

Objectives 1 and 4: Caregivers' Beliefs About AD and Attitudes Toward Aging

The IAT implicitly measured the caregivers' attitudes toward aging. I predicted that their attitudes would be negative because of the suggestion that, because they are frequently exposed to older adults who are frail and ill, health care personnel might be particularly susceptible to negative attitudes, more so than those who do not work in the industry (Kearney et al., 2000; Palmore, 1998; Stevens & Crouch, 1995). Consistent with this prediction, I found that the caregivers' attitudes toward older adults in general were negative. The mean IAT effect with this sample of caregivers was .951 (SD = .44); this positive effect indicates a negative bias toward older people. The caregivers' IAT effects ranged from -.027 to 1.63. Consistent with the findings in the literature, most caregivers displayed a negative attitude toward aging. Only one had a very small positive bias toward older people. Many studies have shown that health care personnel have negative attitudes toward older adults (Huber et al., 1992; Kearney et al., 2000; Lookinland & Anson, 1995; Roberto & Carmichael-Schwab, 1995; Slevin, 1991).

I assessed the caregivers' beliefs about aging and AD in three domains, cognitive, social/emotional and physical, by using two methods, administering the beliefs questionnaire (objective 1) and interviewing the caregivers (objective 4). In the interviews I asked the caregivers to describe people with AD and then, more specifically, how people with AD are different cognitively, physically, and socially from typical older adults. I predicted that the results of the beliefs questionnaire would be consistent with the themes that emerged from the interviews and the beliefs that the literature identified.

When I compared the caregivers' ratings of typical older targets and typical persons with AD on the beliefs questionnaire, I found significant differences in the cognitive domain. The caregivers believe that persons with AD are less capable than typical 75-year-olds in the areas of communication, memory of recent events, distraction, and wisdom/intelligence. However, they believe that the long-term-memory capabilities of persons with AD are no different from those of typical 75-year-olds. These beliefs are consistent with those that the literature identified (Ryan, 1992; Ryan et al., 1992, Ryan & Kwong See, 2003) and with the beliefs that the caregivers stated in the interviews. The themes in the cognitive domain that emerged from the interviews were deficits in recent memory and communication and spared abilities in long-term memory. These themes are consistent with the caregivers' responses to the beliefs questionnaire and offer evidence of the validity of the cognitive domain in the beliefs questionnaire. Other themes that emerged in the cognitive domain were disorientation to person, time, and place; these themes are not represented in the beliefs questionnaire. Cognitive declines with AD are believed to be larger than the declines expected with normal aging in all areas except long-term memory.

A comparison of the caregivers' ratings of typical persons with AD and typical 75-year-olds in the social/emotional domain on the beliefs questionnaire revealed the perception that persons with AD are worse storytellers, less happy, more suspicious, and no different in terms of social interaction, benevolence, cantankerousness, or amenability to help. The caregivers' patterns of beliefs about AD in the social domain differed from those of undergraduate students who completed the same measure (B-AD, Rust & Kwong See, 2010). These students revealed more negative beliefs in all social constructs for AD, whereas the caregivers in the current study displayed more negative beliefs only in the areas of storytelling, happiness, and suspiciousness. Overall, the beliefs about persons with AD in the social domain were more negative than the beliefs about typical 75-year-olds. This overall result is consistent with that of Kahana and Kahana (1996), who compared nursing home employees' attitudes toward well elderly and persons with AD using the items warm, pleasant, wise, good, optimistic, generous, friendly, cooperative, acceptable, and profit from help, which are mostly social in nature. Their overall evaluations were more negative for persons with AD than the well elderly for all of the items except optimistic. The beliefs that the beliefs questionnaire revealed in the social/emotional domain were not consistent with the themes from the caregivers' interviews. The themes that emerged in the social/emotional domain included aggression, agitation, moodiness, and social withdrawal. The caregivers noted that residents are aggressive, agitated, and moody and that they frequently withdraw socially; however, some seek social interaction. The themes of agitation and aggression from the interviews fit into the category of cantankerousness, but there was no significant difference in the ratings of that construct between old and AD.

When I compared the caregivers' ratings of AD and typical 75-year-olds in the physical domain on the beliefs questionnaire, I found that the caregivers considered persons with AD only more likely to be at risk for injury. All other items (sight, taste, hearing, and active) did not differ significantly. The caregivers' overall beliefs about AD in the physical domain differ markedly from those of the undergraduate students who completed the same measure (Rust & Kwong See, 2010). The caregivers' beliefs about persons with AD were more negative than those about typical 75-year-olds, whereas the undergraduate students' beliefs about persons with AD were more positive than those about typical 75-year-olds. The pattern of beliefs also differed greatly between the caregivers and the undergraduate students in that the caregivers perceived no difference in physical abilities between typical 75-year-olds and persons with AD, except that persons with AD are at greater risk for physical injury. The undergraduate students, on the other hand, believed that persons with AD have a higher level of activity and better sensory functioning than typical 75-year-olds (except for taste, for which they saw no difference). They also believed that persons with AD are no more likely than typical 75-year-olds to be at risk for injury. The undergraduate students' positive view of the physical aspects of AD might be a result of the belief that AD is solely a disease of the mind. It is also possible that this difference is the result of the belief that typical institutionalized persons with AD are younger than 75 years old and are therefore in better physical health than typical 75-year-olds and of the more realistic view of caregivers, who are more exposed to persons with AD. A great deal of research has been conducted on sensory functioning and strength in aging, but the literature has not emphasized these areas with AD, which makes it difficult to determine how much the beliefs of caregivers are linked to reality.

The caregivers' beliefs in the physical domain on the beliefs questionnaire correspond, for the most part, to the beliefs that they stated in the interviews. The themes that emerged in the physical domain with regard to people with AD were physical strength, physical deficits, and a lack of difference physically from other older adults. The latter theme was the most common, which corresponds to the results in the physical domain on the beliefs questionnaire. However, caregivers' beliefs vary in the physical domain. They described some residents as physically strong. They work with strong residents, and some have had experience with strong, aggressive residents. The caregivers noted that other residents have more physical deficits than other older adults and described them as "a lot closer to death" and "tired a lot of the time." These beliefs correspond with the results from individual items in the beliefs questionnaire. On the item "Are physically strong people," the caregivers rated persons with AD as stronger (M = 4.04) than typical 75-year-olds (M = 3.73); and on "Have a lot of energy," they rated persons with AD as weaker (M = 3.69) than typical 75-year-olds (M = 4.19). The themes that emerged from the caregivers' interviews are consistent with their responses on the physical domain in the beliefs questionnaire and validate the physical domain.

Some caregivers (23%) completed the beliefs questionnaire shortly before their interaction with the residents, which was only about an hour before their interviews, whereas most completed the questionnaire days before their interaction and interviews. The items might have been fresh in the minds of the former caregivers, which could explain the consistency between the themes that emerged from the interviews and the questionnaire items. However, this was unavoidable because many of the caregivers have responsibilities outside of work (other jobs and caring for children or grandchildren), and it was difficult for them to find time to participate in the study.

Significance and usefulness of the B-AD**.** Overall, the easily administered beliefs questionnaire captured well what the caregivers said about persons with AD in the interviews. The B-AD can be used to obtain information about people's beliefs about aging and AD more efficiently and systematically than other means such as interviews. However, the interviews also provided insight into items that need to be added to the questionnaire when it is refined: moodiness, aggression, and disorientation to person, time, and place. Moreover, the instrument has now been used with undergraduates and professional caregivers (Rust, 2005; Rust & Kwong See, 2010). The findings on the nature of beliefs about AD and the differences across the respondent groups fill an identified gap in the literature. The questionnaire could be used with additional respondent groups to examine how beliefs differ as a function of training or experience with the disease, for example.

Overall, the caregivers' beliefs about AD were the most negative in the cognitive domain, less negative in the social/emotional domain, and the least negative in the physical domain. That their beliefs were the most negative in the cognitive domain is consistent with what I expected, because AD is characterized by progressive memory loss and loss of cognition.

Research has suggested that people are more likely to seek information that confirms their beliefs (Trope & Thompson, 1997) and to remember it (Hirt, McDonald, & Erikson, 1995) than information that is inconsistent with their beliefs. This could cause caregivers to overlook information that is inconsistent with their beliefs when they interact with persons with AD. Because the course of AD can differ for different people, it is important to base interactions on each person's actual abilities rather than on beliefs about their capabilities.

Many of the caregiver's beliefs in the cognitive domain match real-world situations. Persons diagnosed with AD typically perform worse on cognitive tasks than healthy older adults (who typically perform worse on average than healthy younger adults). The belief that there is no difference in long-term memory, on average, between older adults and persons with AD, however, is surprising because, though long-term memory is more preserved than short-term memory, it is typically not as good in persons with AD as it is in normal aging. In the physical domain the caregivers did not perceive decline with AD compared to normal aging, except for the risk of residents' injuring themselves, which is surprising because persons with AD typically have physical impairments.

Stereotypes are rigid and oversimplified sets of beliefs that are applied to all members of a group or category of people. These sets of beliefs offer insight into how others are likely to behave and how we ourselves should behave in social encounters, but oversimplified sets of beliefs become overgeneralized and result in behaviours that are not appropriate when the stereotypic beliefs do not fit the situation. Gathering information about the beliefs of groups of people about other groups of people is a start to identify people’s stereotypes. Many stereotypes have a statistical basis and are applicable, on average (e.g., men are taller than women); others are widely held cultural beliefs that are not applicable, on average (e.g., blondes are stupid). However, the problem with stereotypes is that, though they are applicable many times, on average, or for some members of a group, they are not applicable to all of the individual members of a group. When a stereotype is applied to all members of a group, it is sometimes correct, but many times it is incorrectly applied to exceptions to the generalization. Stereotypes reduce the cognitive effort required in day-to-day life because they tell us what a group is like in general. The B-AD identifies the beliefs of caregivers in the social, cognitive, and physical domains.

Objectives 2 and 3: The Creation of Dependency for Institutionalized Persons With AD and the Factors That Predict Caregivers’ Behaviours

This is the first study that has applied Baltes’s (1988) systematic observation method to an AD sample. Baltes et al. (1987) observed the residents in a nursing home in the morning, before lunch, and again before dinner and found that they were engaged in dependent self-care behaviour 3% of the time; and Baltes et al. (1980) observed residents in a nursing home during self-care activities and found that they were engaged in dependent self-care behaviour 10% of the time. In the current study I observed dependent self-care behaviour 27% of the time. This difference is likely a result of the difference in the nature of the task. Baltes et al. (1980) and I both observed engagement-supportive behaviour as the most common behaviour of caregivers, followed by dependence-supportive behaviour and independence-supportive behaviour.

In the current study I investigated the dominant pattern of interactions between persons with AD and their caregivers. I computed the sequential conditional probabilities and the conditional probabilities of the consequent events (caregiver behaviours) and compared them with their base probability (ratio of the observed frequency of specific caregiver behaviour to the sum of all observed caregiver behaviours). A statistically significant deviation of the conditional probability from the base probability indicates that that particular behaviour follows the antecedent resident behaviour with a probability that is greater than chance.

Residents' dependent behaviour serves as prompts to secure caregivers' dependence-supportive behaviour. This is consistent with the dependence-support script, the dominant script among older adults and their caregivers (Baltes et al., 1980; Baltes et al., 1983; Baltes et al., 1987; Barton et al., 1980; Lester & Baltes, 1978). This script occurred even though the caregivers were in situations in which they were allowed as much time as they needed to complete the task of making grilled cheese sandwiches with the residents, they were interacting with only one resident (thus there were no competing demands from other residents), and they knew that they were being observed, so would likely be on their best behaviour. Under these circumstances it is surprising that the dependent behaviour of the residents was not followed more frequently by independence-supportive behaviour of the staff (e.g., breaking down the task into smaller tasks that the residents could do independently and cueing, prompting, or encouraging them to try to do the task), which would have been consistent with the values and goals that the caregivers expressed in their interviews. For example, one caregiver indicated that even if it takes longer for a resident to complete a task than it would to do it him- or herself, it is worth persevering, because

> if you keep doing everything for them, then it's like they have no sense: "What's the purpose of me being here now? I can't even button my own shirt." So you just let them. So what [if] it takes a little bit longer? Just let them do it. . . . If you keep doing everything for them, they're going to forget. Just like if you do everything for your kids, they're never going to know anything.

Another caregiver suggested cueing residents:

> Let them be independent as much as they need to be. You can cue them on things and just care for them as if they're a regular normal person, . . . because they would lose their independency and they wouldn't be able to do anything if you wouldn't let them do anything.

This finding that caregivers’ behaviours do not correspond with their philosophy is consistent with Rose and Pruchno’s (1999) finding that the behavioural interaction sequences at an assisted living facility that had a philosophy of independence did not differ from the sequences at a nursing home that did not have the same philosophy.

Residents’ independent behaviour secures a variety of behaviours from caregivers: independence-supportive behaviour, engagement-supportive behaviour, and no response. This finding differs from that obtained of Baltes and colleagues (e.g., Baltes et al., 1983), who found an independence-ignore script in which resident independence does not secure a reaction from the social ecology. This inconsistency could be a result of many things. The majority of Baltes and colleagues’ work took place in Germany between 10 and 30 years ago to recognize changes in the nursing culture; nursing-home staff’s attitudes, values, goals; and cultural differences. However, it is more likely that these differences are the result of the one-on-one interactions between caregivers and residents in which the caregivers were under no time constraints in the current study. These factors need to be investigated further. The independent behaviours of residents, such as setting the table, buttering bread, or retrieving cheese from the fridge, were the most frequent behaviours that I observed, and they comprise 65% of all of the observed resident behaviours. This independent behaviour resulted in the caregivers’ dependence-supportive behaviour 9.3% of the time, which indicates that the caregivers were sometimes ignorant of the residents’ competence. Baltes et al. (1980) found that caregivers’ dependence-supportive behaviour followed residents’ independent behaviour 22% of the time, and Baltes et al. (1987) found that caregivers’ dependence-supportive behaviour followed residents’ independent behaviour about 4% of the time, a rate that is greater than chance. This incongruent application of dependence-supportive behaviour when residents display independent behaviour could foster a decline because the residents are being robbed of the chance to maintain the abilities that they still have (Baltes et al., 1994). Assisting people only when required fosters independence; more independent behaviour contributes to greater autonomous functioning in the elderly (Baltes et al., 1994; Baltes & Wahl, 1992). Unneeded assistance can accelerate physical disability. Even though the percentages of caregivers' dependence-supportive behaviours following residents' independent behaviours are not high, they create a negative feedback loop reinforced by operant principles that can increase their occurrence.

The interviews with the caregivers shed some light on why caregivers' might display dependent-supportive behaviour even if residents exhibit independent behaviour. One reason is that caregivers are concerned with residents' safety, and a caregiver discussed her goal of maintaining the residents' independence:

> When we were doing the sandwich thing, the only thing I was scared about was the stove. That was the only thing that I have concern about, because when you have a person in care, that you're caring for, I would feel ever so bad if that person got burned. So when you look at if maybe I shouldn't have been doing what—I was over there and I turned the stove on; I didn't want her doing that, because they don't know the controls and stuff, and I don't want them to get hurt.

Another reason that caregivers use dependence-supportive behaviour is that it takes less time to do a task than it would take the resident to do it, and "it's always easy to do stuff for everybody." So even though many caregivers reported in their interviews that they value maintaining the residents' independence, it can be difficult to behave accordingly.

There was a significant increase in the conditional probability of no response from the caregivers from its base probability following residents' independent behaviour, whereas there was a significant decrease in the probability of no response from the caregivers after residents' dependent and constructively engaged behaviour. Residents' independent behaviour is more likely to secure a no-response behaviour from caregivers than is dependent or constructively engaged behaviour. According to the behavioural principles, regular exposure to such a contingency could reduce residents' independent behaviour and increase their dependent and constructively engaged behaviour.

Residents' constructively engaged behaviour secures caregivers' engagement-supportive behaviour. This behaviour of residents, such as talking to or listening to the caregiver, is almost exclusively followed by caregivers' engagement-supportive behaviour. This is consistent across all three themes that emerged from the caregivers' responses about their values and goals for their interactions with residents and with Baltes, Honn, et al. (1983) and Baltes et al.'s (1987) findings, but it is inconsistent with the findings of Stabell, Eide, Solheim, Nasselqvist Solbert, and Rustøen (2004), who observed mealtimes in a nursing home in Norway. They found that the staff mostly ignored the social engagement of the residents and were more concerned with practical assistance with mealtime behaviours than with the psychosocial needs of the residents. They found that nursing students and casual staff were more likely than regular staff members to talk to the residents.

The Alzheimer care centres in which I conducted this study are specialized dementia-care settings. They have more homelike environments than most nursing homes within the same organization, and the culture might be different. A study with larger samples and in different settings or one in which the researcher observed naturally occurring behaviours could shed light on the differences in the findings between this study and previous work. In the current study the caregivers were paired with residents whom they did not know, whereas Baltes's studies (Baltes et al., 1980; Baltes et al., 1983; Baltes et al., 1987; Barton et al., 1980; Lester & Baltes, 1978) observed the caregivers on their usual units. Perhaps caregivers are more likely to encourage independence if they are familiar with residents' capabilities.

It is also possible that a reactivity effect influenced the results. Two video cameras in the family dining room recorded the interactions. A few residents asked the caregivers about the cameras, and they were constant reminders to the caregivers that their interactions were being observed. This might have prevented them from acting naturally. However, having actual observers in the room would likely have been more intrusive.

Because the sample size was insufficient for straightforward statistical inferences about the role of beliefs about AD and the role of caregivers' characteristics in the creation of dependency, I used bootstrapping but could not reduce the model. Therefore, one can only regard the results of the multinomial logistic regression as suggestive.

Baltes and Wahl (1992) speculated that caregivers' beliefs contribute to the dependence-support script. These results extend Baltes's (e.g., 1988) work and offer some support and directions for future research. I found that more positive beliefs about the cognitive abilities of persons with AD increase the odds of caregivers' independence support rather than dependence support following residents' dependent behaviour and that more positive beliefs about AD in the social domain decreased these odds. If caregivers believe that persons with AD are more cognitively capable, they are more likely to encourage independence when the residents are dependent, but when caregivers believe that persons with AD have better social capabilities, they are more likely to encourage dependence. More negative implicit attitudes toward aging increases the odds of engagement-supportive behaviour rather than dependence-supportive behaviour following residents' dependent behaviour. Caregivers with more negative attitudes toward aging could experience cognitive dissonance so that their negative attitudes toward older people conflict with their role of caring for older adults; perhaps instead of helping the residents, they choose to talk to them instead (engagement supportive) because they feel a social obligation to do something.

More positive beliefs about AD in the social domain and having worked with older adults longer decrease the odds of engagement-supportive behaviour rather than dependence-supportive behaviour following residents' dependent behaviour. Perhaps caregivers with more positive beliefs about AD in the social domain (if they see them as kind, nice people) want to do things for the residents because they want the residents to like them. One can speculate that the belief that persons with AD are more socially capable leads to more dependence-supportive behaviour because caregivers' engagement-supportive behaviour might result in residents' spending too much time being social and caregivers' requiring more time to complete their caregiving tasks. When caregivers have worked with older adults longer, they are more likely to be dependence supportive when the residents are dependent, possibly because the medical model of care, which puts the physical needs of residents first, is engrained in them. Also, caregivers who have worked with older adults longer have had more time to be shaped by the dependence-support script.

The odds of caregivers' engagement-supportive behaviour rather than dependence-supportive behaviour following residents' independent behaviour were greater when the caregivers rated themselves as more effective and less when they had worked with older adults longer.

When I analyzed the more specific beliefs of the caregivers rather than the domain scores, I found that the odds of caregivers' independence-supportive behaviour (rather than dependence-supportive behaviour) following residents' dependent behaviour were greater when the caregivers considered people with AD less at risk for injury and more accepting of help. Similarly, the odds of caregivers' independence-supportive behaviour (rather than dependence-supportive behaviour) were also greater following residents' independent behaviour when the caregivers considered people with AD more accepting of help. This suggests that caregivers support the independence of residents more if they consider people with AD less at risk for injury and more willing/less resistive to being helped. This offers some support to the theory that caregivers' beliefs about the characteristics of people with AD guide their behaviours. If caregivers' beliefs rather than the abilities of residents guide their interactions, it could have consequences for the independence of residents.

Hummert (2011) suggested that patronizing speech is one way that age stereotypes operate implicitly to exert an unconscious influence on behaviour. We predicted that caregivers' beliefs about AD in the cognitive and social domains and their attitudes toward persons with AD would predict patronizing speech, which means that more negative beliefs about and attitudes toward AD predict a greater use of patronizing speech.

Inconsistent with the prediction, none of the caregivers' beliefs predicted the number of tag questions per utterance. Consistent with the prediction, their beliefs about the poorer long-term memory of persons with AD are related to a greater use of diminutives, and their beliefs about the greater resistance to help of persons with AD are related to a shorter mean length of the utterance. Residents' age, functional ability, and cognitive ability did not predict patronizing speech; rather, the use of diminutives and the mean length of the utterance seems to be based on the caregivers' beliefs about persons with AD.

Whether it is helpful or not, patronizing speech can have negative effects on older adults. Kemper and Harden (1999) showed that older adults who were spoken to patronizingly rated their own communication abilities as worse than those of older adults who were not. Also, younger listeners rated the recipients of patronizing speech as less capable than the recipients of normal speech (Hummert & Ryan, 2001; Ryan et al., 2007). These studies provide evidence for a negative feedback loop and the CPAM (Ryan et al., 1986).

There is also evidence of the effects of patronizing speech on persons with dementia. Cunningham and Williams (2007) found an association between patronizing communication and disruptive behaviours among persons with dementia. Similarly, Williams et al. (2009) found that the residents of an Alzheimer care centre were more likely to resist care or behave disruptively when they were addressed in a patronizing manner than in a nonpatronizing manner.

Persons with AD face cognitive and behavioural impairments that decrease their ability to communicate, and the literature has suggested many communication strategies for caregivers of persons with AD to compensate for these impairments. Small et al. (2003) reviewed the literature and found 10 recurrent communication strategies for caregivers of persons with AD: eliminating distractions; approaching them slowly and from the front and establishing and maintaining eye contact; using short, simple sentences; speaking slowly; asking one question or giving one instruction at a time; using yes/no rather than open-ended questions; repeating messages using the same wording; paraphrasing repeated messages; avoiding interrupting them and giving them plenty of time to respond; and encouraging them to "talk around" or describe the words for which they are searching. However, Small et al. found that speaking slowly results in communication breakdowns, whereas using simple sentences, eliminating distractions, and asking yes/no questions are effective. Hopper's

(2001) communication strategies for caregivers to facilitate communication with persons with AD include simplifying syntax, ensuring that the speech rate is not too slow but not very rapid, repeating and rephrasing, asking choice or yes/no questions, using high-frequency words, avoiding the overuse of pronouns, providing contextual support, and validating rather than confronting.

The strategies identified by the caregivers in the current study to maximize the effectiveness of communication with residents with AD include tone of voice, patience, repetition, clarity and specificity, topic of conversation, simple words, getting to know the resident, short sentences, talking slowly, humour, and nonverbal strategies. The caregivers' strategies of using humour, getting to know the resident, tone of voice, and topic of conversation are absent from the list of recurring strategies from the literature that Small et al. (2003) compiled and from the strategies that Hopper (2001) presented.

The use of humour as a communicative tool specifically with people with AD has received little attention in the literature. In a phenomenological study with registered nurses, Beck (1997) found that humour can be an effective therapeutic communication technique to relieve patients' anxiety, depression, and embarrassment. However, the use of humour as a communication technique with people with AD requires further investigation.

The theme of tone of voice is related to patronizing speech. Two aspects of tone of voice, elevated pitch and volume, are elements of patronizing speech. The caregivers indicated that using a soft, calm voice with a nice tone that is not too loud is a strategy to communicate with residents with AD. Caregivers' theme of tone of voice does not reflect patronizing speech.

Two of the themes, speaking more slowly and using shorter sentences, relate to verbal fluency, an aspect of patronizing speech. Several researchers have demonstrated that slowing down speech is not effective in communicating with persons with AD (Small et al., 2003; Tomoeda, Bayles, Boone, Kaszniak, & Slauson, 1990). The caregivers in this current study recommended the use of short, simple sentences as a strategy. Experimental evidence has shown that simplified sentences aid communication with persons with AD. Rochon, Waters, and Caplan (1994) demonstrated that the use of simplified sentences improves the comprehension of AD patients. In a sentence-picture-matching task, their participants were able to comprehend short, simple sentences more than long, complex sentences. However, Small, Kemper, and Lyons (1997) found that AD patients could understand complex sentences if they were repeated either verbatim or paraphrased. They noted that even though the patients in their study found it difficult to understand the complex sentences the first time that they heard them, they were able to comprehend the complex sentences when they were repeated, which demonstrates that AD patients still have the capacity to understand grammatically complex sentences. Small et al. cautioned that caregivers' use of only simplified speech reduces the opportunity for patients to hear complex sentences and ultimately results in a decline in their ability to understand complex sentences. This has implications for the dementia-care training that caregivers receive.

The caregivers also suggested repetition as a strategy. They recommended repeating sentences verbatim or repeating the idea in different words. Because persons with AD show a decline in their ability to recall information after a brief delay (Morris & Baddeley, 1988), caregivers are required to repeat things frequently. Experimental research has demonstrated the efficacy of both verbatim and paraphrased repetitions for sentence comprehension with AD (Small et al., 1997).

The caregivers' strategy of getting to know the residents has not been mentioned in the recommendations on communicating with people with AD. In the communication enhancement model (Orange, Ryan, Meredith, & MacLean, 1995; Ryan et al, 1995), speech modifications are based on the person's abilities rather than on stereotypes about cognitive and communicative limitations. The strategy of getting to know the residents fits nicely into this model. Focusing on a resident's remaining communicative abilities instead of on stereotypes would help caregivers to modify their speech to the abilities of each resident, thus encouraging and maximizing the use and retention of residents' remaining abilities.

Vocabulary restrictions are an aspect of patronizing speech (Kemper & Harden, 1999). There is evidence that people access common words more easily, which improves comprehension (Bayles & Tomoeda, 1993). However, if the caregivers' strategy of using simple words does not include adapting to the abilities of the resident to whom they are talking, the resident's exposure to the regular vocabulary that might still be in his or her repertoire will be reduced. Over time, a lack of exposure can result in a more rapid loss of vocabulary.

Some of Hopper's (2001) strategies to maximize the effectiveness of communication with persons with AD were not included in the strategies that the caregivers in this study suggested, including using choice or yes/no questions, avoiding the overuse of pronouns, providing contextual support, and validating rather than confronting. In addition to the absence of some of the evidence based strategies, some of the strategies suggested by caregivers have not been backed up with experimental evidence. Recommendations for training caregivers to use strategies for communicating with persons with AD have arisen from evidence-based practice (Zientz et al, 2007). Knowing which strategies and accommodations enhance interactions with persons with AD and which do not could improve communication with residents and alleviate some of the stress of unsuccessful or difficult communication experiences.

Objective 4: Caregivers' Philosophy on Interacting With Residents With AD

Having already discussed the other aspects of objective 4 (beliefs in the cognitive, social, and physical domains and strategies for successful communication) in the context of the other objectives, I will now discuss the caregivers' philosophy on interacting with residents with AD.

I asked participants about their caregiving philosophy for people with AD and their values and goals for their interactions with residents with AD at work. Three themes emerged: ensuring that residents have a good day, showing residents respect, and promoting residents' independence. Caregivers' values and goals for their interactions with residents are clearly consistent with the social model of care (e.g., Boyd, 1994).

The theme of ensuring that residents have a good day involves going above and beyond taking care of their basic needs by making them smile, ensuring that they are satisfied, making them happy, providing comfort, making them content, making them laugh, and ensuring that they are not frustrated or afraid. The perception of happiness contributes to quality of life (Albert, 1997). Cott and Fox (2001) found that the determinants of self-rated happiness for elderly institutionalized Canadians include more frequent attendance in group activities in the institution and a flexible schedule. They suggested that a flexible schedule is associated with choice and control. Control is a determinant of not only well-being, but also functional ability, which thus has implications for self-care. The organizational milieu of institutions that operate under a more medical model is driven by operational efficiency and can result in the loss of control for residents, which is an integral aspect of health and well-being, and in learned helplessness and excess disability (Baltes & Horgas, 1997). The caregivers in this study stressed offering choices to residents as an aspect of showing respect for them.

The theme of showing residents respect includes issues of dignity, treating others as you would like to be treated yourself, privacy, offering them choices, and taking time for them. Since Plato, most philosophers have stressed the essential value of retaining free will to maintain mind and body health. However, the medical model presents little opportunity to exercise free will. Agich (1990) observed that true autonomy is not found in monumental life and death decisions, but in the ordinary decisions of daily living. To be truly autonomous, residents have to be permitted to be who they are and to make decisions about their day that allow them to express their identity. Participating in self-care is important because it is a key aspect of caregivers’ values and goals to promote residents’ independence by doing with the resident instead of doing for the resident, by finding activities that residents can still do, and by breaking up tasks that are too difficult for them into smaller components that they can manage. Agich stressed that promoting independence is also important because it affects residents’ well-being and self-esteem. Caregivers’ values and goals to promote residents’ independence put into action can have profound effects on residents with AD. Beck et al. (1991) cautioned that when caregivers do not encourage or allow persons with dementia to perform the activities of daily living to the full extent of their abilities, their skills deteriorate more rapidly than their cognitive decline warrants, which results in less independence in performing the activities of daily living.

The National Advisory Council on Aging (1999) also recognized that people's psychological, social, spiritual, and cultural needs are as important as their physical needs. Although it is now accepted that person-centred care, individual rights and freedoms, and care that emphasizes the individual's autonomy need more attention, more still needs to be done to put these principles into action (National Advisory Council on Aging, 1999). The caregivers' values and goals demonstrate that these principles are important to them in their interactions with residents with AD.

Limitations and Directions for Future Research

The generalizability of this research is limited given the small sample from only one continuing-care organization. The results might have been affected by the characteristics of the caregivers who volunteered to participate. Future research should involve larger samples of caregivers and residents from multiple organizations and types of facilities. Other limitations of the sample include the vast range in age of both the caregivers and the residents, the vast range in mental and physical abilities of the residents, the vast range in experience of the caregivers who work with persons with AD, and the lack of a control or comparison group (e.g., normal aging, no experience as caregivers).

The Research Unit staff assess and record the residents' cognitive and functional abilities annually, and I collected them from the residents' charts within one and six months of when the assessments were conducted. This is a limitation of the study because the residents' cognitive and functional abilities might have declined since the measures were recorded and the study took place. I had originally planned to collect the data very close to the time that a trained individual in the Research Unit collects this information from the residents. In retrospect, I should have conducted these assessments myself. Similarly, in the Alzheimer care centres, either family physicians or geriatricians diagnose the residents' possible or probable AD, and how accurate the diagnoses are is unknown.

I decided to observe the caregiver-resident interactions in a one-on-one situation, with the same set of tasks, in similar environments, and where the caregiver and resident did not know each other to keep as many factors constant as possible. In dyads of residents and caregivers who are not familiar with each other or the residents' capabilities, it is more likely that the caregivers would behave in accordance with their beliefs and stereotypes about the residents with AD. Also, in one-on-one situations without time limitations in which the caregivers were acutely aware that they were being observed, their behaviours would more likely have been congruent with the ways in which they thought they had been trained to behave. However, this also resulted in a situation that is unnatural. Caregivers are always responsible for the care of more than one resident and have limited amounts of time to complete their tasks. Future studies should examine naturally occurring interactions between residents with AD and caregivers who are familiar with each other and in the context of various tasks and activities.

Another limitation of this study concerned the B-AD. Some of the constructs had weak internal consistency and some were only comprised of single items. Also, some of the beliefs identified in the interviews with caregivers were not represented in the B-AD. Future work should refine the questionnaire.

Notwithstanding these limitations, this study is significant in that it highlights caregivers' beliefs about how older adults differ from younger adults and how persons with AD differ from older adults. This study also suggests that caregivers' behave guided by their beliefs rather than adjusting their behaviours to the specific individual needs of the residents, which can miss opportunities to maximise the residents' independence. Caregivers must be aware of their stereotyped perceptions and beliefs about persons with AD so that they can work toward eliminating their use of overaccommodated and patronizing communication. This is significant because these issues can become the focus of future AD education programs for caregivers.

Although bootstrapping could not reduce the model when I tried to determine the effects of caregivers' characteristics on behavioural sequences, the results of the logistic regression provide direction for future research. Primary among these is the exploration of the role of beliefs about AD in the cognitive domain. More positive beliefs are related to a more independence-supportive behaviour profile, and beliefs about AD in the social domain are related to a more dependence-supportive behaviour profile. Also, caregivers' specific belief that persons with AD are at risk of injury and resist help increases the odds of caregivers' dependence-supportive behaviour. These could be areas of focus for future studies.

The items in the beliefs questionnaire were largely consistent with the themes that emerged from the interviews with the caregivers. However, themes also emerged from the interviews that are not represented in the questionnaire (moodiness, aggression, and disorientation to person, time, and place). For this reason, the aggregate belief scores for the three domains might not accurately reflect caregivers' beliefs. Future studies should refine the questionnaire to include these themes.

Future studies could assess whether caregivers actually use the strategies for successful communication with persons with AD. The caregivers suggested repetition as a strategy, and experimental research has demonstrated the efficacy of both verbatim and paraphrased repetitions in the sentence comprehension of persons with AD (Small et al., 1997). Other research has shown that the use of repetition helps them to comprehend complex sentences and maintains their ability to comprehend more complex sentences. Whether the complexity of caregivers' sentences is maintained when they repeat them to retain residents' abilities is unknown and requires further study.

The theme of getting to know the resident is consistent with person-centred care but has not been stressed in the literature on communication with persons with AD. The specific information that caregivers consider important to know about residents, how they use the information, and whether these strategies are effective should be explored. Similarly, the theme of the use of humour as a tool that caregivers can use to communicate with people with AD has not received attention in the literature. How caregivers use humour and the efficacy of humour as a communicative tool for people with AD requires further investigation.

The focus of this study was the social creation of dependency in institutions. However, in Canada a little under half of the people with dementia live in institutions (Alzheimer Society of Canada, 2010); the other half live in the community. Baltes and Wahl (1992) demonstrated the dependence-support script in community-dwelling older adults who are oriented to person, place, and time, but the creation of dependency has not been investigated with community-dwelling persons with AD.

Implications for Caregivers and Caregiver Training

Communication between caregivers and residents with AD can be a tremendous challenge and one that deserves attention as a central component of caregiver training and education programs. The caregivers identified using shorter sentences as a strategy and demonstrated a short mean length utterance when they talk with residents. However, experimental studies have refuted the effectiveness of this strategy. Similarly, slowing down speech is not effective in communication with persons with AD. It is important to inform caregivers of the lack of evidence of the effectiveness of these strategies with persons with AD and to offer them alternatives.

Because caregivers behave in accordance with the dependence-support script, training caregivers of persons with AD to modify their behaviour to maximise the residents' independence is crucial. Baltes et al. (1994) conducted an intervention study with the staff in two nursing homes and a geriatric hospital in Germany. Residents who were moderately or severely demented were not included in the study. The caregivers' training included basic communication skills, the dependence-support script, behavioural plasticity, behaviour modification, and the social creation of dependency. The caregivers and the residents with whom they were working were videotaped as they interacted during self-care tasks before and after the training, and the videotapes were used to demonstrate helping styles to the caregivers. They then designed, implemented, and evaluated behaviour modification plans based on shaping and reinforcement. The caregivers who received training demonstrated less dependence-supportive behaviour and more independence-supportive behaviour posttraining. Additionally, the caregivers who received training demonstrated more independence-related interaction patterns. Given that the goals and values of the caregivers in the current study are consistent with the maximisation of independence, such a training program would likely be well received by caregivers.

Theoretical Implications

An important contribution of this study is that it provides a greater understanding of the social creation of dependency in AD. Previous research explored the social creation of dependency in persons who were oriented to person, place and time. This study adds to the literature because of the focus on AD. Previous work has assessed caregivers' beliefs about AD quantitatively, this study built on this work by exploring caregivers' beliefs qualitatively. Also unique about this study is the focus on the role of beliefs about AD in the creation of dependency in persons with AD. Additionally, previous work on the creation of dependency has been done in the context of self care; this work explored the creation of dependency in the context of one-on-one caregiver-resident interactions in a meal preparation task. Finally, this study contributes to theorizing about how dependency in old age can be conceptualized. With the focus it has on the important interactions between caregivers and persons with AD, it adds to the body of literature that informs understandings of dependence, independence and interdependence (e.g., Fine & Glendinning, 2005).

Conclusions

The goal of many continuing care facilities is to maximize the independence of their residents. Maximizing the abilities of persons with AD for as long as the disease allows is desired and can be accomplished by reducing the socially created dependency. In this study I found the dependency-support script, that Baltes found with cognitively intact older adults, in an AD sample. Additionally, I found some evidence that caregivers' beliefs about persons with AD guide their behaviour and speech towards persons with AD. This is evidence that dependency can be socially created in AD. Because of the large number of people who are projected to have AD, the abilities of persons with AD need to be maintained for as long as possible. Changes to the social environment of persons with AD can reduce socially created dependency.

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APPENDIX A:

B-AD QUESTIONNAIRE BOOKLET

TRASK 183

We are interested in your opinions. There are no right or wrong answers to these questions. Please take your time and answer each of these questions to the best of your ability.

Each statement is followed by seven choices. Draw a circle around the number corresponding to the number that best represents how you feel about the statement. Circle only one number for each statement.

There are five parts to this questionnaire. Instructions for the next four parts will be given later. The questions in the first part ask for your opinion about your own experiences; for example:

I am a responsible person

S	2	3	4	5	6	7
Strongly Disagree	**Disagree**	**Slightly Disagree**	**Neither Agree Nor Disagree**	**Slightly Agree**	**Agree**	**Strongly Agree**

In this example you could choose any one of the answers. If you agree with this statement that you are a responsible person, you would circle 5, 6 or 7 depending on how strongly you agree. On the other hand, if you disagree with this statement you would circle 1, 2 or 3 depending on how strongly you disagree. Please circle 4 if you neither agree nor disagree with the statement.

Please turn to the next page to begin . . .

For the following statements, please indicate your degree of agreement or disagreement using the scale provided:

1 **Strongly Disagree**	**2** **Disagree**	**3** **Slightly Disagree**	**4** **Neither Agree Nor Disagree**	**5** **Slightly Agree**	**6** **Agree**	**7** **Strongly Agree**

1	I am an intelligent person	1	2	3	4	5	6	7
2	I have a lot of energy	1	2	3	4	5	6	7
3	I have good memory for events from my childhood	1	2	3	4	5	6	7
4	I enjoy life	1	2	3	4	5	6	7
5	I am suspicious of other people	1	2	3	4	5	6	7
6	I am easily distracted by random thoughts	1	2	3	4	5	6	7
7	I find it easier to understand a message when simple words are used	1	2	3	4	5	6	7
8	I do not tell good stories	1	2	3	4	5	6	7
9	I have good memory for events that happened to me long ago	1	2	3	4	5	6	7
10	I feel happy a lot of the time	1	2	3	4	5	6	7
11	I seek social interaction	1	2	3	4	5	6	7
12	I find it easier to understand when spoken to slowly	1	2	3	4	5	6	7
13	I am a physically strong person	1	2	3	4	5	6	7
14	I find that people speak too softly to hear	1	2	3	4	5	6	7
15	I may hurt myself while chopping onions	1	2	3	4	5	6	7
16	I would appreciate help	1	2	3	4	5	6	7
17	I am a physically active person	1	2	3	4	5	6	7
18	I prefer to be with other people	1	2	3	4	5	6	7
19	I have a poor sense of smell	1	2	3	4	5	6	7
20	I have good memory	1	2	3	4	5	6	7
21	I prefer to be by myself rather than to be with other people	1	2	3	4	5	6	7
22	I do not trust other people	1	2	3	4	5	6	7
23	I easily grow impatient	1	2	3	4	5	6	7
24	I am a wise person	1	2	3	4	5	6	7
25	I would be accepting of help	1	2	3	4	5	6	7
26	I am a good story teller	1	2	3	4	5	6	7
27	I am a stubborn person	1	2	3	4	5	6	7
28	I avoid social interaction	1	2	3	4	5	6	7
29	I find newspaper print too small to read	1	2	3	4	5	6	7
30	I am a knowledgeable person	1	2	3	4	5	6	7

31	I am not easily upset	1	2	3	4	5	6	7
32	I have good memory for events that happened recently	1	2	3	4	5	6	7
33	I am a smart person	1	2	3	4	5	6	7
34	I am a caring person	1	2	3	4	5	6	7
35	I am not easily irritated	1	2	3	4	5	6	7
36	I find that my mind wanders to random thoughts	1	2	3	4	5	6	7
37	I may drop a boiling pot of water	1	2	3	4	5	6	7
38	I am a kind person	1	2	3	4	5	6	7
39	I find it easy to hear faint sounds	1	2	3	4	5	6	7
40	I do not experience tastes strongly	1	2	3	4	5	6	7
41	I am argumentative	1	2	3	4	5	6	7
42	I am a friendly person	1	2	3	4	5	6	7
43	I have difficulty seeing small print	1	2	3	4	5	6	7
44	I resist help	1	2	3	4	5	6	7
45	I more and more find that people enjoy my storytelling	1	2	3	4	5	6	7
46	I would spill while pouring hot coffee	1	2	3	4	5	6	7

Please go to part 2 now . . .

Part 2

The format in Part 2 is similar to Part 1. Each question is followed by seven choices. Again, please circle the number that best represents how much you agree with the statement

In this part, you will answer each question with a **"<u>Typical institutionalized person with Alzheimer Disease</u>"** in mind. Some of these questions may be very difficult for you to answer. In such cases, please let your response reflect your best guess.

Please begin now answering the questions for **"<u>Typical institutionalized persons with Alzheimer Disease</u>."**

For the following statements, please indicate your degree of agreement or disagreement using the scale provided:

1	**2**	**3**	**4**	**5**	**6**	**7**
Strongly Disagree	**Disagree**	**Slightly Disagree**	**Neither Agree Nor Disagree**	**Slightly Agree**	**Agree**	**Strongly Agree**

Typical institutionalized persons with Alzheimer Disease:

1	Are intelligent people	1	2	3	4	5	6	7
2	Have a lot of energy	1	2	3	4	5	6	7
3	Have good memory for events from their childhood	1	2	3	4	5	6	7
4	Enjoy life	1	2	3	4	5	6	7
5	Are suspicious of other people	1	2	3	4	5	6	7
6	Are easily distracted by random thoughts	1	2	3	4	5	6	7
7	Find it easier to understand a message when simple words are used	1	2	3	4	5	6	7
8	Do not tell good stories	1	2	3	4	5	6	7
9	Have good memory for events that happened to them long ago	1	2	3	4	5	6	7
10	Feel happy a lot of the time	1	2	3	4	5	6	7
11	Seek social interaction	1	2	3	4	5	6	7
12	Find it easier to understand when spoken to slowly	1	2	3	4	5	6	7
13	Are physically strong people	1	2	3	4	5	6	7
14	Find that people speak too softly to hear	1	2	3	4	5	6	7
15	May hurt themselves while chopping onions	1	2	3	4	5	6	7
16	Would appreciate help	1	2	3	4	5	6	7

17	Are physically active people	1	2	3	4	5	6	7
18	Prefer to be with other people	1	2	3	4	5	6	7
19	Have a poor sense of smell	1	2	3	4	5	6	7
20	Have good memory	1	2	3	4	5	6	7
21	Prefer to be by themselves rather than to be with other people	1	2	3	4	5	6	7
22	Do not trust other people	1	2	3	4	5	6	7
23	Easily grow impatient	1	2	3	4	5	6	7
24	Are wise people	1	2	3	4	5	6	7
25	Would be accepting of help	1	2	3	4	5	6	7
26	Are good story tellers	1	2	3	4	5	6	7
27	Are a stubborn people	1	2	3	4	5	6	7
28	Avoid social interaction	1	2	3	4	5	6	7
29	Find newspaper print too small to read	1	2	3	4	5	6	7
30	Are knowledgeable people	1	2	3	4	5	6	7
31	Are not easily upset	1	2	3	4	5	6	7
32	Have good memory for events that happened recently	1	2	3	4	5	6	7
33	Are smart people	1	2	3	4	5	6	7
34	Are caring people	1	2	3	4	5	6	7
35	Are easily irritated	1	2	3	4	5	6	7
36	Find that their minds wander to random thoughts	1	2	3	4	5	6	7
37	May drop a boiling pot of water	1	2	3	4	5	6	7
38	Are kind people	1	2	3	4	5	6	7
39	Find it easy to hear faint sounds	1	2	3	4	5	6	7
40	Do not experience tastes strongly	1	2	3	4	5	6	7
41	Are argumentative	1	2	3	4	5	6	7
42	Are friendly people	1	2	3	4	5	6	7
43	Have difficulty seeing small print	1	2	3	4	5	6	7
44	Resist help	1	2	3	4	5	6	7
45	More and more find that people enjoy their storytelling	1	2	3	4	5	6	7
46	Would spill while pouring hot coffee	1	2	3	4	5	6	7

Please go to part 3 now . . .

Part 3

The format in Part 3 is similar to Part 2. Each question is followed by seven choices. Again, please circle the number that best represents how you feel about the statement.

In this part, you will answer each question with a **"Typical 75 year old individual"** in mind. Some of these questions may be very difficult for you to answer. In such cases, please let your response reflect your best guess.

Please begin now answering the questions for **"Typical 75 year old individuals."**

For the following statements, please indicate your degree of agreement or disagreement using the scale provided:

1 Strongly Disagree	**2 Disagree**	**3 Slightly Disagree**	**4 Neither Agree Nor Disagree**	**5 Slightly Agree**	**6 Agree**	**7 Strongly Agree**

Typical 75 year olds:

1	Are intelligent people	1	2	3	4	5	6	7
2	Have a lot of energy	1	2	3	4	5	6	7
3	Have good memory for events from their childhood	1	2	3	4	5	6	7
4	Enjoy life	1	2	3	4	5	6	7
5	Are suspicious of other people	1	2	3	4	5	6	7
6	Are easily distracted by random thoughts	1	2	3	4	5	6	7
7	Find it easier to understand a message when simple words are used	1	2	3	4	5	6	7
8	Do not tell good stories	1	2	3	4	5	6	7
9	Have good memory for events that happened to them long ago	1	2	3	4	5	6	7
10	Feel happy a lot of the time	1	2	3	4	5	6	7
11	Seek social interaction	1	2	3	4	5	6	7
12	Find it easier to understand when spoken to slowly	1	2	3	4	5	6	7
13	Are physically strong people	1	2	3	4	5	6	7
14	Find that people speak too softly to hear	1	2	3	4	5	6	7
15	May hurt themselves while chopping onions	1	2	3	4	5	6	7
16	Would appreciate help	1	2	3	4	5	6	7
17	Are physically active people	1	2	3	4	5	6	7

18	Prefer to be with other people	1	2	3	4	5	6	7
19	Have a poor sense of smell	1	2	3	4	5	6	7
20	Have good memory	1	2	3	4	5	6	7
21	Prefer to be by themselves rather than to be with other people	1	2	3	4	5	6	7
22	Do not trust other people	1	2	3	4	5	6	7
23	Easily grow impatient	1	2	3	4	5	6	7
24	Are wise people	1	2	3	4	5	6	7
25	Would be accepting of help	1	2	3	4	5	6	7
26	Are good story tellers	1	2	3	4	5	6	7
27	Are a stubborn people	1	2	3	4	5	6	7
28	Avoid social interaction	1	2	3	4	5	6	7
29	Find newspaper print too small to read	1	2	3	4	5	6	7
30	Are knowledgeable people	1	2	3	4	5	6	7
31	Are not easily upset	1	2	3	4	5	6	7
32	Have good memory for events that happened recently	1	2	3	4	5	6	7
33	Are smart people	1	2	3	4	5	6	7
34	Are caring people	1	2	3	4	5	6	7
35	Are easily irritated	1	2	3	4	5	6	7
36	Find that their minds wander to random thoughts	1	2	3	4	5	6	7
37	May drop a boiling pot of water	1	2	3	4	5	6	7
38	Are kind people	1	2	3	4	5	6	7
39	Find it easy to hear faint sounds	1	2	3	4	5	6	7
40	Do not experience tastes strongly	1	2	3	4	5	6	7
41	Are argumentative	1	2	3	4	5	6	7
42	Are friendly people	1	2	3	4	5	6	7
43	Have difficulty seeing small print	1	2	3	4	5	6	7
44	Resist help	1	2	3	4	5	6	7
45	More and more find that people enjoy their storytelling	1	2	3	4	5	6	7
46	Would spill while pouring hot coffee	1	2	3	4	5	6	7

Please go to part 4 now . . .

Part 4

The format in Part 4 is similar to Parts 2 and 3. Each question is followed by seven choices. Again, please circle the number that best represents how you feel about the statement.

In this part, you will answer each question with a **"Typical 25 year old individual"** in mind. Some of these questions may be very difficult for you to answer. In such cases, please let your response reflect your best guess.

Please begin now answering the questions for **"Typical 25 year old individuals."**

For the following statements, please indicate your degree of agreement or disagreement using the scale provided:

1 Strongly Disagree	**2 Disagree**	**3 Slightly Disagree**	**4 Neither Agree Nor Disagree**	**5 Slightly Agree**	**6 Agree**	**7 Strongly Agree**

Typical 25 year olds:

1	Are intelligent people	1	2	3	4	5	6	7
2	Have a lot of energy	1	2	3	4	5	6	7
3	Have good memory for events from their childhood	1	2	3	4	5	6	7
4	Enjoy life	1	2	3	4	5	6	7
5	Are suspicious of other people	1	2	3	4	5	6	7
6	Are easily distracted by random thoughts	1	2	3	4	5	6	7
7	Find it easier to understand a message when simple words are used	1	2	3	4	5	6	7
8	Do not tell good stories	1	2	3	4	5	6	7
9	Have good memory for events that happened to them long ago	1	2	3	4	5	6	7
10	Feel happy a lot of the time	1	2	3	4	5	6	7
11	Seek social interaction	1	2	3	4	5	6	7
12	Find it easier to understand when spoken to slowly	1	2	3	4	5	6	7
13	Are physically strong people	1	2	3	4	5	6	7
14	Find that people speak too softly to hear	1	2	3	4	5	6	7
15	May hurt themselves while chopping onions	1	2	3	4	5	6	7
16	Would appreciate help	1	2	3	4	5	6	7

17	Are physically active people	1	2	3	4	5	6	7
18	Prefer to be with other people	1	2	3	4	5	6	7
19	Have a poor sense of smell	1	2	3	4	5	6	7
20	Have good memory	1	2	3	4	5	6	7
21	Prefer to be by themselves rather than to be with other people	1	2	3	4	5	6	7
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25	Would be accepting of help	1	2	3	4	5	6	7
26	Are good story tellers	1	2	3	4	5	6	7
27	Are a stubborn people	1	2	3	4	5	6	7
28	Avoid social interaction	1	2	3	4	5	6	7
29	Find newspaper print too small to read	1	2	3	4	5	6	7
30	Are knowledgeable people	1	2	3	4	5	6	7
31	Are not easily upset	1	2	3	4	5	6	7
32	Have good memory for events that happened recently	1	2	3	4	5	6	7
33	Are smart people	1	2	3	4	5	6	7
34	Are caring people	1	2	3	4	5	6	7
35	Are easily irritated	1	2	3	4	5	6	7
36	Find that their minds wander to random thoughts	1	2	3	4	5	6	7
37	May drop a boiling pot of water	1	2	3	4	5	6	7
38	Are kind people	1	2	3	4	5	6	7
39	Find it easy to hear faint sounds	1	2	3	4	5	6	7
40	Do not experience tastes strongly	1	2	3	4	5	6	7
41	Are argumentative	1	2	3	4	5	6	7
42	Are friendly people	1	2	3	4	5	6	7
43	Have difficulty seeing small print	1	2	3	4	5	6	7
44	Resist help	1	2	3	4	5	6	7
45	More and more find that people enjoy their storytelling	1	2	3	4	5	6	7
46	Would spill while pouring hot coffee	1	2	3	4	5	6	7

Please go to part 5 now . . .

Part 5

Please answer the following questions about yourself:

Year of birth: _______

Number of years working with people with Alzheimer Disease: _________

Number of years working with people aged 65 and older: ______________

Please circle the answers that apply to you:

We would like to ask a sample of people who participated in this study to participate in another study. Would you be interested in participating in another study?

Yes Maybe No

If you answered yes or maybe, how can we contact you? (e.g., phone number, address, email address, mail at the Alzheimer Care Centre)

Name: ____

Address/phone number/email/mail at work: ________________________________

____

For the following questions please circle the number that best applies to you:

What is your gender?

1 Male
2 Female

What is your birthplace?

1 Canada
2 USA
3 Other: please specify which country ________________________

Are you a native speaker of English (i.e., was English the first language that you learned)?

1 Yes
2 No (at what age did you begin to speak English?________)

If you are not a native speaker, please rate your proficiency in English by circling one number:

poor			good			excellent
1	2	3	4	5	6	7

What language do you primarily speak at home?

1 English
2 French
3 Other: please specify which language(s) ____________________________

What language do you feel most comfortable speaking?

1 English
2 French
3 Other: please specify which language__________________

Circle the one number that is most descriptive of your educational background

1 Less than grade 8
2 Completed grade 8
3 Some High School
4 Completed High School
5 Some College or University
6 Completed College or University
7 Graduate studies

Do/did you have contact with your grandparents?

1 Yes
2 No

If yes,

How much contact do/did you have with your grandparents?

not at all						very much
1	2	3	4	5	6	7

How positive would you say your contact with your grandparents is/was?

not at all						very much
1	2	3	4	5	6	7

Do you have contact with seniors (persons older than 65 years of age) in general?

1 Yes
2 No
If yes,

How much contact do you have with seniors in general?

not at all						very much
1	2	3	4	5	6	7

How positive would you say your contact with seniors is?

not at all						very much
1	2	3	4	5	6	7

How much knowledge do you have about Alzheimer disease?

not at all						very much
1	2	3	4	5	6	7

Do you have contact with people who have Alzheimer disease or related dementias?

1 Yes
2 No
If yes,

How much contact do you have with people who have Alzheimer disease or related dementias?

not at all						very much
1	2	3	4	5	6	7

How positive would you say your contact with people who have Alzheimer disease or related dementias is?

not at all						very much
1	2	3	4	5	6	7

How *competent* do you feel when dealing with elderly adults with Alzheimer disease?

not at all						very much
1	2	3	4	5	6	7

How *effective* do you feel when dealing with elderly adults with Alzheimer disease?

not at all						very much
1	2	3	4	5	6	7

How *useful* do you feel when dealing with elderly adults with Alzheimer disease?

not at all						very much
1	2	3	4	5	6	7

Have you attended any courses/education/in-services about Dementia or Aging?

1 Yes
2 No
If yes,
What courses/education/in-services have you attended?
1 *The* CAPITAL CARE *Group* Dementia Care Education
2 Personal Care Aid Course
3 Other (please specify) ____________________________________
____
____
____

APPENDIX B:

STIMULI USED IN IAT

Evaluative Categories

Unpleasant: war, filth, murder, slime, anger, poison.
Pleasant: paradise, gift, peace, happy, love, lucky.

Target Categories

Old:

Young:

APPENDIX C:

GUIDING QUESTIONS FOR INTERVIEWS WITH CAREGIVERS

1. Beliefs about AD
    a. What are people with Alzheimer disease like?
    b. Tell me about the cognitive aspects of Alzheimer disease. How are people who have Alzheimer disease different cognitively from typical older adults?
    c. Tell me about the physical aspects of Alzheimer disease. How are people who have Alzheimer disease different physically from typical older adults?
    d. Tell me about the social aspects of Alzheimer disease. How are people who have Alzheimer disease different socially from typical older adults?
2. Views on caring for persons with AD
    a. What is your caregiving philosophy for people with Alzheimer disease?
    b. What are your values for interactions with residents with Alzheimer disease at work?
    c. What are your specific goals when you interact with residents with Alzheimer disease at work?
3. Communication with persons with AD
    a. What challenges do you face in communicating with residents with Alzheimer disease?
    b. What strategies do you use for effective communication with residents with Alzheimer disease?
    c. How do you change the way that you communicate, verbally and non-verbally, when communicating with residents with Alzheimer disease?

APPENDIX D:

CAREGIVERS' VALUES AND GOALS FOR INTERACTIONS WITH RESIDENTS WITH AD

Theme	Supporting Caregiver Quotations
Giving Residents a Good Day	"To make them happy. To give them satisfaction. Because if you're the only one who wants to be satisfied or to be happy and you tried to push her without her knowing or just to push her on what she doesn't want to do then it's not good because she's going to be upset, then you be upset too. So it's better like as long as she's happy, she's satisfied with trying to do that like that." 1013 "Yeah, the most important is the residents to make them happy. Because I work in the nursing home too before and I noticed like if the residents has no family who comes to visit and if you don't give them the good care then you would see their face. They're so sad and they're really very irritate easy to irritate and they won't eat like that. But at least if the caregiver is good to them they know how to deal with that. At least for a few minutes you could see them smiling. So that's a good thing. That's what I want to see. Make them happy." 1013 "Yeah. I want a friendly atmosphere. A friendly environment, yeah so I and then I want them to make happy, to be happy so sometimes I sing I sing with them, you know, I dance with them, things like that. I just want them to be happy and be content." 1009 "Um, I just want them to be happy and be involved because I don't want them to be sitting by themselves, you know." 1009 "Have fun with them, it's all about having fun and making the best of their day." 1002 "Joking, like I said having fun, joking um." 1002 "To have fun, to make the most, most of the day I guess that's my main that's the biggest thing." 1002 "Um, letting people complete tasks that they're able to do. Encouraging them to do it, to maintain those skills, um. And making their day the best day that they can have. I mean that's part of Capital Care's philosophy actually you know and, and doing things that are fun and exciting and even though there's chores involved, you know, you know if you have a group in the kitchen, you know, making it fun as well, it's not so much of a task right. But because they're used to doing those things and that's what as housewives or whatever we all do, or as women we all do those but, uh, yeah maintaining the skills that they have and trying to maintain independence. It's always easy to do stuff for everybody." 1001 "Oh yeah and and yeah the laughing, the laughter, the you know having music involved, with interaction I mean like I look after someone that you know if you're singing and humming and whatever it just makes looking after them that much better. You know I mean if you've gotta make a funny face or whatever to get someone laughing I mean so be it. I'm, you know, yeah I think people if people outside of my work saw me {laughs} how old are you. But it makes the, it's all about making the residents day and you know. Yeah and that, yeah just making, making them feel important too by showing genuine interest in their, in their interests and in their life and stuff like that." 1001 "Um, that they have a good day or if they're not, if they're, you know, sad or

Theme	Supporting Caregiver Quotations
	unhappy let’s find out, try and find out why, what triggered it. Um, and try and you know redirect or get them thinking of something else. Or try and, you know make them happy. I mean life’s too short to be sad and there’s too many good drugs out there for these guys to be sad as far as I’m concerned {laughs}.” 1001 “ . . . try to keep them, um, on even keel, like to have a good day, a productive day and, ah, and still help them along, cue them, help them be as independent as they can.” 1006 “Um, just to keep them happy, keep them feeling comfortable and not afraid.” 1019 “Um, it doesn’t matter where there’s whether there’s something odd but as long as their day, as long as you make their day really happy that’s the most important thing. It doesn’t really matter, because of course when you’re working there are certain routines. But it doesn’t matter if you go a little go detour to your routine to, um, reach out to them.” 1010 “Uh, just I guess to make their life comfortable, and, um, make them happy. I think to myself how they would, how they used to be and like I try and remember them as the person they maybe used to be and treat them how I’d like to be treated if it was the same circumstance.” 1014 “Just the feeling of for them of well being and and and that they are important because one thing I really notice and I’ve really, really noticed that a lot. If you sit and spend time with somebody they’re totally different. A light goes on in their eyes. Or even if they’ve gone out for a day or two with their, um, relatives, with family they come back it’s almost like there’s a different, yeah. So I well my goal {unintelligible} is to is for them to to be involved. I want them to be involved. I want them to participate and and to, you know. Whether it’s bowling, whether it’s, you know, cheering for another guy and clapping hands.” 1028 “I try to make them laugh. I try to make them have a good time. There’s no point of being mean and pushing them around. Let them be happy. When they’re happy you’re happy. There’s no frustration. That’s what I say. Let them be they’re happy. As long as you smile and joke with them and always make them laugh. There’s a lot of them that don’t know how to do that.” 1023 “What’s important? To make them smile. To make them have a good day, good time, good day. Just to see them wake up and have a big cheery smile on their face. That’s what I like. And I always know which ones are always happy and I know which ones to say stuff to and make them happy and just to make them smile.” 1023 “Just to make them smile. Just to be a goofball and then they laugh at you.” 1023 “ . . . try to make each resident have a bet a little bit better day.” 1026 “ . . . my major goal is to have fun with them and to make their day better.” 1026 “To keep them as independent and safe as possible and to make sure they have a good day. You know, like for the Alzheimer person it’s not just looking after their daily needs. It’s making them smile, so they have a good day. Right. And sometimes, you know, their little thought processes don’t work and they feel so bad that they can’t remember. But that’s not a big deal, you know, and you have to downplay a lot of things, right. And sometimes you have to lie. So I’m going to hell. You know if it’s the answer that they need to hear they you, you know, you fudge the truth just so they’re happy. That’s the way I look at things.” 1031 “Just to go out and take part in rec and enjoy the day, you know, and, um. So at night, you know, they’re tired but they’re happy because I feel there’s too much sitting altogether for those people. Like we do three recs a day and sometimes it’s

Theme	Supporting Caregiver Quotations
	still not enough for some of those people. To keep their muscles going, to keep their mind going because once they loose it that's it, you know. And I mean we've got women doing dishes and we find the stuff all over the place. Who cares, who cares? It's not important, right. That's how I feel about them." 1031 "I want them to have a good day. That's what I want them to do. I'd like to see them smile and enjoy their day. That's what I go to work for." 1031
Showing Residents Respect	"My values, okay, with me, um, okay, friendship I, I always tell them that I am a friend and I'm just not a co-work, a worker, or a caregiver because I value their friendship. And, um, number two, the privacy. It is very important, you know, because, just because they're ill or something we can do everything, you know, without without their permission. Or or for example where I I, um, caring for somebody I'm changing. I make sure that the door is closed and also I knock on the door before I enter. It is very important because that is their property, you know, instead of being just intrusive, you know, into their property, you know, into their room. Um, trust and respect because, you know, especially with them what majority of them they was somebody else when they were when they were younger, you know. But when they're ill sometimes they don't know who they are. Sometimes they cannot identify that the, ah, you know the picture on the wall is them, you know." 1009 "I respect them, you know, just just like if they want to be called by their name I don't give them names like hey Mr. Somebody or something like that, you know. I address them the way they wanted to be called. That is one of the respect. And and I it's the same thing likewise with the family. It's not only the resident, but I respect the family too. You know, because I'm sure, um, we work, basically we work hand in hand with the family, yeah." 1009 "What is my caregiving philosophy? Hmm, to treat them with respect, you needs to take the time, you need to repeat yourself in a lot of cases with doing the personal care that they might not understand what to do but you have to just give it a bit and repeat yourself." 1002 "Every resident is different, certain residents like to fold clothes you know which ones like to fold clothes, which ones like to help in the kitchen. If they don't want to do that you just respect that, you just don't pull, if they don't want to go to an activity you don't force them, there are some residents that like to stay in their room and sleep you ask them you give them the choice and if they want to want to attend and if they don't that's their choice if they want to sleep let them sleep." 1002 "Patience, um, caring, kindness and understanding. I think I relate pretty good to, you know, to them. Maybe I'm older too and I can relate to them better. Because I can you know generally when I, you know, I try to be optimistic and jovial and stuff and I can usually get them to do things like come on we're going for exercises ladies, come on and you know try to perk them up a little bit and they'll say no I'm sleepy, I'm tired because there's some that they just want to sleep and. But then you don't push it either right, and I don't push it. If they don't want to and then you just leave them or you can like you say come back again and try again but just like any other senior whenever too, they have their days. You know say they've got arthritis and the weather's bad, they're not feeling well, they're aching all over, you know. Respect their, um, privacy I guess too and their individuality." 1006 "Yeah so that's why we decide to give them the the right, ah, choice to tell no or yes. We can't just force them to do things that they don't want to." 1005

Theme	Supporting Caregiver Quotations
	"Um, go with what their needs are in the moment . . . Um, if our schedule says that it is time for recreation and somebody doesn't want to participate in recreation I think that that is their prerogative. And I think it's a matter of, like, besides trying to encourage them in, I think that they should we should adjust to what they want because sometimes, I mean sometimes people can be swayed into doing things, like they just need to be convinced or, you know, they need to be encouraged. But I find that if somebody's adamant on not wanting to do something it can wait. {laughs} And even with meals and stuff like that if it, anything. If they decide this isn't a good time or if they have another agenda then it's probably important to follow through with that first and then deal with what our other needs are." 1019 "Treat them with respect, as you would want to be treated. They do at times need a bit of extra help, but that is what I'm there for. And it's not to fully do everything for them, but it's just to encourage then and, um, just help them with the minor details, or like if they need more help, more details in their life." 1016 "Um, keeping their privacy is number one, very important." 1020 "Patience, ah, you have to have patience all the time. Respect for that person. Uh, and just listening to them because I, I often see how frustrated they get and, and I I would don't think there would be anything worse than being that frustrated and and thinking that nobody cares or wants to take time to listen to you." 1014 "Listening to them. Treating them as, ah, normal people, as normal as they can be. Basically it's some of the same things, just treating them with respect and dignity. I look at some of these people and I think to myself what they used to be and I try to remember them as that person. We've had people that have when they first just came to our center and, ah, they were just coming on a day program and, ah, when they came in they saw the other residents and they said I never want to be like this, please shoot me if I get like that. And now those same people are doing the things that that person didn't want to be like when he got and he's very badly now but. So I still see him as this man that said this." 1014 " . . . if they have an accident they're incontinent I don't scream at them because I realize it's an accident and they don't, they know. And sometimes if their disease hasn't progressed that far they still know enough that. And they never loose their feelings. They could have the worst case of Alzheimer's but they still have feelings, so." 1014 "I I'll look at it for their own self esteem because we have guys come in there and you know the first time they come in there and somebody's trying to give them a bath or anything like and it's just no, you know. And so to give them, to allow them that privacy and to allow them that, you know, give, just allow them some respect. Basically, you know, give them some respect and then just say okay I'm turning around, I'm walking away, you know. But at the same time I'm out of the room and left the door ajar and, you know, I know what's going on." 1028 "What are my values is is that they're not bored and that they have stuff to do and that they're treated just like another person an aging person with respect and dignity." 1028 "Friendly and respectful." 1026 "First of all you respect them." 1031 "Well respect them that's very simple . . . Well you know like we were making the sandwich today that lady is capable of making her own decisions. So how would you like to make this sandwich, she buttered the inside, I don't usually do that but

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	that's how she wanted it. How many pieces of cheese would you like on there, some people like two, she wanted one. Um, some people don't want to eat what there is and they go and help themselves. That's fine. Or if it's bath day and they don't want a bath, that's fine. That world's not going to fall apart, right. So that's what I mean about respect." 1031 "I like to treat them the way I'd like to be treated, or my grandmother would like to be, I, I would like to see my grandmother treated, or my grandfather with dignity, respect, like to see them treated as normally as possible. You don't treat them different because they have Alzheimer's. And if it means going through the same conversation over and over again in a very short period of time {laughs} in a very short period of time, or repeating instructions, or repeating explanations, well then you just have to be patient and remember that some of these things are because they're ill." 1022 "With respect, with dignity, with love, with patience . . . .What does that look like? well we have an issue right now in our center where there is a lady that is confined to a, a chair and some of the staff members want her in an open backed nightgown because it's easier for them. And I insist on putting slacks on her because she will not leave a blanket over her legs and I think that's part of dignity that she needs, or she has the right to be covered even though she doesn't know that she's pulling the blanket off of her legs and showing her legs right up to the top. That that's part of dignity, that it doesn't matter how convenient it is for me or one of the other staff members when it comes to whether we put on slacks or not. That's dignity, that's, that's respect. She needs to be treated like anybody else. That she needs to have the right to her modesty." 1022
Promote residents' independence	" . . . try to encourage them for their independence . . . So that they think they're still living in their own place because that's sometimes that's why they're so upset. They were thinking like everything was taken away from them. But if you're trying to encourage them for their independence they're still thinking like, oh. Especially if the person is professional, they were thinking like if they're still independent they were thinking like they're still living in their own place, and they're the one who is dealing with everything, the money, the stuff that they had in their house. They are the one that's deciding if they have to go out or not. So, if you're trying to encourage them for independence {unintelligible} the more easier for them and for you. Yeah, especially the nurses, the retired nurses. Yeah they're think, they're still thinking like they're a nurse so you don't need to tell them what to do. They know what they're doing. So, you have to play with them." 1013 "Hey, with me it's not just because I'm a care giver and I care, okay. I care with all my heart, you know. It's my commitment, my my commitment and we fascinate with your job. It's just for me it's not just a job. {laughs} I think it's, you know, hmm, that's the reason why I took nursing because I like caring for people, and I like to be with people. And I like doing things for people, you know, not just doing them for them but doing with." 1009 "To we do things together, just like what we did with, ah, Eileen. You know, that's the thing. And, um, you know, as much as possible I am encouraging my co-workers to be a team player too. Because it it's nice when you do things together. But doing for you basically do everything for this person, you know. But if they can still do something for themselves, you know, why not involve them. And and in a way it makes them independent, their sense of well being and also you're boosting their self esteem too." 1009 "For me, if you're if you can still do something that is very important because that is a little accomplishment on their part. And I'm sure they're very proud that they can

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	still do something, you know, that is independence. Just like, ah, whenever I'm setting the table I just don't do it myself. I can easily do it myself in in just a short time, but that's not the purpose. The purpose is to make them independent and be able to do something. You know, the involvement is very important. So that is independence for me." 1009 " . . . let them do as much as they can, for themselves um, if we can just do cuing that's great, if we fill the sink with water and soap and tell them you know wash your face, and wash under your arms they usually can do all of that. Apply their own deodorant, lay their clothes on the bed, ask them what they want to wear, they'll get dressed, some need help with socks just because they can't bend that far down but, let them comb their hair, brush their own teeth if they're able. Anything that they can do for themselves the longer the better." 1002 "Um, letting people complete tasks that they're able to do. Encouraging them to do it, to maintain those skills, um. And making their day the best day that they can have. I mean that's part of Capital Care's philosophy actually you know and, and doing things that are fun and exciting and even though there's chores involved, you know, you know if you have a group in the kitchen, you know, making it fun as well, it's not so much of a task right. But because they're used to doing those things and that's what as housewives or whatever we all do, or as women we all do those but, uh, yeah maintaining the skills that they have and trying to maintain independence. It's always easy to do stuff for everybody." 1001 "Well just I guess breaking down step by step like, getting washed in the morning, okay the person may not be able to run the water but once the waters run and their hands are in the sink, they're able to wash, you know, squeeze the cloth that's there and wash their face. But to get to that point they may not have got, been able to do that, you know even though, you know, they couldn't get to that or the next person could, at least that person's participating in their care." 1001 "I mean I have someone that I look after that basically the only thing she can do or is dry her hands after we wash them. But she's doing it. So I'll wait until she sitting down and then I, you know, soap up her hands and then she takes the towel and dries. Because other than that it probably she couldn't manage." 1001 " . . . a full task may not always be able to be completed and that it's okay to do part of it. That that's still an accomplishment and that tomorrow maybe it's a different part that gets, that they're able to complete or maybe they can complete the whole thing. Like just don't assume that because one day it can't be done, I mean maybe they've been up all night and they're just exhausted. You know I mean that every day is different." 1001 "Um, well I think anybody that I not really train but, you know, when someone new comes in and just say, you know, always, um, try and see what someone is capable of doing. So how I do that like, you know, maybe they can't come into the kitchen and make their own breakfast but offer the choice of what you'd like, you know, we've got bread here, we've got muffins, you know, so you're still they still have to put some thought into it. Um, and then when the, you know, they're going to have cereal or whatever don't automatically put the milk on the cereal. Like put the jug or the milk creamer in front of them or jug in front of them and if they're really fumbling or they don't or they try to eat it dry and you know they don't want to then offer to pour the milk on would, you know, would you like milk on your cereal, oh yeah I would well here's the milk jug. Like I mean there's ways that you know, and then if they still don't pick it up then pour it on, like would you like me to pour it offer like don't just automatically do it. Like here's your cup of coffee, there's your sugar, there's you milk. I mean even though someone can't get that themselves they

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	can still put in their own milk and sugar, most times. There is a time or occasion I mean maybe to the point where they, they've stopped putting the milk in you say well would you like milk in your coffee, oh yeah that would be nice. Because they've just, they're not thinking that much more anymore about doing that. But still I mean if you can at least do part of that it's like the washing thing if you, you may not be able to fill the sink with water but if you can still take a cloth and wash your face you know rather than someone take it for you and wash." 1001 "Oh with Alzheimer's and any other seniors is allow them to maintain their independence as long as possible and let them, ah, um, have a feeling of self worth that they can do as much as they can for themselves. Even if it requires cueing they don't remember because they can maybe still do the task but they just have to be reminded, yeah." 1006 " . . . try to keep them, um, on even keel, like to have a good day, a productive day and, ah, and still help them along, cue them, help them be as independent as they can." 1006 "Yes, yes that that's why you know you don't do things for them you try to, um, what you what we do is we try to get them to do as much as they can. That's why we don't rush let they take their time. Um, what you what you do is, um, that's why we give them choices. The the the right choice to do what they they they can. And then, um, if they can still help we we will let them do whatever and then if they can still dress we don't we don't try to to take over we let them. And then sometimes they can put their clothes backward and then later we're just going to go to the washroom and said come on we'll just move this one oh look at this the tag is in the front do you want me to turn it around and sometimes they don't. We just let them. And I mean this is their home they can do what what they want and what they makes them what makes happy let them do it we're not in the center all day long. And I said to myself yeah I wear a night gown and pajamas sometimes when I'm off and then I don't have to force them if they don't want to take their clothes off. But if it is necessary that they have to go out we have to get them to get dressed right you have to do be very patient and explain things to them. Kay you're gonna your son's going to come out and going to take you out for dinner or for lunch we going to take this off and then they love that one." 1005 "I would say, um, let them be independent as much as they need to be. Um, you can cue them on things and just care for them as if they're a regular normal person . . . I guess because they would lose their independency and they wouldn't be able to do anything if, ah, you wouldn't let them do anything. They need to be the same person, just cause they have a disease it's not going to change who they are. So they need to know that they can still do what they do." 1012 "You promote their independence all the way along. Um, I, you've, I the big thing is you learn what each of them need and you cue them or allow them to do what they can first. And then they may need assistance . . . I think it, they're not children that they are adults. They still need to be treated like adults. And the longer they maintain their independence the, the better off they are. Like, I mean, the final stages of the disease are not a pretty sight, right?" 1007 "It's my care giving philosophy for anything, to assist them in interdependence, er, not interdependence, uh, independence, um, that they want, like, the level that they want of of dependence or, in, in. That's not what I'm looking for. Independence. Like they'll be days that, you know, you might only assist for fifteen minutes with a couple tasks and then there'll be other days where they might want you to do everything for them. It it's depends on their day. And the well-being, you know. All areas of their well-being have to be met and do the best that we can to help them

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	achieve that.” 1017 “Hmm, to keep them safe, and happy, um, fulfilled, clean, you know, the basic stuff that we have to make sure that they’re clean and safe and free from harm. Get them to do as much as, you know, as they can for themselves. I think that’s pretty much anything within health care. You want them to do as much as they can for themselves and then assist them with what they, you know, what they don’t.” 1017 “Dignity, I mean, it’s it’s if everybody did everything for everybody, we wouldn’t want to live I mean it’d be a pretty boring place. We wouldn’t be, why would we, I mean I don’t know right now l’d like everybody to do everything for me. {laughs}But I I’m not there yet and I, I’m thinking, you know, from their point of view they probably need that just so that they have a a sense of self worth knowing that they can still dress themselves or assist with dressing themselves. Or, like Pam today doing the the grilled cheese sandwich, it, you know she said she can’t remember the last time that she made a grilled cheese sandwich but she did it and I mean was shocked it was like right on because I don’t see that anymore. Like we’re in McConnell we don’t see too much of that anymore of anybody actually being able to, to, to do it. They’re not there physically and and probably mentally too. I just like it when they help me fold laundry because that helps. And they do, you know, it’s it’s good that they can still do some things.” 1017 “Um, trying to encourage them to do whatever they can do for themselves, um, up unto, up to the point where they’re, you can see that they’re kind of getting frustrated and then trying to help them out. But I think encouraging them because I am a very independent person and I value that. So, and I think that people always want to have their independence as much as we can and we all loose a little bit of it.” 1019 “Because it [independence] determines, it kind of determines who you are. If you’re, you know, once you’ve you get all of those you can’t do anything you don’t fell like you can do anything anymore then your personal, personal value is decreased I guess.” 1019 “I think it is important because in that way if you make them independent they don’t forget. They don’t forget, I mean like at least. You cannot stop their memory loss, but at least if you let them do their task it, they tend to remember more. So I think it independence is vey good.” 1010 “Treat them with respect, as you would want to be treated. They do at times need a bit of extra help, but that is what I’m there for. And it’s not to fully do everything for them, but it’s just to encourage then and, um, just help them with the minor details, or like if they need more help, more details in their life.” 1016 “Because they’re still and individual and they still, a lot of them wish that they were still in their home and you’ll find that if you allow people they enjoy helping with dishes once in a while and they enjoy to do the laundry because that’s what they’re used to when they lived in their homes. So if you, they enjoy their stay more because it starts to feel more like their home rather than oh I’m living in a cooped up environment. So just encourage them in what they’re doing and just help them with it.” 1016 “I think that that is really good for a citizen, um, residents as, because they are, a lot of them still are mobile and a lot of them are able to do it. I don’t think it should be forced that if they aren’t capable of doing something, or if they feel too much like oh I can’t carry this cup of coffee. But I think that they should be encouraged to and because a lot of them can do it and even with picking up dishes at the end of meals, they a lot of them just think that we’re their house cleaners. But we’re not and a lot of them are capable of picking up their dish and bringing it to the sink. And so we

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	just encourage them to do their own, like just bringing it to the sink because at home they wouldn't be just leaving it there, they would have to go bring it to the sink themselves. And so we're there for helping with some of the cleaning, but at the same time we encourage them to be independent in themselves and do what they can." 1016 "Because that's something that's going to disappear soon enough on its own and it seems once they start doing things they forget how to do things really quickly. So yeah I think it's very important to whatever they can do to be encouraged to do with no more help than you have to give." 1018 "To keep their independence. To help them, uh, do as much for themselves as they can and if you have to help them, uh, to help them in a way that they think that they are doing it rather than you're doing it. And I find this really works for me because I've been doing it for a lot of years and a lot of people ask me how do you do it because if will be a a resident that's really hard to do and they'll say well how did you do it. But it's your approach, definitely your approach. You have to win them over. Make them feel very, very comfortable with you and that you're not a threat to them. That you're not, um, undressing them and, and when they're very private, you know what I mean. So you do it in a way that they don't even realize you're doing it, you know what I mean. Um, I can give you an example, would that be good?...Say like Loraine in the green house she's very hard and she strikes out to some people. She's never done that to me. But I will approach her by saying oh Loraine today is, say it's Sunday, today is church day, you love to go to church, should we get up now and get something really nice on for church. And she always jumps up and says yes. And then I'll open the closet and say do you like wearing this. Yes, it wouldn't matter what you picked out but she's not really capable of picking it out herself so I show her. And then I'll say well let's go to the bathroom so we go to the bathroom and I go from behind her okay and I'll say so let's get these wet ones off first so we can get all this nice stuff on. So I'm constantly talking and making, reassuring her and making her feel good about herself and before you know it I have her undressed. Then I'm running the water and I say here you wash your face I'll wash your back and then we kind of do it like that. And then I'll say okay now you sit on the toilet and let's should we put your socks on, do you like these and I'm kind of giving her choices at the same time and put the first thing you know she's dressed really fast. I do it very fast because I don't want the person to feel like they're naked and sitting there for a long time and you know and going about doing something else. We do it in dum, dum, dum, kind of real fast. And, uh, then I'll say okay let's fix your hair nice and constantly talking like that reassuring her, making her feel good about herself. And she's happy and then I'll say how does that look, now look in the mirror doesn't that look good. And then she'll smile and give me a hug and then the first thing you know she's out and then I run around clean up everything, you know what I mean. But I like to make them feel good about themselves and, uh, I think it has worked over the years. I've worked for twenty some years and I've had some pretty tough people to work with. But I've always made them feel secure about themselves and that and that I'm not a threat coming in there and taking over and because that's very important to them because they've had so many losses that they feel like now you're coming here and telling me how to dress and how to do this. But I do it in such a way that it's, they don't think that. And I think that's very important because they're always happy then when they come out and it makes their day. Like they start out happy, they're happy for the day." 1020 "My goal is to help them to stay as independent as they can and to be able to do, whether it's exercise or whatever, to to maintain that and be do what they like to do

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	as long as they can." 1020 "Because that's what I would want for myself. {laughs} You know, you know do unto others as you would want them to do unto you I think that's important." 1020 "To allow them to do as much as possible for themselves. And I'm not sure that that sort of would prolong independence or not. I, I'm not sure about that. But I think that, um, my view on that is is to allow them to do as much as they can for themselves regardless of how long it takes. Um, you know, it's it's just because I feel not only is it an orientation but it also is, um, that it's less boring for them to to have things done for them and I think it sort of keeps them independent . . . Um, for their own self. I I'll look at it for their own self esteem because we have guys come in there and you know the first time they come in there and somebody's trying to give them a bath or anything like and it's just no, you know. And so to give them, to allow them that privacy and to allow them that, you know, give, just allow them some respect. Basically, you know, give them some respect and then just say okay I'm turning around, I'm walking away, you know. But at the same time I'm out of the room and left the door ajar and, you know, I know what's going on." 1028 "I try to make them be independent. I try to help, like let them fold. Guys can you help with the laundry and then they get the laundry, fold it. Or there's one lady that she's always sweeping the floor or. Just, ah, make them feel like they're still useful. Like there's one lady and she's like, oh I love helping you do the dishes. And just to make, then they have a purpose and a sense. And we always joke a woman's work's never done. Never I said I bet you even in the grave we'll still be doing something I said. She starts laughing at me. She goes you're so right." 1023 "Because then if you keep the keep doing everything for them then it's like they have no sense. You know like, like what's the purpose of me being here now. I can't even button my own shirt. So you just let them, so what it takes a little bit longer, just let them do it. Then they still fell like an. You know when you learn your, teach your child to tie their shoe or to do their buttons and they're like ooh I'm a big boy right or a big girl. It's just it's the same thing. You just let them have a sense of being them. I don't know just as long as it. Who cares it takes forever to get them dressed they're still doing something for themselves. If you keep doing everything for them they're going to forget. Just like if you do everything for your kids they're never going to know anything. That's why I teach my son too now don't expect a woman to do this for you you're going to have to do it yourself. The next the next lesson I said how to sew the holes in your socks." 1023 "Throughout the whole life, doesn't matter if it's Alzheimer's or kids. Make them feel special, wanted I don't know. They're always happy to do something for you." 1023 "Try to encourage the residents to do what they can for themselves. Um, it keeps them more, um, more vital. They feel more, they, they, um, they keep what, they keep as much of, of themselves instead of going into the darker depths of Alzheimer's. So as much as, as much of, of normal, of normal that they had before they had Alzheimer's until they can't do anything. Until they go downhill I think it's important to keep as much as they can. Even if it's just a little bit, even if it's just a little bit every day that they can do I think it's better than not encouraging them to do anything . . . When it gives, it keeps, it keeps them, it keeps them able to do what they could a little longer. It, um, helps them from being bored. And it makes them feel good that they, most of the time, that they've still, that they're still able to help." 1026

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	"To keep them as independent as possible. When we were doing the sandwich thing the only thing I was scared about was the stove. That was the only thing that I have concern about because when you have a person in care, that you're caring for, I would feel ever so bad if that person got burned. So when you look at if maybe I shouldn't have been doing what, like I, I was over there and I turned the stove on. I didn't want her doing that. Um, because, uh, they don't know the controls and stuff and I don't want them to get hurt. And just like the water, you know." 1031 "And then modify at times, you know, it's if there's something they they can do but they can't do the whole thing you modify it, right, to keep them as independent as possible. Um, you encourage them to be, well, to to be the best they can be for as long as they can I guess . . . Okay so, so say this person could wash themselves totally and all of a sudden they're forgetting oh I've got to put the toothpaste on the toothbrush. Like, you know, like, it's simple, a simple thing like that would cue them. You know, in order to keep as independent as possible. Or maybe they don't know how to choose their clothes any more. So you lay them out for them and ask them what they think of it, if that's what they want to wear. Okay, yeah so that's what I mean about that." 1031 "So when I first started I had no idea and I just thought we're there to help and you just want. They're like your grandparents and you just want to like oh it's easy for me to get them a cup of coffee or I can clear their dishes like you don't want them to. They have so much on their going on that you just want to do it for them. But I've so learned and just been it's best it's my my attitude is whatever they can do for themselves makes their life it's better for them. So it's easy for me to grab a dish and because I want to get the dishes done or to go and, you know, rush someone along because we have a time constraint or, you know, they have a doctor's appointment at a certain time. But it's bottom line I always ask okay if you're in doubt about something what's the best interest of the resident because that will always give you the answer. Because sometimes, you know, it's going to be more difficult for them if you're trying to encourage them to do something and they're not it's not going to happen that day or it's bedtime and they're tired. Then sure, but in all circumstances I say, okay try to get them to do as much as they can. So independence and they and I think they feel better about themselves too. It's funny I've seen some people be new to the center and their independence increased hugely because the staff was simply not doing everything and their caregiver at home was doing everything for them. And suddenly they're bringing up their dishes, they're helping with things, they're folding laundry and it's great to see that because they are they're, I dunno, they just seem happier, more confident with themselves." 1024 "So I always think too that, um, you know you're you're the quality of their life is better if, you know, the more that they can do because they're going to take more initiative. Um because if they're just if they're kind of are going downhill all the time they're just gonna want to be in their rooms sleeping all the time and if you can get them in the habit of just okay well let's go see what's happening or what's happening out here or what activities do we have or why don't you come help with this baking or anything. And they may not. And a lot of times they're not interested but if they're given that opportunity if kind of opens up a little bit rather than just assuming that that they're not going to want to. So I think it kind of builds on itself." 1024 "I feel like they should be directing. It's their home. It's their life and it's funny because there are some residents that think oh I guess I should be going to bed now and I'm like, you know what, and I just use humor a lot because I've learned from other residents, other staff members that that so helps, you know, just being able to

Theme	Supporting Caregiver Quotations
	joke and getting your message across that way. And I'll just say, you know you're not, you're you're a grown up you can decide your own bed time and they look at you like really, you know like, but but this is what time we're supposed to go and I'm like no, you know, you can make that decision. And those little kind of things just if they they we're just there to help them and that's all and so we're not there to tell them what to do." 1024 "And I'm like no and it's like oh okay, you know, like, okay maybe I'm rushing this person a little too much. And it's like no I've got time, that's fine. So and I always have to say to myself if I feel like oh there's so much to do, I'm going to be with this with this one person for half an hour and you're thinking about everything else. And they have no, to them they're the only one there and they're they don't have anything to hurry for. So, this one lady it's like okay I could help her with her teeth, I could help wash her but she can do everything but she just does it painstakingly slow. And she's the sweetest, sweetest, lady, but, so you just, I try to like okay well here's the towel now and. But there's only so much of that you can do because that one minute you spend with her, that's like, in her day she needs that to kind of slow down." 1024 "And also trying, um, to help them do something which more and less helps for them, you know, to regain in some way their motor skills or do something which it's helping them in this way, you know, to remember some dates or faces, like, you know, all the time repeating them. Or asking them questions, what is this or what is that. It's I think this is important for them. Try to orientate them where they." 1032 "I think independence is important for everybody. But for them it's dangerous sometimes. They can injure themselves. So probably they, that's why I think are these centers, you know. In some things they could be independent. But in some you have to help them a lot, like in the kitchen especially, not to injure themselves. And, but it's good for them, you know, in some way for them to feel that they're independent. Because nobody wants to be helped by anybody else. What I think, you know. And most of these people they have lived a very independent life. Some of them are housewives who had taking care of her kids, like five or six what I see. So they used, uh, you know, to be, uh, like independent at home. To do everything, the dishes, you know, the clothes and all this. And when somebody comes there and tries to mix with them I think it becomes difficult for them." 1032 " . . . strategies is like, you know, I'm trying to be friendly with them. Slowly explaining the things. Um, as much as possible interact with them and talk with them. Do some puzzles for example in the center, or trying to color because these are the things which they, on this level can do still, you know, in some way. So more on basically this is it." 1032

APPENDIX E:

QUOTATIONS THAT SUPPORT THE THEMES OF CAREGIVERS' BELIEFS

Theme	Caregiver Quotations
Memory general	"Like, um, usually confused, um, of course forgetful." 1022 "They're like everybody else just not, not their memory, that's all that's gone is their memory not the person who they are." 1012 "They can be normal, the same as anybody else, your grandparents, mine or. They can also be have memory cognitively impaired with memory problems. So they can forget things ask thing numerous times, um, may need more direction or redirection. But, with all that being said they're still people and enjoy normal things." 1007 "No, um, maybe taste-wise but that has more to do with their memory because they don't think to eat so they, tasting isn't an issue." 1007 "Yeah, but, yeah the thing is that, um, it's their memory I mean like, that's what I see, it's their memory that and then other things come after that." 1010 "They're just more elderly people that sometimes forget more of what they have done and they are just like normal people wanting to live normal lives still, but just with a little bit of memory loss." 1016 "They're a lot the same as older adults it's just some of them with memory loss. And, um, sometimes, like you get that with older people as well." 1016 "Well with folding laundry there was one time where a lady she's like oh can I help you and I was like sure, but then she forgets how to fold a shirt or how to fold a towel. Or even with dishes they want to help, but they're like I don't know what to do." 1016 "Um, they forget things easily." 1025 "Well they're like everybody except they've got poor memories." 1018 " . . . it's the sad part is that they forget." 1028 "Very forgetful." 1023 "Well they forget everything. They have no clue it's like they go backwards and, you know what I mean. It goes like adult form back into being a baby again. It is they, they completely have no sense of anything anymore. God I hope I don't get it." 1023 " . . . difficulty with their memory. And, um, usually affects, the people that I've worked with anyway, it it's to the degree where it affects their daily life. So it affects their activities for daily living." 1024
Short term memory/ Recent memory	"After she finished her sandwich I asked her how's the sandwich and she said she can't remember. And this just happened like few minutes ago." 1013 "Repetition of words and sometimes even actions. They they do forget what they have said a few minutes or a few even a few seconds ago. You know, or even sometimes they're they're still in front, you know, after having a meal, they're still in front of their plate and they will complain how come I haven't had my my lunch yet

Theme	Caregiver Quotations
	or my supper, you know. Yeah we, we had one at the at the a Rose House, she was saying how come I don't have my coffee, I ask for coffee. {laughs} And she just had it, you know, yeah. It it's the recent, recent the recent memory, yeah." 1009 "I'm just thinking about the kitchen that we're just sitting in the kitchen but um they can leave out of the door and say they're going for a walk but have no idea how to get back." 1002 "Well they have better long term memory than short term memory, they forget, yeah. They don't remember what they had for breakfast, or who came to see them and over a period of time they don't even recognize family members anymore, you know. Yeah, and they might not even remember certain foods, you know, how they tasted or whatever too eh." 1006 "What what we are doing um the day they forget it for tomorrow." 1005 "If you don't tell them to to, um, if if you don't tell them to come and eat they might not going to come and eat because they forget that's the difference." 1005 "And then you talk to them sometimes they don't want to, they don't respond but sometimes if you talk to them they can understand you no matter, like, no matter how sometimes they're really into say I don't want it get out of my room. You give them time come back. Give them fifteen minutes you come back. They will be different person. They won't even remember that you are the person who came there earlier and do things." 1005 "Cognitive, um, I'd say because more their memory because they forget. So it's more in they may be walking out of their room to the kitchen but not get to the kitchen they may turn around and go back to their room forgetting that they have to eat breakfast or that type of thing. Or they might be in the middle of watching something on TV and forget that they're actually watching TV and get up and do something else. So it's more they don't have the attention span a lot of times to continue on with their activities or doing what they need to do." 1007 "Because their memory problems and they forget that they have been they've just seen their family or, you know, they could have fifty people in to visit them but ten minutes later after they've all left they're clinging to you wanting attention because they say their relatives have never come see them." 1007 "And I think that they're, I, I don't know I find they're kind of innocent too, they're . . . .Just that when, if they have a bad moment or day or whatever, it's just that it's a new experience because tomorrow it might not be there or yesterday it wasn't there and so it's, they're innocent because it's new for them all the time." 1019 "But one thing is that the recent ones, the recent memories are the ones that get lost right away. And, uh, it's because the they get kind of frustrated, that's that's why they get kind of restless and agitated. I mean like it's more on the memory that they cannot remember and then other things come after that. And like, I mean like the ordinary ones who seem to have, um, just forgotten something but it will come back in the sense that yeah once you think about it okay it will come back to you. But nothing that way that you're, you're going to get agitated. You sure can be stressed, but not in that way." 1010 "Yeah, they tell the same thing over and over and over again. And, um, it's also that time when you see, um, the paranoia because they don't seem to remember where they put something and so. But they cannot, well I mean like their brain just cannot process that they put something somewhere." 1010 "Well, ah, Alzheimer's will be a lot more, they'll remember at some moments what

Theme	Caregiver Quotations
	they're supposed to be doing and then other times they forget and they will, um, just need a little prompting about what to do. They still, um, know what, like when you're washing them they still need to know what you're doing because they still have the feelings and are like why are you touching me. So you just have to be aware of what they may be feeling too, so. Respectful." 1016 "Sometimes they don't understand what you are doing when it's just a repeated task of the day. And so you just have to repeat it to them, sometimes slower, sometimes rewording it and saying just, like how I told you earlier about, like, the bathroom experience, where I was like would you like to go to the bathroom and she's like, yeah I have to go to the bathroom. I was like okay let's go to the toilet but then once she was on the toilet and had some difficulties getting there she was like I'm just so confused, she was like why am I here. You're like, well we just worked five minutes to get you there. But just because they forget at moments and so you just have to work with them and just be patient because they honestly forget it and it's not like they're just trying to be annoying to you. So, just, yeah." 1016 "Like, um, for, uh, them like story you tell them right now, they forget in five minutes, or ten minutes. But, um, something happened long, long time time in their life, they go, they will remember. They can tell you." 1025 " . . . well it's the short term memory and they might not, just forgetting events." 1018 "Well they don't remember, um, they might remember way back but they don't remember, you know, what's happening today, you know, right away. They can't remember, like if you tell them something they might not remember in a few minutes, um, and so then they repeat. Uh, um it's mostly things like that like more of the memory type problems, short term. Most of them, uh, know long term, like go way back. They can remember, they may not remember they were married but they remember before they were married and they remember children and that type of thing." 1020 "Well for one thing they forget, ah, five minutes after you've, not even five minutes, two minutes after you've told them something they're they're asking you the same question, very repetitive. Uh, um, I guess that's mostly the way and I think they get more frustrated especially in early Alzheimer's." 1014 "They have short term memory and, um, but otherwise very nice people to work with." 1028 " . . . you have to be almost repetitions with them because they're forgetting. So, um you have to, um, they're different in the sense where they don't remember what happened just a few minutes ago. Um, therefore you, you constantly have to remind them and, um, that's I believe that's how they're different because they just don't remember." 1028 "They have problems remembering, ah, more the, the recent events. As in recent as a few minutes ago or recent as in yesterday. A lot of them still have memories of years and years ago." 1022 "Like you know then there's the, you know the loosing of the short term memory." 1013 "They'll often remember things from years ago but to just remember if they've just eaten a meal is some for some of them completely gone." 1024 " . . . you'll tell them something and in two seconds they'll forget. Like a regular senior wouldn't forget it." 1023

Theme	Caregiver Quotations
Long term memory	"And the Alzheimer, with the Alzheimer, they remember the thing like it happened forty years ago sixty years ago, but not the latest one." 1013 "But you know it seems that, it's that that is amazing with this Alzheimer's is that, you know, there is a portion in the brain where in the past was intact. They can sometimes they can go in detail of what happened you know during their childhood, especially what they used to do when, you know, they were walking to to school, things like that, or riding on a horse, things like that, you know." 1009 "Um, because those are the songs that they used to know. Because once you play the music, you know, some we have, we have ladies who are very good. Their memories when it comes to lyrics are still good. And, ah, also, um, videos, yeah. You know we videos, especially the comedy, they like those. With Lucille Bull. And one more is they can, um, I have list of couples, like Elizabeth Taylor. Sometimes I will start with Elizabeth Taylor and? Richard Burton they will say. Or sometimes I will, I will start with Richard and they will be able to come up with with the partner, you know. Whereas there's Amos and Andy, Lucille Bull and Dacy Arnoss. Yeah, those things." 1009 "Well they have better long term memory than short term memory, they forget, yeah. They don't remember what they had for breakfast, or who came to see them and over a period of time they don't even recognize family members anymore, you know . . . they can remember things when way back, you know, relating back to some of their childhood experiences and that. Or when they were raising kids." 1006 "I'd say they're like everybody else, but their mind is in the past." 1012 "I would say going to what they know. Like how they were when they were a child. You'd always go back to the past because that's what they know best." 1012 "Their memory is good from the past. So go based on the past, because that's what they know best and it's easier to communicate with them using the past. And they need lots of social interaction." 1012 "Like, um, for, uh, them like story you tell them right now, they forget in five minutes, or ten minutes. But, um, something happened long, long time time in their life, they go, they will remember. They can tell you." 1025 "Uh, forgetful, uhm they have a lot of life experiences but they remember the ones in the distant past better." 1018 "Well they don't remember, um, they might remember way back but they don't remember, you know, what's happening today, you know, right away . . . Most of them, uh, know long term, like go way back. They can remember, they may not remember they were married but they remember before they were married and they remember children and that type of thing." 1020 "They have problems remembering, ah, more the, the recent events. As in recent as a few minutes ago or recent as in yesterday. A lot of them still have memories of years and years ago." 1022 "Uh, let's see, there's a couple ladies that walk around and talk to everybody. But I think it agitates them too if they can't answer your questions or don't know how to answer your questions. They get so frustrated. You'll I there's a couple people that I work with and you'll ask them like, what year were you born, I don't remember. Like they they don't know how to answer some stuff. What did you do to I don't know. I think they just get frustrated by themselves because they don't know what's

Theme	Caregiver Quotations
	going on.” 1023 “it’s really, really difficult to say because so many are different. {unintelligible}But I guess the, the common denominator is that they don’t remember things that are more in the present than things in the past. But they, uh, when the further they go the more they loose all of their memory.” 1026 “Their, you know, their memory sometimes it you know, it goes in spurts like they’ll remember fifty years ago and then, you know, the next minute they won’t. Sometimes they think they’re eighteen and then they’re fifty and, you know it goes like that.” 1031 “They’ll often remember things from years ago but to just remember if they’ve just eaten a meal is some for some of them completely gone.” 1024 “But they still, most of the time, they remember for, ah, part of their past, you know. Which is the last things which they start to forget, to loose.” 1032
Disorientation General	“They’re seniors, generally, um, confused at times, disoriented to time person and place at times.” 1001 “ . . . basically they don’t really know what they’re doing.” 1005 “Sweet, caring, sometimes confused.” 1017 “So sometimes like it works, because sometimes you know that her mind is really working very well but at there are times that she is so confused. Yeah, confused confusion really makes it so hard on them too and so hard for the caregivers.” 1010 “ . . . the Alzheimer people they, they like they they do everything like they don’t know what they are doing.” 1025 “ . . . of course the confusion that is is something that really, really, um, agitates them.” 1028 “They can’t help the fact that their brains are are not functioning properly that they are confused or that they’re asking the same question over and over again. That’s that’s their illness and you have to respect that.” 1022 “ . . . there’s one lady that went with her family one day and for two days it affected her so much, she was so confused.” 1024 “If I know the resident well enough, and if I know she’s got let’s say four daughters then I could say, you know, so do you have children rather than oh I hear you have four children. I’d rather ask, but if, I want to know the answer already because if they get all confused like oh I don’t know, oh yeah I do remember now you do have four daughters and these are their names and just to kind of help them out a little.” 1024 “Like, um, usually confused, um, of course forgetful.” 1022
Disorientation to Time	“Confused in the sense they don’t know what they’re supposed to do next. That’s something I hear quite a bit is I don’t know what I’m supposed to be doing now. They don’t know if that was breakfast they just had, or supper they just had, or whether they actually ate or didn’t eat. They don’t seem to know what to do next.” 1022

Theme	Caregiver Quotations
	"He thinks he's much younger so he comes on to all ladies because he thinks that, you know, that that's that it's okay. He doesn't have that remembering of that it's socially not acceptable to just say what you're thinking about that all the time." 1024 "They're seniors, generally, um, confused at times, disoriented to time person and place at times." 1001 " . . . well they, I think they reminisce a lot where I mean, I think we all do that but I mean they're they're believing they're in that, that time too when they're reminiscing." 1001 "That they they can't, um, they don't even know that the the time and then the like what is summer what is winter {unintelligible} they don't even know the seasons any more." 1005 "I'd say they're like everybody else, but their mind is in the past." 1012 " . . . they don't remember that they even have kids all they remember is when they were teenagers or something or young children and they're missing their parents why haven't their parents come to visit them. It doesn't matter that they may have been dead for fifty years or forty like, so yeah." 1007 "They their mind does not work the same way as it once did. I find a lot of, um, residents refer back to their younger days as opposed to living in the present. You know, you might say it's your birthday today, you're eighty-seven and they'll look at you and say, no I'm twenty-five. {laughs} And you can't argue with them because in their mind that's where they're at. They go back to that spot. Some go way back some, you know, twenty-five, thirty, thirty-five, depending on where they want to be." 1017 " . . . they're forgetful and they repeat, um, events that, events that have happened to them or that they perceive to be real or present, I guess I shouldn't say real because a lot of the stuff is real, but it's not necessarily in the present." 1019 "Well seeing as they don't know the difference between day and night, you know, like usually a healthy elderly adult will get up in the morning and start the day. Whereas they don't know the difference between day and night so that's where, you know, you tell them it's morning there's things going on you get them going and if you don't keep them busy and mobile then they'll loose that." 1031 "Time of day like they're, you know when you go through your day, you know, when you say good morning to someone or, um, have a meal together if you don't know if it's what day it is, what season it is the conversations that come of that are just it it can disturb everybody. So if someone comes in and says oh no it's summertime and why is it snow and then they're upset that there's snow and it's dark out it's supposed to be summer in the morning. They may have just woken up and had a dream and they get everybody else going then." 1024 "They are disorientated for place, for, um, time, for even for themselves in the end of the disease." 1032
Disorientation to Person	" . . . unaware of who their family members are." 1002 "They're seniors, generally, um, confused at times, disoriented to time person and place at times." 1001 "Well they have better long term memory than short term memory, they forget, yeah. They don't remember what they had for breakfast, or who came to see them and over

Theme	Caregiver Quotations
	a period of time they don’t even recognize family members anymore, you know. Yeah, and they might not even remember certain foods, you know, how they tasted or whatever too eh.” 1006 “They, ah, forget, um, they they tend to forget the member of the family.” 1005 “And then sometimes I come they come down the hallway they will say oh there’s my mum and in here I look behind me and there’s nobody in there I know they think I’m their mum.” 1005 “Um, they seem to, um, relate you with somebody from their past. They, um, also socially, yeah, they forget who their sons are and they I mean like they mistakenly, um, identify you as the husband or the or the instead of the son or daughter. I mean like you are related they just don’t know, they just don’t know how you are related to her.” 1010 “Um, well someone who’s. There’s one gentleman who’s, um, you know kind of very sexually like he those feelings are there but he, he doesn’t know that. Like it you you’d know when you’re aware that oh I can’t say that. I can’t say that to somebody or make an advance. But he’s not aware of that. He thinks he’s much younger so he comes on to all ladies because he thinks that, you know, that that’s that it’s okay. He doesn’t have that remembering of that it’s socially not acceptable to just say what you’re thinking about that all the time.” 1024 “They try to have friendships but they forget that they’re friends with someone so it’s really hard to maintain that. There’s, um, where I, the center that I’m working at there’s three sisters and one has passed away. And, you know, that they were told, these other sisters were told but they don’t remember that she’s passed away. So it’s, you know, they’ll kind of say oh you know I haven’t seen my sister for a while and you’re like well, you know and so she’s, you know, they’re just missing, missing them. And they have another sister in the center but some days they know that’s their sister and some days they don’t. So there’s a lot of those, the relationships are kind of different. And if family comes in, um, or even just staff they sometimes remember staff and some they sometimes don’t so the continuance of relationships is very different.” 1024 “They’re not orientated . . . They are disorientated for place, for, um, time, for even for themselves in the end of the disease.” 1032
Disorientation to Place	“Like not aware, on awakening not aware of where they are, um don’t know the difference between going to the kitchen table or going to eat somewhere else, not, not sure where the bathroom is will void anywhere not a specific place.” 1002 “ . . . sometimes unaware of their surrounding.” 1002 “I’m just thinking about the kitchen that we’re just sitting in the kitchen but um they can leave out of the door and say they’re going for a walk but have no idea how to get back.” 1002 “Scared I’d say, scared at times not knowing where they are, hmm, they need a lot of direction.” 1002 “They’re seniors, generally, um, confused at times, disoriented to time person and place at times.” 1001 They don’t know where they, then they forget, you know, many things.” 1032 “They are disorientated for place, for, um, time, for even for themselves in the end of the disease.” 1032

Theme	Caregiver Quotations
Receptive Communi-cation	"Perhaps the biggest challenge is when they're incontinent and they don't understand that they are incontinent and trying to clean them up and they don't know that they've done anything out of the ordinary and that's the biggest challenge is getting, having BM flying around and not being able to say if they were, if they could understand and say sit down let's clean up, wash your hands and stuff, they just don't understand, that's a, that's a challenge for me. Um, that's the only big challenge that I can think of that's could be a little stressful." 1002 "Um, no my mood is basically the same always cheery and upbeat, and residents can tell if you're stressed. If you come and you're stressed about something they can sense that I've noticed." 1002 "Well sometimes if they're not very verbal that can be a challenge too, you know, to communicate what you want them to do, usually by actions and that and gestures and that they'll do it." 1006 "And, um, they're understanding is very limited. You have to talk slowly and clearly and you have to have patience with them." 1005 "They don't maybe understand what I'm saying as well." 1017 "Um, you have to speak, um, clearly to them and look at them so, you know, because they don't always understand a big, a long sentence." 1020 "Some of them they, some of them get angry and you can't, ah, it's very hard to explain to them about different things because they don't understand and they forget as soon as you've told them something. So it's sometimes hard to communicate and to, to get through to them because they don't understand as well, and if they do for a second, the next second they don't." 1014 " . . . directions it it sometimes it's really challenge. It's a challenge because they can't really follow." 1028 "Sometimes they don't understand what it is you want from them. Sometimes you have to approach it in a different way with different words." 1022 "The sight goes first the and then the hearing I think. I'm always yelling." 1023 "You'll ask a question and they have no clue how to answer it. They don't. It's kind of sad." 1023 "That sometimes it's hard to get your point across because they just don't understand what you're saying to them. Because that sense of what did she just say to me it's gone. They can't put it together. Like even to brush their teeth they don't know what they're doing with the toothbrush half of the time and then you're like brush your teeth brush your teeth and you sound so repetitive. You have to sometimes just take it and put it to their mouth so then they know that it goes there. We'll have them comb their hair with it and then they come out with toothpaste all over them. Do you know how hard it is to get toothpaste out of hair?" "I think that we have to be more polite with them. Uh, slowly explaining to them what to do, everything, all the tasks which you give to them to be one at a time. And very clear, simple words, because some of them don't understand. Even sometimes repeating to them what have to be done." 1032 "Um, the difficult part is, you know, when you try to explain some of them what they have to do. Like, you know, go to the bathroom and some of them don't know even, when they go in the bathroom they don't even know 'what is this'?, you know, this is

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	the hard part. So here you have to be very, very specific and slow with them. This is and, um, the other thing sometimes is their mood which changes quickly also.” 1032
Expressive Communi-cation	“ . . . they’ll forget what things are, or what they’re for. Um, yeah actually that happens a lot, yeah, everyday, yeah. An object isn’t the same for them anymore . . . .The bread maker sitting on the counter would be that white bucket.” 1018 “They keep on repeating, repetition.” 1009 “Repetition of words and sometimes even actions. They they do forget what they have said a few minutes or a few even a few seconds ago.” 1009 “They use, their shorter vocabulary so they’ll they’ll use shorter sentences perhaps and be very friendly go up to people and say hi and right off the bat a lot of people kind of confuse them thinking that they’re just a normal senior visiting or something but if you have a conversation with them they might be a couple of things that distinguish them from not being a normal senior visiting, that they do have Alzheimer’s. But some of them can do a very good job of pretending that they don’t have the disease maybe.” 1002 “ . . . it’s surprising I mean we think that our Alzheimer’s residents don’t remember and I mean just because they don’t know the words for things or they don’t know how to say a full sentence doesn’t mean that they don’t know who you are and that they don’t want to be involved in a conversation. You know if their words come out backwards it’s it’s listening to what’s, how it’s being said not necessarily what’s being said. Like, you know, maybe the language isn’t there but the communication is still there and a lot of people don’t recognize that I don’t think. I shouldn’t say a lot, some people don’t {laughs}.” 1001 “Um, them not being able to express themselves the way they would like to, and them knowing that they’re not getting that across. There are times I can think of a lady in particular and she would know that that, no that’s not it, that’s not it but gets very frustrated and so it’s having the time to say it’s okay think about it for a few minutes or whatever it will come. I mean we all have moments like that where that word is just sitting right there and it doesn’t come out. So it’s giving people the time to be able to think about what they want to say, if they’re at that level and sometimes the words just come out and you have to kind of go with what’s going and think oh yeah well you you, once you get to know somebody, especially someone who has a second language. I mean it’s quite easy to know what they are saying even though half of the sentence is in another language it’s very, you know, if you know who you’re working with. You know when they’re holding up a flower and they gibbering something and they’re just like so happy that this flower is there, you know they’re talking about the beautiful flower they just picked. You don’t have, it’s not wrong, you know so that just being, paying attention I think. And then again maybe they’re not, maybe she’s telling you this stupid flower or whatever {laughs} but I mean it’s all body language and that too right.” 1001 “A lot of times, well most of the ones that I’ve dealt with now but some reach a point where they can’t express themselves and they can’t tell you, you know what’s what’s bothering them, you know. So that’s a challenge in a way too right. You have to use well simple language of course too and talk slowly to them and if they can only get one word out or whatever you know question them what’s wrong and that right if they have some problems.” 1006 “And then you have to have a capabilities of understanding what they’re trying to say because sometimes they say different things, and they they mean different things too so.” 1005

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	" . . . because sometimes they say different things and then they mean different things. So that's the most important thing is to adjust into their level and then the understanding the concept of what they were trying trying to say." 1005 "It's ah when they say a different things and they mean different things. Say they they wanted to, um, they're hungry and then, ah, if you ask them if they wanted to, um, eat and then, um, and they don't know whether they said that or maybe they said they want toast and then here you you just misunderstood they're pointing some different things but you don't know what it is." 1005 " . . . like they don't even say words anymore they just say dut dut dut dut dah. So it is very difficult for us to communicate the best way is to to, ah, stand there and then you agree to whatever the person say. And then we have Hungarian. We don't know how to speak Hungarian. What best way to do is we get little things and then we tell the family maybe just make a little note the simple, ah, command and sit down, are you hungry, are you okay. You know the little things. We get that one. That is the most challenging things when if they go downhill that they, um, they they reverse back to their, ah, mother tongue or whatever that the the language that they learned." 1005 "They're forgetful, uh, sometimes their cognition impairs them with walking and talking. The ability to do things, they can't quite do what, you know, a regular seventy-five year old person could do." 1017 "Um, some of them don't talk anymore, like, they I don't know if whether that would be a side effect of Alzheimer's or if it could be from a stroke but in the two years that I've worked you come across them that don't talk. They don't say nothing. They'll smile. You might get a chuckle out of them every once in a while." 1017 "That they know that I'm there. That that, you know, if they need something they can come to me and they can, they can ask me or if they can't ask me they can guide me through, you know, the non-verbal stuff of. Like I have one that doesn't talk so, you know, if she needs something she'll often just touch my arm and get me to go with her, which is okay with me. We figure it out. It's a little hard to to figure it out but we usually get it together. So I mean I value them they're, they're wonderful people that I think society has forgotten, unfortunately." 1017 "Well sometimes you don't know what they're talking about. Um, and I I a lot of it could be too misunderstanding." 1017 " . . . they're forgetful and they repeat, um, events that, events that have happened to them or that they perceive to be real or present, I guess I shouldn't say real because a lot of the stuff is real, but it's not necessarily in the present." 1019 " . . . some will have more speech problems, whether they're, um, just unable to form the words, or they're not understanding the, um, I guess it's hard at that point to tell whether they're not understanding it or whether they're." 1019 "Like say, um, they're really trying to get something across to you and their words aren't coming our properly and yeah then there, of course there's a communication gap there and you have to guess." 1019 "So they can forget things ask thing numerous times, um, may need more direction or redirection. But, with all that being said they're still people and enjoy normal things." 1007 "Um, they don't always just blurt things out. Like they don't have their thoughts right at the front of their brain so you just have to stop and wait if you ask a

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	question.” 1019 “If it’s in the first few stages of, I mean like fist early stage of the Alzheimer’s it’s like there’s nothing, there’s nothing wrong. It’s in the later stage of the Alzheimer’s that it’s kind of annoying that they tell the same thing all over.” 1010 “They, they do keep to themselves a lot. Although if you get them involved and get them talking between each other, like if they’re not too tired, they will talk about their past history and their lives and just reminisce as well as they can remember and sometimes it’s clearer than other times.” 1016 “ . . . they keep telling you, they ask questions over and over same, every less than five minutes they ask you the same thing.” 1025 “Um, they’ll tell you the same stories over and over . . . Well you’ve got to know that you’re going to hear the same thing over and over and, um, if they ask you questions and you explain it to them you can be prepared to do it again in 5 minutes.” 1018 “They like to tell you stories . . . They get all excited about telling you stories and, uh, they’re very interesting listening to them.” 1020 “Um, they may not get all the words out but if you’re reading their body language and can pick up on a word you can carry on quite a conversation and they, you know, because they might find it hard to find that exact word. But they know in their mind what they’re trying to say. And I find it very interesting, like, to listen to them talk about the olden days or, you know, and they get real excited about that, you know.” 1020 “ . . . they don’t get all the words out that they want to say.” 1020 “Um, well you meet all sort of different ones. The ones I’ve worked with some days they’re very, very loving and and, ah, they want to help, and other days I find they’re very frustrated and they know what they want but they can’t communicate and so they get really frustrated.” 1014 “Well they, I guess they can’t communicate like typical a adult people or seniors because they loose that ability to communicate and their words are all kind of jumbled in there so they don’t have the ability to communicate. And they may think they’re communicating and they’ll communicate back and forth with each other and a lot of times it doesn’t make any sense. But I think to them it makes perfect sense and they’re sit they can sit there and communicate back and forth and carry on a repertoire and both be quite happy with it. Where other senior, normal senior citizens would look on and maybe say whoa those guys are kind of strange. But I guess just in their ability to converse and their thinking processes.” 1014 “Patience, I’ve got to be very careful not to loose my patience because some of them ask you the same question over and over and over and you tell them over and over and over.” 1014 “ . . . they have these questions all the time but otherwise, yeah, very nice people to work with.” 1028 “I guess the repetition is the biggest challenge, how to continue a conversation when you’ve been down that road before. Um, just as an example the lady I just spoke with I heard the same story three or four times but I tried my best to, to respond to her in the way that I would want to be responded to.” 1022 “They can’t carry a conversation. They loose their conversation skills. They have no clue what, they’re bab they babble basically. Like you’ll say something and they

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	flip it completely different and then you're like you're lost because you're like what did they just say. You'll ask a question and they have no clue how to answer it. They don't. It's kind of sad." 1023 "Uh, let's see, there's a couple ladies that walk around and talk to everybody. But I think it agitates them too if they can't answer your questions or don't know how to answer your questions. They get so frustrated. You'll I there's a couple people that I work with and you'll ask them like, what year were you born, I don't remember. Like they they don't know how to answer some stuff. What did you do to I don't know. I think they just get frustrated by themselves because they don't know what's going on." 1023 "It's I think a lot of times it's just the fact that they can't communicate what's really wrong with them. But physically unless they get an infection and they can't tell you and they go downhill I don't feel there's a whole. If you keep them active there's no reason why they should go downhill any any more than any other senior because it's the brain that's going it's not their body." 1026 "Or they'll just start talking about something and nobody knows what they're talking about and those social boundaries are often just not there at all." 1024 "And at the later stage they just their speech and everything it makes no sense. So to they're talking to someone else who has cognitive problems. When they're speaking to each other it can be just either go really well where they're neither one of them know what they're talking about but they think they are so they're having a wonderful conversation and it's great. And other times one, one person, you know it's different if you're talking with if they're talking with a staff member or a caregiver because one person can kind of guide that conversation. But if they're two people that they're cognitively at completely different places it can start arguments and a lot of confusion and annoyance and they don't realize oh that person doesn't know what they're saying. So there's not a lot of that because they're always around people with Alzheimer's that that's bound to happen." 1024 "Um, most of the time when they also cannot, um, ah, you know because some of them are suffering from aphasia. They cannot, you know, express themselves. They, you see like on their face they're sad about it they cannot say this." 1032 " . . . when we make jokes you have to laugh. Or, you know, or when you don't like, you know, the what they're doing sometimes, you know, the wrist you just point, you know, with the hands. Or you have just to, with your face, you have to remind them something is wrong probably I guess. So I don't know. I never think about this. {laughs} But sometimes it's very important the expression of the face because whenever you see the expression and see that they're not happy, you know you'd better just also leave them for a while until the anger calms down." 1032
Physically Strong	"A very agile eighty year old man. He jumped the fence. He jumped the fence and what he did was he was walking home and that was it. So the police found him, brought him back. So now we've had to modify how things go so that for the man's safety." 1031 "So physically they in early stages and that they're still very mobile and, and and if they're upset or, you know, angry their strength is there. Um, whereas maybe the average senior they may be weaker but for some reason, I don't know someone who's confused and whatever and thinks they have to get out that door they, I mean if you're holding it shut there's a lot of power there when they want to go. Uh, physically, yeah they probably don't realize their limitations I guess physically so

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	that doesn't stop them. You know like forgetting that they have a sore knee or they broke their arm or whatever, you know." 1001 "There are some in my experience that are strong people but there's of course some of them that are more fit than others um some are able to do the task like lifting the weight some can only lift it part way because of their arthritis and every day is different too, how the weather is and stuff." 1002 "They're very strong when it comes like they're aggressive. They can beat you. It looks like they're they're so old it looks like they're not really healthy any more. But once they're aggressive, oh, they're strong. That's the thing I noticed to them." 1013 "They like to work out. Most of them are in really good shape." 1012 "Oh I don't think there is a whole lot different, actually it seems, maybe it's just that that's who we have in our centers but they seem to, a lot of them seem to be better physically than a lot of like other ninety year olds." 1018
Physically Same as Seniors	"They're a lot the same as older adults it's just some of them with memory loss. And, um, sometimes, like you get that with older people as well. They can be a bit more shaky or unstable, but that's older people in general." 1016 " . . . other than them not being able to communicate I don't feel that there's a whole lot of difference. It's I think a lot of times it's just the fact that they can't communicate what's really wrong with them. But physically unless they get an infection and they can't tell you and they go downhill I don't feel there's a whole. If you keep them active there's no reason why they should go downhill any any more than any other senior because it's the brain that's going it's not their body." 1026 "Physically they may have some other, um, problems other than, you know, some other physical problems that may cause them to walk slower or whatever. But it's not much different than somebody that hasn't Alzheimer's." 1020 "I think, um, physically they're almost the same. They're also old people. If you look at them they have the same diseases like all the others. So weak like all the others, you know." 1032 "The people with Alzheimer's disease, like, in their body what they think in their health they are still thinking, like, they are still okay they can still do everything what they want. But the problem, their mind doesn't coordinate with their movement." 1013 "They're some of them are in a lot of pain. I don't know if that's with the disease or just being a senior." 1023 "Well you wouldn't, you probably wouldn't even notice it otherwise until they started talking and you related to them more. Physically just look at them, other than that they walk with a walker, you know if they have problems walking if they have physical problems because, ah, regular seniors have physical problems too right, and they have that just on top of that." 1006 "So if they're they sometimes will get unsteady in their gait, um, which is, could be the Alzheimer's or could be age." 1019 "I'm not sure if it's, uh, I know we have some like ladies in that are in their nineties and they are still very, well I shouldn't say athletic, but they're, they don't need walkers they don't need, um, wheelchairs. Like I'm not, I don't know if that's typical for a lot of ninety year old's but, um, it seem that the older ones we have don't seem to be, you know, until everything starts shutting down type thing. They

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	don’t seem to have different ailments than anybody else.” 1018 “ . . . to hear somebody you know I think half of them wear hearing aids so that’s just like a normal senior, some of them can hear and some of them can’t hear.” 1002 “When you get, when your age progresses your hearing does go and it’s still the same as any older adult age hearing, senses it all goes away anyways so Alzheimer’s I don’t think affects their, any of those senses.” 1012 “I don’t think there’s any difference between one older adult and the next. I mean an eighty-year-old adult probably percentage-wise ninety percent are going to have the decreased hearing because it’s the body functions the same whether you’re got a disease or not.” 1007 “I don’t know that, that seem to have eye problems. Um, to where it gets really bad, but it’s not, it’s not everyone. But there are quite a few that, that seem to have bad eyesight. That could go along with the fact that they’re also getting older but I don’t know if it’s really a proven thing of Alzheimer’s or not . . . Um, smell. Some of them I’m sure can’t smell a whole lot, but. {laughs}But I don’t know that, I think that might be just the aging process as well.” 1026 “Um, I think probably there is some difference. Hmm, I didn’t actually I didn’t since I’m working two years now I didn’t see some so big difference, you know, in this. I think it’s the same.” 1032 “I think that those kinds of things [senses] deteriorate with age, it doesn’t necessarily mean that it’s with Alzheimer’s.” 1022
Physical deficits	“Like if you were to ask them from walk from one end to the other they’d probably get exhausted halfway through and stop. I get that a lot at where I work. They can’t even walk half a distance. They have to sit. Um, they seem more frail to me. Like they, they loose their appetite and they don’t eat or they don’t know how to eat anymore so they loose their body strength.” 1023 “Um, people with Alzheimer’s I think sit around more perhaps than a, than, other seniors that I know go to the mall and mall walk and understand that it’s important to have physical exercise whereas Alzheimer’s they couldn’t care less.” 1002 “They get weaker, yeah. Um you can’t really say it’s in their face because you can’t because some people don’t even know. Um, different, less able to do stuff . . . They’re more tired. I notice a lot of them have walkers here, walking assistance. Um, I don’t know. Good question. I’m stuck.” 1023 “They’re forgetful, uh, sometimes their cognition impairs them with walking and talking. The ability to do things, they can’t quite do what, you know, a regular seventy-five year old person could do.” 1017 “ . . . they would have maybe some, um, the body functions slowing down or inability to control body functions. Um, so they a lot of people will become incontinent and not able to distinguish when they need to go or where they need to go to go. That sort of thing, where’s the bathroom.” 1019 “A lot of them though, from my experiences of working with them, is they also are a lot closer to death and so they still are like a lot tired a lot of the time.” 1016 “I think they loose their vision more faster than a regular senior. I’ve noticed that a lot. Like they don’t know where. Like if you were to place the food in front of them they, we have some that have no clue where the plate is because they can’t see it anymore. And sometimes they can’t see the hallway either and they can’t walk.”

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	1023 "I would say that they probably have a diminished capacity for sensing, like smell and taste. I don't know if, I don't know if if if that works with everybody but I mean some people will not notice that it's, you know, spaghetti sauce that's on their their plate because they can't really taste." 1017
Moodiness	"Most of the time the one with Alzheimer's disease, there's a, there's a it depends on their mood. It's very moody." 1013 "So, the mood is very, swing they it swings so quick, yeah." 1013 "Changeable like the weather {laughs} . . . They're, ah, sort of unpredictable, you know their mood swings vary. You can say well, um, I I want to give you your pills now they'll refuse to take them, you come back later and they'll take them, you know. Or we're going to have a bath, we'll get washed up, or brush, you know, so brush your teeth but one time they're adamant and stubborn they won't want to do it and then you know when you leave them alone for a little bit they'll, they'll come around." 1006 "Um, just you know sometimes the the sadness. The the appearance of their faces. Because they don't know they don't even know any more about the, um let's say if they see one thing if you're happy and then um they remember different things and they become sad about that. And then, um, maybe it it reminds them of something that happened in, ah, in during their their time or part of their life that they become so sad and maybe sometimes they looks so happy when they see people happy." 1005 "I can also say that they can be very emotionally." 1005 "Let's say,um, one person will say, um, um, you it someone will make a comment ah to that lady and she can cry easily and then um you say oh you you took the the spoon off that on that table and they be can be very negative and then they can they can be very emotional they can cry because they don't know and then if you if you just make a real comments they take that in very easily in a negative comment or in a positive way. It depends on how they do they do things. Like they snap fast and they will cry because they in their mind or maybe how they feel they think that they made a I mean they they did something wrong." 1005 "You also have to have a good sense of humor with them. {laughs} That works very very well, sometimes you have to to. Um, you can't just tell them what to do right away. You have to be you you have to to see what their moods like because their moods change. You have to make sure that that person might be able to respond to you in a better way if the person is happy. If not happy leave don't talk. Leave, leave the give them time a chance to, um, calm down. Or if they're not in a good mood or if they they're not ready to get get up yet leave them." 1005 "With Alzheimer's you have to be cautious what you say because anything can set them off. Even if you're saying it nicely it can set them off. Uh, they can take it differently than other adults. Um, so you have to be cautious with what you say and how you say it to them." 1012 "They get angry easier. Um, forget who their friends are if they're in like a care center. Um, I mean, so. You know, or they can lash out and then realize they haven't. They could hurt somebody's feelings and not realize they're done it where that person may realize and hold a grudge. And not, you know, so it can be a two-way thing there." 1007 "Well, because they can flip on a switch and turn that switch off in a matter of two

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	minutes apart. They could be happy one minute and throwing something at you the next." 1017 "They will be, you know, sitting in the great room watching TV with five other people and they'll be chatting amongst themselves. But you'll get the odd case that will, you know, you're, you're doing morning care and everything's fine and then all of a sudden it's not fine and the towel's being thrown at you and, you know, because I I don't know why that happens. I I wish I did know. {laughs} Because I know the first time it to me I was a little bit taken aback because I wasn't expecting it and now working as long as I have, which isn't very long, in the dementia unit I now know that, you know, it's like the wind it it changes. It could change within minutes, within seconds. And be happy one minute and want to slap you the next." 1017 "Um, see residents that are, ah, really, really stuck in a very negative place and they're, they're really, um, angry or, um, unhappy, like, distressed of in some way and I and then I and then I can't get them out of it then I get very, I find that really difficult because then I know that, you know, they're living in that little space and they if you can't, you know, because sometimes you just cannot get, you know, convince them or, you know, assure them that this is what's going on and they're scared. And, and that's frustrating. I find that really frustrating." 1019 "Um, sometimes they can be a bit more, like, you kind of say it like moody. But, I don't know, like I haven't worked with them that long." 1016 "And some of them are angry because of the disease and angry because they're frustrated and, um, but they're I think they always like to have hugs and and for you to let them know that you care about them. So I think they go through a lot of different emotions." 1014 "But once one person or two people get agitated it really makes a difference with the rest of the residents . . . They'll either pick up on it or they'll get, or some of them will get scared. Um, and they can, they can be upset for a long time. It's hard to get them back to normal. Like it sometimes it can affect them for hours after." 1026 "Hmm, the mood swings . . . Um, you can be walking with somebody and or you can be in a person's room visiting or giving pills and they can come out five minutes later and they can be just like a different person. Or you think a person's fine and no time later they're not so great. They're quite aggressive, they're verbally, um, abusive, not only to us but to everybody. And it can escalate very, very quickly. And it doesn't necessarily have to be the the sun, what do they call it, the sundowners or whatever it is. I don't find, quite frankly that. I hate that term because I don't really feel that. I've worked all the shifts and I don't really feel that sundowning is appropriate as a term because you can get them up in the morning and they can be in just as bad a state or by right after lunch they can be just a bad state. I think a lot of times it just depends on the day, where their medication is or there, there's so many things that can, um, be a factor. It could be somebody said something and it just triggered it." 1026 "But if they're in a bad mood you leave them alone, right." 1031
Agitation	"To make them happy. To give them satisfaction. Because if you're the only one who wants to be satisfied or to be happy and you tried to push her without her knowing or just to push her on what she doesn't want to do then it's not good because she's going to be upset, then you be upset too. So it's better like as long as she's happy, she's satisfied with trying to do that like that." 1013 "Yeah, the most important is the residents to make them happy. Because I work in

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	the nursing home to before and I noticed like if the residents has no family who comes to visit and if you don't give them the good care then you would see their face. They're so sad and they're really very irritate easy to irritate and they won't eat like that. But at least if the caregiver is good to them they know how to deal with that. At least for a few minutes you could see them smiling. So that's a good thing. That's what I want to see. Make them happy." 1013 "Yeah, like if the residents can't hear really good and you yell at her, then you won't be satisfied with your work because they gonna be upset with you. So if you know like there's a problem on hearing try to be a little bit closer. Try to touch her hand, like not touching like, you're don't grab, just touch it gently and then try to talk slowly and in a nice tone in her close to her to her ear and explain to her, yeah, what you want to do." 1013 "Well, one with, a a typical adult, if they knew that they forgot something they're very much aware of it. But, the one with, you know person with Alzheimer's disease they're not aware that they are forgetting it. So out of that they become frustrated. Frustrated and sometimes they become agitated, you know if, if they're losing something. And they're always on the go. That's one more thing that I have noticed. You know that that's the reason that they wanted to unlock the, the door, because they are always on the go. Yeah. But some of them, it it depends on the a stage of the illnesses." 1009 "Well, well working with the Alzheimer's for eleven years, you know, I have, I've noticed quite a bit. Like, um, you know a people who are quite advanced once they are agitated right there and then they will become so frustrated and be angry, you know." 1009 "When when they're agitated, when they're agitated no matter what you do it's it's it's their way. So what I do is I respect that and I leave." 1009 "When they're frustrated, yeah. We have, we have somebody in the Rose House, she's she's still young. She's just sixty years old. And a lot of times she wanted to be, she wanted to be with her husband. But you know we cannot be calling her husband constantly every day every time she needs him eh. So what I do sometimes I take her for a walk or redirect her, you know, take her for a walk. Or sometimes we will just look at the aquarium, you know, it's very peaceful or sometimes we will go see the birds. So her focus will be, will be changed. But there are times when no matter what I do it's not going to work.{laughs}" 1009 "The noise level, the talking, the kids screaming, the it becomes very agitating actually. And that's why a lot of times people are better in some cases smaller groups as far as like functions, like family functions." 1001 "They might be a little impatient, I think a lot of times they'll know, they'll know that they can't do things well and maybe they kind of know it, you know, and it it they're more irritable or mad at themselves or frustrated." 1006 "I do walk fast. And I've been told by several care managers that yeah, slow down you're making them agitated because if you walk too fast you do. They, they don't comprehend that. They don't comprehend why you have to run or. They think you're running, you're not really running, but to them you are running. It, their perception of it is that, like, you're going way to fast. So you have to slow down." 1017 "But one thing is that the recent ones, the recent memories are the ones that get lost right away. And, uh, it's because the they get kind of frustrated, that's that's why they get kind of restless and agitated. I mean like it's more on the memory that they

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	cannot remember and then other things come after that. And like, I mean like the ordinary ones who seem to have, um, just forgotten something but it will come back in the sense that yeah once you think about it okay it will come back to you. But nothing that way that you're, you're going to get agitated. You sure can be stressed, but not in that way." 1010 "Um, for one thing they easily get frustrated. Um, there are more negative things that come into their mind now." 1010 "Um, well you meet all sort of different ones. The ones I've worked with some days they're very, very loving and and, ah, they want to help, and other days I find they're very frustrated and they know what they want but they can't communicate and so they get really frustrated." 1014 "Well for one thing they forget, ah, five minutes after you've, not even five minutes, two minutes after you've told them something they're they're asking you the same question, very repetitive. Uh, um, I guess that's mostly the way and I think they get more frustrated especially in early Alzheimer's." 1014 "Patience, ah, you have to have patience all the time. Respect for that person. Uh, and just listening to them because I, I often see how frustrated they get and, and I I would don't think there would be anything worse than being that frustrated and and thinking that nobody cares or wants to take time to listen to you." 1014 "Well you have to be more repetitious and, um, I think you have to be more patient because they can feel when you're getting angry and that makes them agitated. So you've got to just be more patient with them and, ah, you also have to be persistent with them and, ah, like some of the things that they want to do but they can't do you have to be persistent. That's not allowed and stuff, yeah." 1014 " . . . of course the confusion that is is something that really, really, um, agitates them." 1028 "Well you know, it's quite something, uh, a lot of them, um, withdraw. Which a lot of them are very repetitious so then if somebody is higher functioning, and I'm talking from where I work, higher functioning and you give the people who are repetitious it sort of agitates them. But the good part of it is that, um, it's always new. And, and, and I also feel it just depends. Um, some people just naturally withdraw because I find that because of them not remembering it's almost like this is almost like what happens they can't get it out. They can't really, you know, formalize it or formulate a a sentence so it it just sort of frustrates them, that's the difference. They're frustrated and there again it depends on the level of, you know, of Alzheimer's, you know, how how cognitive they are and how badly the Alzheimer's has, you know, affected them." 1028 "It okay, um, again it depends like if somebody's really, really upset I redirect them take them somewhere else. We just have a gentleman, let's call him Mr. H, um, when he gets really upset about something I just basically take him by the hand , rub his back and just sort of or, you know, even his arm and just sort of redirect him. Let's go have a tea, I am really thirsty, you know, what would you like to eat. Um, another thing is is I, um, you have to use a lot of distractions." 1028 "Some people were controlling type of, ah, people to start with and if you take that control away from them they, they become irritated and unmanageable. But if you let them think that it was their idea in the first place." 1022 "Sometimes agitated." 1023 "I think if you have a highly functional, like early stages of Alzheimer's and you put

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	them at a table with somebody who's more down the road of Alzheimer's and they try to talk I think they get frustrated with the. I've seen that a lot too. So sometimes they walk away and don't even want to carry a conversation." 1023 "Uh, let's see, there's a couple ladies that walk around and talk to everybody. But I think it agitates them too if they can't answer your questions or don't know how to answer your questions. They get so frustrated. You'll I there's a couple people that I work with and you'll ask them like, what year were you born, I don't remember. Like they they don't know how to answer some stuff. What did you do to I don't know. I think they just get frustrated by themselves because they don't know what's going on." 1023 "That if you say the wrong thing it'll set them off. Then they get mad. So you have to be more, um, you have to choose your words and your what you say to them better so you don't get them all mad and agitated and then that's it for that day. Forget it. Try the next day. Because I know, um, there's this one lady we have a difficult time with sometimes. So you just try to go around what to say to her. Yesterday she hugged me and told me she loved me and that was a shock." 1023 "Um, I think if you have set programs and they're encouraged they will come to the activities. If you encourage, um, participation you get a lot more. A lot of times even when they're older they just wanna, they want quiet. They don't want to to be over stimulated at any point. And a lot of times if you try to over stimulate them they get agitated. And it's doesn't take much to to get some of the residents some of the, well I'll say residents because that's what I deal with, um, agitated. And some are easier than others. But once one person or two people get agitated it really makes a difference with the rest of the residents . . . some of them will get scared. Um, and they can, they can be upset for a long time. It's hard to get them back to normal. Like it sometimes it can affect them for hours after." 1026 "But I think their movements are slower because of the thought processes, you know, when they're walking or whatever. But on the other hand if they get agitated or they're sundowning they're walking really fast so, there you go. Like I said it's individual." 1031 "And one lady she, she was sitting in there and she was like get out, get out, get out and pointing at the door and getting upset and so I didn't want her to be upset. I didn't want to push it so I said okay, you know what, and I just tried to distract it and say you're such a nice kind lady I'm not used to you talking to me like that. And she felt so bad and she said get out please {laughs} and I said well I appreciate that, thank you and then, you know, just left." 1024
Aggression	"There's a time like they're so aggressive, even if you don't ask them to help you to wash the dishes, they can help you without asking. But sometimes you ask them, they refuse and they're upset the way they answer. So, the mood is very, swing they it swings so quick, yeah." 1013 "They're very strong when it comes like they're aggressive. They can beat you. It looks like they're they're so old it looks like they're not really healthy any more. But once they're aggressive, oh, they're strong. That's the thing I noticed to them." 1013 "My views, I'll try my best to do the care for them with lots of patience, lots of encouragement, like you have to spend lots of time. You don't need to be in a hurry. You can, because if you are in a hurry to them, then the more you're in trouble they get upset. They might hit you. And also like whatever you want to do with them

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	you have to explain to them what you're doing. That's the most important because if you just go there without saying anything for sure they're gonna hit you without asking. Because even the doctor they hit the doctor on their face when the doctor just introduce himself, yeah." 1013 "And we have a resident also before he's a tall guy. He's six foot three, I think six foot five and maybe she thought he thought I'm a little kid too. So one time I'm just by myself and then that's the time he tried to corner me and tried to hit me, punch me. Yeah without saying anything, I'm just washing the dishes and then all of a sudden he was behind me. So maybe they were thinking like what I'm doing there I'm a small kid, especially it's late in the evening, because I'm working three to eleven. So maybe that's the thing." 1013 "And last week we have a resident, like, you can take out her teeth. Then she bit me here. Yeah, the mark is still here. The LPN wants to help me but there's another resident who wants to come with us in that room and it's a guy, so the LPN's trying to stop the guy, not to come in in the room. So I'm the one who was in there so I can't ask help right away. So she won't open her mouth then all of a, all of the sudden she moved like this so my hand get like in between, instead of here because there's technique. You have to put your hand over here so that you she won't bite you right. But because she move my hand goes like this and then she open her mouth and then she bit me. So my fingers really blue." 1013 "Because sometimes if they can't understand you then there's a chance they might hit you and they gonna be upset." 1013 "Well when their mood changes to redirect can be a very big challenge. Something just sets them off we just not quite sure what and it could be another resident. There's a lot of fighting amongst the residents, the ones who are able to know each other's names and stuff they nit pick and and so there's a lot of stuff going on like that. But when that happens we try to remove one from the situation I guess you could say." 1002 "So physically they in early stages and that they're still very mobile and, and and if they're upset or, you know, angry their strength is there." 1001 "Well I mean they can be aggressive and stuff at times too, you know, so you have to know the techniques to, to, ah, distract them. You can use distraction and talk in a calm voice, you know, don't, don't get angry or anything. That doesn't do any good." 1006 "But if they seem like if the first thing in the morning and you you're you're getting all these people and then you're forced in then they kick and swear at you. Oh my goodness you have to be very patient with them. So, you always have to make sure that first thing you have to do is give them a smile, make the day run smoothly, do something better and they will do things better for you." 1005 "You know what we let let's say there's some residents that they're really , um, u,m aggressive." 1005 "Um, ay if you say oh can you get up they might think you're being harsh to them, but you have to be more gentler with them sometimes. Explain yourself more to them on what you want from them, because they can take it the wrong way at any time and they can get more aggressive with you in some aspects." 1012 "Okay, they can get more, um, aggressive towards each other. Like I've seen it a lot between women, um, that they will not like other women and they will be aggressive towards them . . . Swearing or saying rude things usually is what they'll do. I haven't seen anything beyond like, I haven't seen like hitting or anything but mostly

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	that's how their aggression is towards them is either by moving or making like mean faces you know or them end up storming off because they're mad." 1012 "Well, because they can flip on a switch and turn that switch off in a matter of two minutes apart. They could be happy one minute and throwing something at you the next." 1017 "They will be, you know, sitting in the great room watching TV with five other people and they'll be chatting amongst themselves. But you'll get the odd case that will, you know, you're, you're doing morning care and everything's fine and then all of a sudden it's not fine and the towel's being thrown at you and, you know, because I I don't know why that happens. I I wish I did know. {laughs} Because I know the first time it to me I was a little bit taken aback because I wasn't expecting it and now working as long as I have, which isn't very long, in the dementia unit I now know that, you know, it's like the wind it it changes. It could change within minutes, within seconds. And be happy one minute and want to slap you the next." 1017 "Like some of them are friendly, some of them are aggressive." 1025 "Hmm, like sometimes they are angry. They don't want to talk so you can't." 1025 "Some of them they, some of them get angry and you can't, ah, it's very hard to explain to them about different things because they don't understand and they forget as soon as you've told them something. So it's sometimes hard to communicate and to, to get through to them because they don't understand as well, and if they do for a second, the next second they don't." 1014 "Um, you get more, more things that, that they can't, physically can't do. Um, sometimes you get aggression. Sometimes, um, a lot of the normal things that just every day life things like their bowels, their ability to just do the normal everyday tasks diminish. Um, sometimes they get aggressive, sometimes they get passive, you just don't know. But they tend more to get a little bit more tending towards the aggressive side I would say." 1026 "They're quite aggressive, they're verbally, um, abusive, not only to us but to everybody. And it can escalate very, very quickly. And it doesn't necessarily have to be the the sun, what do they call it, the sundowners or whatever it is. I don't find, quite frankly that. I hate that term because I don't really feel that. I've worked all the shifts and I don't really feel that sundowning is appropriate as a term because you can get them up in the morning and they can be in just as bad a state or by right after lunch they can be just a bad state. I think a lot of times it just depends on the day, where their medication is or there, there's so many things that can, um, be a factor. It could be somebody said something and it just triggered it." 1026 "And then sometimes there's aggression. Sometimes there isn't." 1031 "There are times like an aggressive." 1031 "Like one lady will say oh well, like, how did you finally convince so and so to go and have a bath it's been, you know, five six days and she's just refusing and it's to the point where she'll be aggressive and just be upset." 1024 "Um, one thing I definitely do, um, because sometimes you can almost see if there's a, like, not aggression but you can tell they're going to be, there's you get to know people and you just know, okay, it's going to go this way or it's going to go that way. And I can see they're kind of like putting up that guard and I always often think oh maybe that's just a trust issue or they're feeling threatened in some way." 1024 "But sometimes it's very important the expression of the face because whenever you

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	see the expression and see that they're not happy, you know you'd better just also leave them for a while until the anger calms down." 1032
Withdrawal	"But once their socialize almost started to be gone then they withdraw a little bit." 1013 "Like if they're deteriorating you will find out because their social thing you could see like it's getting down and getting down too. Yeah because like before the person who likes to dance, once they start to deteriorate they're not interested to dance. Yeah, they just go there, you can invite them to go there but they won't stay to dance, they just keep on walking around back and forth, back and forth. Yeah, and when you approach them they get upset so it's better to let them walk and walk." 1013 "The social, the ordinary, ah, adults, like, like one who's old, if they like to dance they're still there but with the Alzheimer's people usually you have to encourage them more before they could come. You can't call them just for one call. Sometimes the dance is almost over before they're coming and they will complain how come it's too short. {Laughs}" 1013 " . . . for some reason sometimes they just want to stay in their room totally like totally, um, ah, how do you call, isolate themselves into." 1005 "And there's some people that they used to do those things but for some reason they just lock themselves in their room or do something and then they don't want to do anything. Like they they totally, um, don't want to do it no matter how you ask them. Just that's it that's it I don't want to do no more you know." 1005 "Um, with the disease process they can isolate themselves from others, not wanting people to realize they have a problem. Um, so they can become loners, depressed." 1007 "Um, but I mean they, they don't, they still participate, you know, as long as you, uh, encourage them and and offer it. Like, if you just if you just see they're laying in their room and you don't want them, you think well they're better off there, then they're not going to get up because they're not going to know that the activities going on. But if you go and knock and say, we're doing bowling in the in the great room would you like to join us nine out of ten times they'll join you, so." 1017 "Well you know, it's quite something, uh, a lot of them, um, withdraw. Which a lot of them are very repetitious so then if somebody is higher functioning, and I'm talking from where I work, higher functioning and you give the people who are repetitious it sort of agitates them. But the good part of it is that, um, it's always new. And, and, and I also feel it just depends. Um, some people just naturally withdraw because I find that because of them not remembering it's almost like this is almost like what happens they can't get it out. They can't really, you know, formalize it or formulate a a sentence so it it just sort of frustrates them, that's the difference. They're frustrated and there again it depends on the level of, you know, of Alzheimer's, you know, how how cognitive they are and how badly the Alzheimer's has, you know, affected them." 1028 "Well I've noticed that they they don't seem to, or some of them seem to want to socialize at all. They would just as soon sit in their rooms. They need to be encouraged to come out and take part in activities. But then again some of these people the families have said to us they weren't social in the first place. So whether that has anything to do with Alzheimer's or just being elderly that you just finally want some time to yourself. You couldn't be bothered. It's hard to say whether it's

Theme	Caregiver Quotations
	something to do with Alzheimer's. I think it's something that happens in a lot of the elderly, it's just easier to stay at home." 1022 "Well I've found in our center that a lot of people make friends. If they were social people to start with they go out of their way to, to make friends and visit. I don't think they loose that I think that's something that, that continues. If they were shy and private then they continue to be so." 1022 "I think if you have set programs and they're encouraged they will come to the activities. If you encourage, um, participation you get a lot more. A lot of times even when they're older they just wanna, they want quiet. They don't want to to be over stimulated at any point. And a lot of times if you try to over stimulate them they get agitated. And it's doesn't take much to to get some of the residents some of the, well I'll say residents because that's what I deal with, um, agitated. And some are easier than others. But once one person or two people get agitated it really makes a difference with the rest of the residents." 1026 "And there's, there's a quite a few that just especially as their, their disease progresses that they just it to have a conversation it just doesn't happen it's just gone and they don't want to come out and do activities and you feel like you're really coaxing them to be involved in in things." 1024 "But some of them who are already having, I think starting suffering from depression they just isolate themselves" 1032 "It's just like two, um, how to explain, it's like, you know, it's not a middle thing in them. They are very much socializing or what I mean they like to be with somebody all the time and on the other the end is that they just isolate. They don't want anything. Their mood is very changed and they don't like to be bothered for." 1032 "So, um, they, um, they're more isolating themselves. Uh, they're not so happy. You see on their faces, some of them. Um, most of the time when they also cannot, um, ah, you know because some of them are suffering from aphasia. They cannot, you know, express themselves. They, you see like on their face they're sad about it they cannot say this." 1032 "Um, some, uh, kind of draw back and aren't quite as sociable but they may not have been, you know, if they didn't have Alzheimer's. And some are very social and they like to be around people all the time. They like, um, lots of social interactions." 1020

APPENDIX F:

CAREGIVER QUOTATIONS THAT SUPPORT COMMUNICATION THEMES

Theme	Caregiver Quotations
Tone of Voice	“Yeah, like if the residents can’t hear really good and you yell at her, then you won’t be satisfied with your work because they gonna be upset with you . . . then try to talk slowly and in a nice tone in her close to her to her ear and explain to her, yeah, what you want to do.” 1013 “So it’s one sentence, you know, three or four words at a time. Very simple to understand. And in a slow manner and in soft voice. But make sure it’s clear that they can understand well.” 1009 “Well they can, sometimes if if you come out with a loud voice, in a in a loud manner they can be startled. Yeah, and also, um, if if you’re talking in a loud manner it looks like you’re angry, you know. It it’s not a good approach.” 1009 “Well I mean they can be aggressive and stuff at times too, you know, so you have to know the techniques to, to, ah, distract them. You can use distraction and talk in a calm voice, you know, don’t, don’t get angry or anything. That doesn’t do any good.” 1006 “ . . . a quiet tone and, you know, not loud or boisterous.” 1006. “And then, um, you can also explain to them sometimes they can even hear so you sometimes you have your voice the tone of you voice has to be really, um, not too loud not to soft because sometimes they can’t hear you and sometimes too too loud they think they hear and they they think that you’re yelling at them, you’re screaming at them. So you have to also look at the person whether that person is capable of hearing good or not. And then, um, we adjusting to their level they can see your face when you talk to them.” 1005 “Um, you know, tone of voice . . . Well if you’re sarcastic or have an attitude in your voice that can really affect the way they communicate with you.” 1007 “I would probably, I would slow my my speech down. Um, make sure that my, my voice is the tone is is something that they can hear. Like, I’m not going to go, {whispered} hi Mrs. Smith how are you {whispered} because they’re not going to hear me, right?” 1017 “Um, I the my approach is usually, uh, talking to them right in front of them. Like you know come up to them and talking to them and, uh, very softly and a lot of times the people with hearing problems will almost respond more to a normal level of talking instead. Because we, we tend to talk louder when we thing somebody has a hearing problem.” 1028 “Yeah, direct eye contact. Depending on the person some people can hear well some people can’t. So if you know they can’t hear well you make sure that you look at them and speak a little bit louder but not yell and adjust your tone to what they can hear.” 1026 “Like if they can’t hear they’ll do something for a smiling face or a quieter voice, you know what I mean. They don’t need a big, loud. Most elderly people with Alzheimer’s do not like loud noises at all. Yeah, so you just talk quietly, and, and if they don’t understand you just say come with me. That’s a such an easy phrase to say, come with me and they come, yup.” 1031

Theme	Caregiver Quotations
	"If they don't understand what you're saying they might be hard of hearing, you might put your pitch up a little more." 1031 "And I can see they're kind of like putting up that guard and I always often think oh maybe that's just a trust issue or they're feeling threatened in some way . . . I will bend down and then sometimes just take their hand or just touch their hand even just so they know, and talk in a really calm, quiet voice . . . So it's you're just trying to let them know that it's okay and if they're upset just putting your arm around them or holding their hand. Or just talking really calmly and, um, not talking down to them because they, people can sense even in your tone and and how you're talking to them. Um, I think they can tell whether they should trust you or not." 1024
Patience	"My views, I'll try my best to do the care for them with lots of patience, lots of encouragement, like you have to spend lots of time. You don't need to be in a hurry. You can, because if you are in a hurry to them, then the more you're in trouble they get upset. They might hit you. And also like whatever you want to do with them you have to explain to them what you're doing. That's the most important because if you just go there without saying anything for sure they're gonna hit you without asking." 1013 "Um, them not being able to express themselves the way they would like to, and them knowing that they're not getting that across. There are times I can think of a lady in particular and she would know that that, no that's not it, that's not it but gets very frustrated and so it's having the time to say it's okay think about it for a few minutes or whatever it will come. I mean we all have moments like that where that word is just sitting right there and it doesn't come out. So it's giving people the time to be able to think about what they want to say, if they're at that level and sometimes the words just come out and you have to kind of go with what's going and think oh yeah well you you, once you get to know somebody." 1001 "So always be slow you know wait. Slower questions and wait for them to respond if we're asking them another one and stuff like that. It's hard, and that's not always the easiest thing to do, you know." 1001 "And, um, they're understanding is very limited. You have to talk slowly and clearly and you have to have patience with them." 1005 "Alzheimer people you have to be very patience with them and try to understand what they're trying to say because sometimes they say different things and then they mean different things." 1005 "Yeah the best the thing is in Alzheimer's is no do not rush these people." 1005 "You would speak a little bit slower and, um, you would give them time to think about it because you can't rush them into thinking, because they're going to get, they're going to get really confused. So you just give them time in between talking to them and use simple words." 1012 "Patience . . . they don't always just blurt things out. Like they don't have their thoughts right at the front of their brain so you just have to stop and wait if you ask a question. And you stop and wait until they answer because their, their wheels are turning or whatever right, they're trying to, trying to process that. And I find that if I'm rushed and I don't have that time, then there's, you know, I notice and I sense that they're not as happy in, in the interaction right. Because I know if I'm somebody's asking me a question I like them to wait until I, my wheels turn all the way. So you just treat them the way you want to be treated I guess and and realize that there is a slower process. And sometimes they might not ever answer.

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	{laughs} So then I ask a different question or ask it a different way.” 1019 “Um, you have to like I said be patient. Listen to them because they keep telling you, they ask questions over and over same, every less than five minutes they ask you the same thing.” 1025 “Patience, ah, you have to have patience all the time. Respect for that person. Uh, and just listening to them because I, I often see how frustrated they get and, and I I would don’t think there would be anything worse than being that frustrated and and thinking that nobody cares or wants to take time to listen to you.” 1014 “Like I have one lady I’ll get her ready for bed and she’ll say well what do I do now and I’ll say, ah, you go to bed. So I take her to her bed and I sit her down well what do I do now I say you sleep, you lay down. What do I do now, I say you go to sleep. I mean so, I guess just keeping your patience and being persistent.” 1014 “Well you have to be more repetitious and, um, I think you have to be more patient because they can feel when you’re getting angry and that makes them agitated. So you’ve got to just be more patient with them and, ah, you also have to be persistent with them and, ah, like some of the things that they want to do but they can’t do you have to be persistent.” 1014 “I mean kindness goes a long way and patience goes. Patience is one of the key things you have to have around Alzheimer’s.” 1026
Repetition	“ . . . to hear somebody you know I think half of them wear hearing aids so that’s just like a normal senior, some of them can hear and some of them can’t hear um, maybe you have to repeat yourself more I think with Alzheimer’s.” 1002 “I try to make myself clear, I have a loud voice as it is, sometimes I do have to repeat myself.” 1002 “Oh, well you have to, like you say you have to be more patient. You might have to be a little more repetitive, you know, to get your point across so they understand you. You might have to show them something, you know, like nonverbal communication more so, yeah.” 1006 “Um, take, like I I’d probably it would take longer for me to talk to them than it would for me to talk with a cognitive person. You know, we I might you might have to repeat or reword things so that they understand better.” 1017 “Sometimes they don’t understand what you are doing when it’s just a repeated task of the day. And so you just have to repeat it to them, sometimes slower, sometimes rewording it and saying just, like how I told you earlier about, like, the bathroom experience, where I was like would you like to go to the bathroom and she’s like, yeah I have to go to the bathroom. I was like okay let’s go to the toilet but then once she was on the toilet and had some difficulties getting there she was like I’m just so confused, she was like why am I here. You’re like, well we just worked five minutes to get you there. But just because they forget at moments and so you just have to work with them and just be patient because they honestly forget it and it’s not like they’re just trying to be annoying to you.” 1016 “I don’t know just a lot of time you just have to repeat it if they don’t understand you. Just repeating it and giving it in a different way, like presenting it to them. Sometimes it could just be, um, I don’t know, just you have re like just redo it.” 1016 “I mean if you’re trying to engage them in a conversation you probably just have to

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	repeat yourself more often." 1018 "Well you have to be more repetitious and, um, I think you have to be more patient because they can feel when you're getting angry and that makes them agitated. So you've got to just be more patient with them and, ah, you also have to be persistent with them and, ah, like some of the things that they want to do but they can't do you have to be persistent." 1014 " . . . you have to be almost repetitions with them because they're forgetting. So, um you have to, um, they're different in the sense where they don't remember what happened just a few minutes ago. Um, therefore you, you constantly have to remind them and, um, that's I believe that's how they're different because they just don't remember." 1028 "I repeated a lot of stuff. Like I wouldn't have to repeat to you all the time." 1023
Clarity and Specificity	"Simple words, one thing at a time because they will be confused. They already confused. But if you will say, oh let's let's ah put this in the garbage and then after that, you know, you you always come out with with sentences. That is very confusing. So it's one sentence, you know, three or four words at a time. Very simple to understand. And in a slow manner and in soft voice. But make sure it's clear that they can understand well." 1009 "I try to make myself clear, I have a loud voice as it is, sometimes I do have to repeat myself." 1002 "And, um, they're understanding is very limited. You have to talk slowly and clearly and you have to have patience with them." 1005 "So that's the most important thing is to adjust into their level and then the understanding the concept of what they were trying trying to say. And then a speaking you have to be very clearly." 1005 "You have to speak clearly. And, um, you use also, um, you have to take that let's say that you get them to what they want to wear. Take the clothes show which one. You take two two things and then get them try to choose what they want. And, um, effective the the way also the best way to do is, um, get them to come and show you. Yes. To let them to I mean, ah, take them take their hands and let them show what they're trying to say." 1005 "Slower, more clear . . . Well just making sure that they can understand the words as sometimes when you talk with other people it can be more, well sort of like you're just talking, you know, with your friends kind of understand you. But I probably, like, even like this, I probably wouldn't even be talking to my residents like this because for them it needs to be more annunciate, more and just more like speaking right to them, like you can't talk too much behind them. You have to go up to them and make sure they recognize that you are there and that you're talking to them and so that they can, like, look at your face and understand what you are trying to tell them." 1016 "Um, you have to speak, um, clearly to them and look at them so, you know, because they don't always understand a big, a long sentence. You have to kind of explain to them in simple terms and then they. You know, and read their body language more than anything." 1020 "Yup, well you've got to make eye contact. You have to speak clearly and not to complicated, you know what I mean, quite simple, if those are the words to use. And um, and it's all in the approach too. You know how you come up to a person and speak to them, um, and you're smiling at them, you know, because they, like

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	we say well we read their body language but they also read yours and I think that's very important. And even if they can't find the words to say they know if you're smiling and you say Hi, than if you just walk by and say Hi. They know Oh and then they're really Hi, you know what I mean. They're happy as you are happy. And I think it makes their day if they, you know, everyone's cheery around them instead of just, you know." 1020 "So, yeah you you learn on, like, in dealing with each person what helps for them. With some people you can be really direct and say, you know like if they say well what, you know, where am I. For some people if they're told well one lady knows. As soon as if you give her any kind of vague answer it doesn't work but if, and a staff member's told me that, that she knows what Alzheimer's is and so if you say, you know, you're in the Alzheimer's center, you have Alzheimer's, you're in it's just a mild form right now. That just she's like oh, she's not happy about it but it's it brings her back to okay, I get it and she's a bit calm and she's all fine and and she gets on with her day. But if you just are vague it doesn't work. So it's knowing each person and, um, communicating." 1024 "Um, the difficult part is, you know, when you try to explain some of them what they have to do. Like, you know, go to the bathroom and some of them don't know even, when they go in the bathroom they don't even know what is this, you know, this is the hard part. So here you have to be very, very specific and slow with them." 1032
Topic of Conversation	"I read, I read stories during the depression, stories, um, from the reminisce. ah, magazine. Oh, very interesting, you know. Sometimes we talk about schools, or if there is, um, a holiday coming just like Remembrance Day we talk about those things. Or Halloween." 1009 "Well the magazines, you know, the the to reminisce, because they can relate to the story. And once I start reading something all of a sudden one will come out with a story and then another one will come out with a story and there goes, it goes in circle, yeah." 1009 " . . . talking about the past if they remember certain things." 1002 "Oh just even reminiscing, talking about their past as far as their family or their children. I mean most people are pretty receptive to family conversations or children conversation. You know if the cat walked by or something and you're talk about animals I mean just any. I mean our centers are so great about having, ah, you know pictures and other cueing things I mean so if someone's you know you can if you're walking by a picture and just talk about you know the farm scene or the airplane or whatever you know. Just those regular social conversations about oh what did you do for a living, or did you ever fly a plane, like you know whatever. I mean the same as we would if we we're out in public right. Yeah, just yeah cues around the center or cues that they, I guess things that they would bring up. You know trying to get more explanation into things that interest them or whatever that they show interest in." 1001 "I would say going to what they know. Like how they were when they were a child. You'd always go back to the past because that's what they know best." 1012 "Their memory is good from the past. So go based on the past, because that's what they know best and it's easier to communicate with them using the past." 1012 "But one thing that's good is that when you talk about their old days and how it's different they tend to talk more and they tend, um, to open up and you learn a lot of wisdom from that too. Yeah, so, at least they could really still sense that they can

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	really talk, they can really talk sense." 1010 "That really depends on the person and what works with one you know doesn't work with the other. You know some if you sit down and, you know, ask them about their, you know, if they grew up on a farm and you know what they used to do. They are very willing to tell you. Some will say well why do you want to know, you know, it's not really any of your business and and that's true. So you got to find I guess flexibility is another big thing." 1018 "Trying to pick up on something that you know they like. Like if they like children then talk about children or flowers or, you know, if they like to walk or whatever. Just pick up on something that they like and then go from there. Family, they like to talk about their family." 1020 " . . . more detailed conversations about things happening in the world perhaps with regular seniors than with Alzheimer's. Alzheimer's I find is just basic, talk about the day." 1002 "Just get just getting their hair done brush their hair and you compliment them oh my goodness you look so lovely you still look sixteen years old. Oh I love that just compliments all the time and that that helps them." 1005
Simple Words	"Simple words, one thing at a time because they will be confused." 1009 "Well one thing I can say is always simple words, use simple words." 1009 " . . . keep everything light meaning not, not too detailed when you're asking them to do a task just use simple, simple words and make it short." 1002 "A lot of times, well most of the ones that I've dealt with now but some reach a point where they can't express themselves and they can't tell you, you know what's what's bothering them, you know. So that's a challenge in a way too right. You have to use well simple language of course too and talk slowly to them." 1006 "So you just give them time in between talking to them and use simple words. Don't use anything like big huge sentences because they won't be able to catch what you're saying. Just use simple words, simple sentences." 1012 " . . . don't use slang." 1007 "And don't complicate anything with, with, ah, big words because they probably have no idea what those words are anymore." 1017 "You have to speak clearly and not too complicated, you know what I mean, quite simple, if those are the words to use." 1020 "Simple. I make things very simple . . . So simple words . . . Um, what do I mean by simple words, um, such as, um, um, when I give them a choice. When you give a person a choice to what they want to wear is to say, um, do you want to wear blue, black or green and they'll always say oh no most times they wouldn't be able to say how about that, you know, but at least you've given them a choice. That's what I mean. It's just simple." 1028 "Sometimes they don't understand what it is you want from them. Sometimes you have to approach it in a different way with different words." 1022 "Um, knowing your residents, trying different, different approaches, different wording." 1026 "If they don't understand one thing you talk to them about then you change your wording or you say it differently or simplify it more or whatever because eventually

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	the simple words they can understand. You know, it it's just what the person, the difference as they go down, you know." 1031
Knowing the Resident	"First I'm, when the residents is new I'm trying to talk to the residents so that I can see like she he if she can hear good or if she can understand you more in action. Then that's what I do." 1013 "Well I think it all comes from knowing your residents really well too, because you know how they communicate." 1001 "Well and I guess it depends on what kind of deficits they have too I mean obviously if they are more hearing impaired you're going to be speaking up louder rather than soft, but I mean softer approach like in your advancement and stuff like that too not necessarily always a whisper or whatever." 1001 "No I think and I think of the residents that I work with and I mean it's just, you can laugh and be goofy and you know but I mean that comes from knowing them too who you can do that with and who you can't and respectful I mean respect still has to be there." 1001 "So that's the most important thing is to adjust into their level and then the understanding the concept of what they were trying trying to say. And then a speaking you have to be very clearly." 1005 " . . . you adjust to the level of the it depends on what the level of the disease they have." 1005 "So you have you know the best thing is to learn their past. You get to know them and you learn and then you read also their, um, chart and then you get to know this person what their likes and dislikes and then you can you can apply and sometimes is still works. Most of the time it still works whatever that they used to do in their when they were young." 1005 "I think you've got to reach each person at their own level, so that can be the challenge. Um, saying to one person like, you know, do you want to watch or the radio even, like, you know, do you want this type of music on. They might be able to tell you what they like, whether it's country or blues or something, where another might tell you they don't know what music is until you put it on and then they can tell you if they like something. And some just like the sound or don't like the noise or. So, each person's different so I think it's finding out what triggers them and then once you know that I mean communicating with them is second nature, so." 1007 "Because a lot of these people come into your centers and stuff and they speak English, but that's not their first language and as the disease progresses it doesn't matter that they've been with you for ten years, or five years, or two or six months suddenly they start reversing back to their native tongue and that can be a challenge because they can understand you but you're not understanding what they're saying and then it becomes frustrating. So you're more looking for the physical clues of what they're trying to tell you and, you know, so that's where I think communicating with them all along and getting to know them and what they like can make a big difference." 1007 "Well you might have a client that wanders, so walking with them, you know, and pointing things out may get them to communicate with you more and trust you, um, or learning what they like, like singing or that type of thing. Um, sometimes it's just getting yourself to their level." 1007 "Um, eye contact, or some of them don't like eye contact it's I mean it once again

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	it’s getting to know them.” 1007 “I think once again well once again it becomes down to the type of person. I mean if you’re suddenly communicating going from Alzheimer’s to children, you know, your tones and behaviors probably aren’t going to change much. Because somebody that’s, you know, quite cognitive cognitively impaired and a child man be at the same level in a lot of ways so that’s not going to change. But if you’re suddenly going to working with, you know, teenagers or adults obviously winking at them would be inappropriately taken. Or, you know, touching them, like hugging.” 1007 “That really depends on the person and what works with one you know doesn’t work with the other. You know some if you sit down and, you know, ask them about their, you know, if they grew up on a farm and you know what they used to do. They are very willing to tell you. Some will say well why do you want to know, you know, it’s not really any of your business and and that’s true. So you got to find I guess flexibility is another big thing.” 1018 “That helps because, uh, you know by being with someone all the time you kind of, if you’re tuned in to that, tuned into them, which I, I tune myself in right away because I want to make sure that, uh, because I I realize that they don’t get all the words out that they want to say. And I don’t want to be standing there saying what did you say I didn’t hear you or all this stuff. I never want to be that way and I never want to say that because that upsets them even more because they already know they can’t. So if you can finish their sentence or help them they’re happier and it it carry on more of a conversation like that. So I think it could have something to do with it but also just listening to the person and not just tuning them out just because they’re Alzheimer’s. Because I, I see that a lot, you know where someone oh what did she say I don’t know what she said and walk away kind of thing. Uh, you see and I, I can’t do that. I will tune myself in and listen for that particular word or how they’re being and pick it up from there.” 1020 “Of course that depends on the person. Um, knowing your residents, trying different, different approaches, different wording. Um, sometimes you, you have to ask some other people how they handle things.” 1026 “So, yeah you you learn on, like, in dealing with each person what helps for them. With some people you can be really direct and say, you know like if they say well what, you know, where am I. For some people if they’re told well one lady knows. As soon as if you give her any kind of vague answer it doesn’t work but if, and a staff member’s told me that, that she knows what Alzheimer’s is and so if you say, you know, you’re in the Alzheimer’s center, you have Alzheimer’s, you’re in it’s just a mild form right now. That just she’s like oh, she’s not happy about it but it’s it brings her back to okay, I get it and she’s a bit calm and she’s all fine and and she gets on with her day. But if you just are vague it doesn’t work. So it’s knowing each person and, um, communicating I’ve just learned don’t ask certain there’s certain questions that are just. Like if even dealing with Shirley today I was really tempted to say because she was looking at the picture of all the kids going on the bus and I was talking about my children and I was tempted then to ask. If I know the resident well enough, and if I know she’s got let’s say four daughters then I could say, you know, so do you have children rather than oh I hear you have four children. I’d rather ask, but if, I want to know the answer already because if they get all confused like oh I don’t know, oh yeah I do remember now you do have four daughters and these are their names and just to kind of help them out a little.” 1024 “A lot of it is you learn as you go and ask other people that have, like if it’s family just getting to know what they like or what their preferences or other staff because

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	I'm just there causal." 1024 "And we always give each other tips too. Like one lady will say oh well, like, how did you finally convince so and so to go and have a bath it's been, you know, five six days and she's just refusing and it's to the point where she'll be aggressive and just be upset. So we're like okay what do, you know, she's had {unintelligible} care done daily but not an actual, you know, shower, washed her hair. So like, well what did you do, what worked? And they'll say oh I just said I'm going to get a gold star if you can do this and so I'm like okay good to know and so you've kind of got that one down and think, okay, you know, but you don't want to be deceptive but at the same time it's like those little things that can help, um, you know, getting things done. Then you kind of learn from other staff of what works in their experience." 1024
Short Sentences	"Um, maybe not ask as many questions, you know, simplify the questions or simpler, you know, so that you're not demanding too much of them at once. That's the big thing because that just gets them flustered too. So always be slow you know wait. Slower questions and wait for them to respond if we're asking them another one and stuff like that. It's hard, and that's not always the easiest thing to do, you know." 1001 "Just simple sentence . . . Simple words, one thing at a time because they will be confused. They already confused. But if you will say, oh let's lets ah put this in the garbage and then after that, you know, you you always come out with with sentences. That is very confusing. So it's one sentence, you know, three or four words at a time. Very simple to understand. And in a slow manner and in soft voice. But make sure it's clear that they can understand well." 1009 Speak slowly, although I tend to speak a little bit faster when I'm excitable um, repeat if need be um, keep everything light meaning not, not too detailed when you're asking them to do a task just use simple, simple words and make it short." 1002 "Don't use anything like big huge sentences because they won't be able to catch what you're saying. Just use simple words, simple sentences." 1012 And use you're your sentences, um, simple sentences. And don't complicate anything with, with, ah, big words because they probably have no idea what those words are anymore." 1017 "Um, give simple directions and and instructions so that it's easy for them to understand as opposed to a a big long story of how to put your stockings on in the morning." 1017 "We're going to make our bed. We're not going to sit there and say okay today we're going to make our bed and we're going to get dressed and we're going to do this and we're going to do that. We do one thing at a time and so just keeping the tasks little. Or, um, if you're going to ask them a question about how they are and what they are doing and blah blah blah don't give them three questions all at once. Give them one question. Simple. And then the next question, that kind of simple. And, and then wait for them to respond." 1019 "Um, you have to speak, um, clearly to them and look at them so, you know, because they don't always understand a big, a long sentence. You have to kind of explain to them in simple terms and then they. You know, and read their body language more than anything." 1020 "Simple. I make things very simple. Very short sentences. Don't go into a long

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	explanation because you're lost them right off the hop. So simple words just, you know, and um facing them because a lot of people because I have one lady that is a little bit hard of hearing and on top of Alzheimer's. And we give them a choice what would you like to wear today, right, and sometimes I forget and I talk into the closet as I'm going to the closet and she goes I'm not in the closet I'm over here, you know. So yeah, simple short sentences. Keep things very simple and to the point." 1028 "The speed at which you speak really makes a difference. If you blah blah blah blah blah blah a whole bunch of instructions, then they're lost. Or if you talk too fast, they're lost. But if you give them one part of the instruction at a time and speak slowly, and face them, like, try not to have your head in the drawer looking for socks when you're trying to tell them to do something or ask them to do something, because they have no idea what you're, you're trying to communicate to them." 1022 "Eye contact is very important, if you look at them face to face, you know. Um, and you know your facial expressions say everything to them. Like if they can't hear they'll do something for. And to show them as you do it, like to show as you speak. You don't say go over there and wash your hands you say come with me let's wash our hands and do it together and show them what you want them to do. And that, that applies to just about everything. You know, have some actions with your words, some demonstration a smiling face or a quieter voice, you know what I mean. They don't need a big, loud. Most elderly people with Alzheimer's do not like loud noises at all. Yeah, so you just talk quietly, and, and if they don't understand you just say come with me. That's a such an easy phrase to say, come with me and they come, yup. And smile, smiling is so important." 1031 " . . . use less words because there's one lady who's so hard of hearing and she'll ask over and over again what you said and finally you're just down to come, with, me. If you say Mary it's time we need to, you know, it's are you done your coffee I think it's time for bed, are you getting tired. Too many words and it just throws, throws some people off so we're like okay come with me and then it's just simple. So, yeah, simplifiying things and not making too many explanations because sometimes that makes it even worse because if you say okay we're going to do this, this and this they forget it because they start asking questions about the third thing you're doing and why and it just confuses some people. So I find just saying okay we're just going to go down this hall and they don't need to know where you're going after that. Then we're going through the kitchen and then we're going to your room, um, and we're not saying why. It's just, you know, okay and then once they see it they go oh is it time for bed, yes. So just one little step at a time." 1024
Talk Slowly	"You don't need to be in a hurry. You can, because if you are in a hurry to them, then the more you're in trouble they get upset. They might hit you.." 1013 "Try to touch her hand, like not touching like, you're don't grab, just touch it gently and then try to talk slowly and in a nice tone in her close to her to her ear and explain to her, yeah, what you want to do." 1013 "Speak slowly, although I tend to speak a little bit faster when I'm excitable." 1002 " . . . my speech is a lot slowed down with Alzheimer's." 1002 "Um, maybe not ask as many questions, you know, simplify the questions or simpler, you know, so that you're not demanding too much of them at once. That's the big thing because that just gets them flustered too. So always be slow you know wait. Slower questions and wait for them to respond if we're asking them another

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	something, because they have no idea what you're, you're trying to communicate to them. And to show them as you do it, like to show as you speak. You don't say go over there and wash your hands you say come with me let's wash our hands and do it together and show them what you want them to do. And that, that applies to just about everything. You know, have some actions with your words, some demonstration." 1022 "And a lot of people, I don't know if it's just age, but speaking slowly because I tend to you're always like okay what's the next thing talking too fast. I really have to slow down." 1024 "Um, the difficult part is, you know, when you try to explain some of them what they have to do. Like, you know, go to the bathroom and some of them don't know even, when they go in the bathroom they don't even know what is this, you know, this is the hard part. So here you have to be very, very specific and slow with them." 1032 "My strategies is like, you know, I'm trying to be friendly with them. Slowly explaining the things. Um, as much as possible interact with them and talk with them." 1032
Humour	"Or sometimes I try to play like a kid like I'm dancing or I'm pretending like I'm singing or I'm doing exercise, yeah, just to get their a attention. Then once I've got their attention for sure then they're gonna smile at me or they're gonna laugh at me what I'm doing then that's the time I'm gonna. But if I know the resident is serious I'm not doing that. I have to be serious also like I'm treating her like I'm treating her like really, really old, like I'm treating as a parent or a grandmother, yeah, with respect like that." 1013 "Joking, like I said having fun, joking." 1002 "Oh yeah and and yeah the laughing, the laughter, the you know having music involved, with interaction I mean like I look after someone that you know if you're singing and humming and whatever it just makes looking after them that much better. You know I mean if you've gotta make a funny face or whatever to get someone laughing I mean so be it. I'm, you know, yeah I think people if people outside of my work saw me {laughs} how old are you. But it makes the, it's all about making the residents day and you know. Yeah and that, yeah just making, making them feel important too by showing genuine interest in their, in their interests and in their life and stuff like that." 1001 "And humor, humor it's amazing how far humor goes. If you can't laugh at yourself {laughs} which I'm very good at." 1001 "No I think and I think of the residents that I work with and I mean it's just, you can be laugh and be goofy and you know but I mean that comes from knowing them too who you can do." 1001 You also have to have a good sense of humor with them. {laughs} That works very very well." 1005 "Well, sometimes we have a sense of humor maybe that they might just not get, so you're saying something kind of a little on the, not necessarily sarcastic, but in a joking way." 1019 "Um, I usually make them laugh." 1010 "I don't know you just take your cues from them and, ah, you figure out what the best way to approach them is and I find they're very easy to joke around with. You

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	know they have great senses of humor and as long as you, you know, don't move fast and tell them what you're doing they'll, you know they're very cooperative on most days. Some days it doesn't matter what you do." 1018 "Well you've got to know that you're going to hear the same thing over and over and, um, if they ask you questions and you explain it to them you can be prepared to do it again in 5 minutes and I used to find that hard you know {unintelligible} these poor people. But, you know, you just do it. Have a sense of humor about it. Be friendly. I mean they all respond to a smiling face. Most of them {laughs}." 1018 "I sometimes joke with them or use humor." 1014 "Basically smiled, had a good time. I don't know if you could hear me laughing outside." 1023 "Um, happy and cheerful works a lot. Um, good humor, um, gentle encouragement. You really don't want to try to make somebody frustrated because then they can escalate very quickly into something you don't want." 1026 "Um, for me it's just to try and make their day go easier. Like just to get, whatever it takes to get things accomplished. So, you know, if they need, you know, help with, um, well {unintelligible} for example, getting washed up in the morning and they really have no need, they're like I had a bath yesterday and, you know, they don't get it. So I'll sometimes even joke well I know you weren't working out in the fields but we'll just, you know, freshen up. And so just sort of whatever you need, whatever tools you've got whether it's words or distractions anything to just get what needs to be done, what's best for them." 1024
Nonverbal	"So if you know like there's a problem on hearing try to be a little bit closer. Try to touch her hand, like not touching like, you're don't grab, just touch it gently and then try to talk slowly and in a nice tone in her close to her to her ear and explain to her, yeah, what you want to do." 1013 "And I always hold their hands, hold their hands, hug them if, if they help us, you know, even though they don't help us, you know, greetings, things like that, yeah." 1009 "Like this lady that I was with today, you can tell that she likes to touch and and stuff, but there's some residents that don't but for the most part they like to hold hands or have an arm around them and just to feel loved I guess." 1002 "Um, I think, um, I tend to hug the residents a lot, um , and I get lots of hugs so it makes my day really nice because then I go to work and I get lots of hugs and kisses. So, um, I tend to do more encouraging than I, than I would, um, because that's what they need. Um, hmm." 1026 "But there's not an elder around that does not like to be hugged, not like to be talked to. You know, when you when you guide a person you hold their hand so they can feel safe, right, because like it's a real scary disease. They're scared an awful lot because they just don't know any more. Yeah." 1031 "Um, I think a lot, a lot of Alzheimer's enjoy the tactical part like you know like the hugging, and so when you're socially, you know, saying hello, the touch, the hug. Not all of them, there are a few people that don't. But that becomes very important, you know, I think it's just a, it's a a love thing knowing that someone cares enough that they're touching them or something." 1001 "Sometimes nonverbal communication, sometimes like a hug or something you know they appreciate that. They like that and they're huggy some time kissy and

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	feely you know so you kind of, that's kind of a way of communicating, right." 1006 "I tend to be more, um, close, like, the touch, yeah. I yeah, yeah and yeah I hold their hand, I hug them, um, something that will make them feel that, um, I'm a friend. I'm I'm something, I'm somebody whom they can trust." 1010 "Sometimes you'll like put your hand on their shoulder just letting them know that you're there and you're not mad at them or anything." 1016 "You get to know them it's like they're a family a part of the family that, you know, that you you love them and it's like and then they will love you in return and they will know you and just touching them even if they're sick that by the touches they will feel that they're being cared for and they know they respond to that even though they can't hear they can't do things anymore just rub give them holding your hand makes them makes them really happy and it makes your day really happy." 1005 "I think once again well once again it becomes down to the type of person. I mean if you're suddenly communicating going from Alzheimer's to children, you know, your tones and behaviors probably aren't going to change much. Because somebody that's, you know, quite cognitive cognitively impaired and a child may be at the same level in a lot of ways so that's not going to change. But if you're suddenly going to working with, you know, teenagers or adults obviously winking at them would be inappropriately taken. Or, you know, touching them, like hugging." 1007 "I probably do a lot more hugging with the Alzheimer's residents and, you know, holding their hand or offering my arm when we walk, you know. But they seem to like that so you do it, you know. Whereas with an average adult I'd have to get to know them a lot better first {laughs}, yeah." 1018 " . . . see if they're watching TV or whatever sometimes I'll just be I'll come up and I'll put my hand on their shoulders behind them and they're like, Ah, so I'm scaring them. Shouldn't do that, {laughs} but I realize that as soon as I do it, nope shouldn't have done that. Um, I mean they're generally okay with it but it's not, I guess to anybody that's not a very nice thing to do. Just, you know, because I'm just a touchy kind of person." 1019 "And some of them are angry because of the disease and angry because they're frustrated and, um, but they're I think they always like to have hugs and and for you to let them know that you care about them." 1014 "Touch. A lot of time touch just, you know just." 1028 "So it's you're just trying to let them know that it's okay and if they're upset just putting your arm around them or holding their hand." 1024 "Or sometimes I use action. Yeah, action is the best like going to the bathroom like let's say to sit down I show like to sit down. Yeah, and to eat I'm showing like let's sit down and we're going to eat with action. Yeah, sometimes it helps." 1013 "Um, them not being able to express themselves the way they would like to, and them knowing that they're not getting that across. There are times I can think of a lady in particular and she would know that that, no that's not it, that's not it but gets very frustrated and so it's having the time to say it's okay think about it for a few minutes or whatever it will come. I mean we all have moments like that where that word is just sitting right there and it doesn't come out. So it's giving people the time to be able to think about what they want to say, if they're at that level and sometimes the words just come out and you have to kind of go with what's going and think oh yeah well you you, once you get to know somebody, especially

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	someone who has a second language. I mean it's quite easy to know what they are saying even though half of the sentence is in another language it's very, you know, if you know who you're working with. You know when they're holding up a flower and they gibbering something and they're just like so happy that this flower is there, you know they're talking about the beautiful flower they just picked. You don't have, it's not wrong, you know so that just being, paying attention I think. And then again maybe they're not, maybe she's telling you this stupid flower or whatever {laughs} but I mean it's all body language and that too right." 1001 "Um but yeah there's the nonverbal and well just the facial, like well I guess that's nonverbal too facial expressions or whatever. You know if they're looking happy or they're looking sad and you're trying to make them laugh and they're not wanting to." 1001 "Well sometimes if they're not very verbal that can be a challenge too, you know, to communicate what you want them to do, usually by actions and that and gestures and that they'll do it." 1006 "Oh, well you have to, like you say you have to be more patient. You might have to be a little more repetitive, you know, to get your point across so they understand you. You might have to show them something, you know, like nonverbal communication more so, yeah." 1006 "You have to speak clearly. And, um, you use also, um, you have to take that let's say that you get them to what they want to wear. Take the clothes show which one. You take two two things and then get them try to choose what they want. And, um effective the the way also the best way to do is, um, get them to come and show you. Yes. To let them to I mean, ah, take them take their hands and let them show what they're trying to say." 1005 "You need, you know, smile all the time because that the communication, they know that everything's good. You need, you need a happy approach because they can read you pretty good. If you're sad or upset they'll be able to read that." 1012 "Uh, nonverbally it would be cues, like brush your hair. Using you hand movements to get them to do what you need them to brush their teeth." 1012 "Because a lot of these people come into your centers and stuff and they speak English, but that's not their first language and as the disease progresses it doesn't matter that they've been with you for ten years, or five years, or two or six months suddenly they start reversing back to their native tongue and that can be a challenge because they can understand you but you're not understanding what they're saying and then it becomes frustrating. So you're more looking for the physical clues of what they're trying to tell you and, you know, so that's where I think communicating with them all along and getting to know them and what they like can make a big difference." 1007 "Um, I mean sometimes it's as simple as walking past somebody that you've gotten a relationship with or something and winking or whistling and they get the big smile and they're happy and they're content again for twenty minutes." 1007 "That that, you know, if they need something they can come to me and they can, they can ask me or if they can't ask me they can guide me through, you know, the non-verbal stuff of. Like I have one that doesn't talk so, you know, if she needs something she'll often just touch my arm and get me to go with her, which is okay with me. We figure it out. It's a little hard to to figure it out but we usually get it together. So I mean I value them they're, they're wonderful people that I think society has forgotten, unfortunately." 1017

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	"Eye contact. You have to talk to them, like, you got to look at them and talk to them because it's like anything as we get older, you know, your hearing diminishes you're a lot often your sight is diminished. You've got to be there and be able to, they've got to be able to see you speaking to them in order for them to be able to respond back. Like I could, I could walk into somebody's room and they could have their back to me and I could be rambling away all I want but they're probably no hearing any of it because they haven't had that contact of eye contact or good morning the touch on the shoulder, good morning Mrs. Smith to let them know that I'm not just standing there rambling for nothing. {laughs} And I do sometimes ramble, so." 1017 "Um, smile, I mean you've got to smile with them. Be upbeat, cheerful. Assist them as as much as they need." 1017 "Sometimes showing them by example of what they want to do." 1016 "Alright, so you mentioned showing by example, um, can you think of an instance where you had to do that?" 1016 "Well with folding laundry there was one time where a lady she's like oh can I help you and I was like sure, but then she forgets how to fold a shirt or how to fold a towel. Or even with dishes they want to help, but they're like I don't know what to do. And you're like well you wash the plate and then you have to stick it into the other sink and then I'll do the rest and I'll put the sink into the sterilizer. And it's just, just showing them oh this is what you have to do and they're like oh yeah this is what I do. Or even with like brushing their teeth, they're like this looks familiar but I don't know what it is. So showing them put it in your mouth and brush your teeth and yeah." 1016 "Well just making sure that they can understand the words as sometimes when you talk with other people it can be more, well sort of like you're just talking, you know, with your friends kind of understand you. But I probably, like, even like this, I probably wouldn't even be talking to my residents like this because for them it needs to be more annunciated, more and just more like speaking right to them, like you can't talk too much behind them. You have to go up to them and make sure they recognize that you are there and that you're talking to them and so that they can, like, look at your face and understand what you are trying to tell them." 1016 "Well you've got to know that you're going to hear the same thing over and over and, um, if they ask you questions and you explain it to them you can be prepared to do it again in 5 minutes and I used to find that hard you know {unintelligible} these poor people. But, you know, you just do it. Have a sense of humor about it. Be friendly. I mean they all respond to a smiling face. Most of them {laughs}." 1018 "Um, you have to speak, um, clearly to them and look at them so, you know, because they don't always understand a big, a long sentence. You have to kind of explain to them in simple terms and then they. You know, and read their body language more than anything." 1020 "Um, they may not get all the words out but if you're reading their body language and can pick up on a word you can carry on quite a conversation and they, you know, because they might find it hard to find that exact word. But they know in their mind what they're trying to say. And I find it very interesting, like, to listen to them talk about the olden days or, you know, and they get real excited about that, you know." 1020 "Yup, well you've got to make eye contact. You have to speak clearly and not to complicated, you know what I mean, quite simple, if those are the words to use. And um, and it's all in the approach too. You know how you come up to a person

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	and speak to them, um, and you're smiling at them, you know, because they, like we say well we read their body language but they also read yours and I think that's very important. And even if they can't find the words to say they know if you're smiling and you say Hi, than if you just walk by and say Hi. They know Oh and then they're really Hi, you know what I mean. They're happy as you are happy. And I think it makes their day if they, you know, everyone's cheery around them instead of just, you know." 1020 "I'm very good at body language, reading body language. Like I can give you an example, Delphene came out of the room and, um, we were having lunch and she was very sad, very, very sad and she was trying to explain to one of the staff, um, what she was making her sad and this and that. I picked up on one word and watching her body language and I said to her you want to go to the graves to see your husbands grave. Well she went yes yes, and she went oh swinging her arms and that and the staff looked at me and said how did you get that out of that. And you know she, it's just one little word that I picked up because she couldn't get it out. So then I went on to explain to her well when her family comes maybe you can talk to them because by then she would maybe forget for the time, you know, and okay yes and that I couldn't take her but her family would when they have time and all this kind of stuff. But that was just an the latest example, you know what I mean." 1020 "Um, it's kind of simple approach and being, you know, making things simple not too complicated and talking to them. Trying to pick up on something that you know they like. Like if they like children then talk about children or flowers or, you know, if they like to walk or whatever. Just pick up on something that they like and then go from there. Family, they like to talk about their family. Uh, and reading body language I guess is." 1020 "They love to be touched. And you can tell if there's a person that doesn't want to, that's kind of stand-offish. And I can give you an example of that is Rita. When she fist came to us you couldn't go near her, you could not touch her, nothing. She was with us for, hmm, I would say several months before she'd come a little closer to you and I reached out like this to her and she put her arms and she hugged me and it was like she wanted that all the time but she didn't know how and she didn't know what. And some of them like that hugging, like to give you a hug, and, um, like to take your hand and some don't. And you have, it's a sort of, um, reading their body language you have to know that. Some feel very comfortable like that and they need it. Um, like the rest of us, you know. And if someone doesn't then you've got to respect that. Um, but I haven't really met too many that were that way. Most of them like it if you give them a little hug, or you know what I mean." 1020 "We just have a gentleman, let's call him Mr. H, um, when he gets really upset about something I just basically take him by the hand , rub his back and just sort of or, you know, even his arm and just sort of redirect him. Let's go have a tea, I am really thirsty, you know, what would you like to eat. Um, another thing is is I, um, you have to use a lot of distractions." 1028 "The speed at which you speak really makes a difference. If you blah blah blah blah blah blah a whole bunch of instructions, then they're lost. Or if you talk too fast, they're lost. But if you give them one part of the instruction at a time and speak slowly, and face them, like, try not to have your head in the drawer looking for socks when you're trying to tell them to do something or ask them to do something, because they have no idea what you're, you're trying to communicate to them. And to show them as you do it, like to show as you speak. You don't say go over there and wash your hands you say come with me let's wash our hands and do

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	it together and show them what you want them to do. And that, that applies to just about everything. You know, have some actions with your words, some demonstration." 1022 "They don't, like, um, sometimes I motion them to come or I motion them to do something. Um, because sometimes you say come here and they don't know how to so you go like this to them {motioned come with hand}. Or you'll say sit and you pat. It's I don't know if it's they don't understand that you mean sit and she doesn't know what to what sit is anymore. So you just go like this {pat the chair}, then they get it." 1023 "Basically smiled, had a good time. I don't know if you could hear me laughing outside." 1023 "But there's not an elder around that does not like to be hugged, not like to be talked to. You know, when you when you guide a person you hold their hand so they can feel safe, right, because like it's a real scary disease. They're scared an awful lot because they just don't know any more. Yeah." 1031 "Eye contact is very important, if you look at them face to face, you know. Um, and you know your facial expressions say everything to them. Like if they can't hear they'll do something for a smiling face or a quieter voice, you know what I mean. They don't need a big, loud. Most elderly people with Alzheimer's do not like loud noises at all. Yeah, so you just talk quietly, and, and if they don't understand you just say come with me. That's a such an easy phrase to say, come with me and they come, yup. And smile, smiling is so important." 1031 "Well isn't it nicer to see a smiling face than a grumpy face, huh? And if it's a face you don't know it's the smiling face that gets the, that gets the candy. Let's put it that way." 1031 "You look at them. Eye contact, number one. You smile, number two. If they don't understand what you're saying they might be hard of hearing, you might put your pitch up a little more. Simplify things. And, you know, with a lot of them, like, that are higher functioning you ask is it okay, do you mind. You ask, you ask, you don't tell." 1031 "And I can see they're kind of like putting up that guard and I always often think oh maybe that's just a trust issue or they're feeling threatened in some way. So, because when if they're in bed and they need to have, you know, their pills and they need to get up and that kind of thing and they're have no intent of waking up or getting out of bed, they're cozy. And I'll just come and kind of kneel beside the bed then and I'm not standing over them like I'm a nurse or something so I will bend down and then sometimes just take their hand or just touch their hand even just so they know, and talk in a really calm, quiet voice." 1024 "But just non-verbal is, like, so many times I just want to be, like, let's go, because we're so slow and they get distracted. Well even Shirley today, like, she's walking around and we're like okay, this way. And you're, you're so wanting to just take them and like even today twice I just grabbed her by the hand but just really gentle. Like just take her hand as though you're just guiding them or leading them, not taking them somewhere. So, that's probably another thing you need to do with Alzheimer's because you can't reason and say okay well we're going to go now and they'll see something on the wall. And they it's so easy to get distracted so well just keeping them going is I guess one other thing that you would do differently, um, because if they stop that's it you're going to be starting. They'll sit down and then you're like back to square one. So just that cueing all the time of okay what's next and let's, yeah, to get things done. Then so I guess the non-verbal

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	communication there would be just not, like, really rushing them. Like I don't want to be nudging someone and pushing them but I kind of feel like it sometimes. But, you know, you just, like, gently guiding them along because I think even in how you touch them can affect how their, they, they know if you're rushing them. They know like if you're, you know, because I've even had people say well if you have other things to do you can go and come back. And I'm like no and it's like oh okay, you know, like, okay maybe I'm rushing this person a little too much." 1024 "So sometimes they don't, ah, if they cannot hear your voice you can even use probably signs. The expression on your face is also very important." 1032 "Or, you know, or when you don't like, you know, the what they're doing sometimes, you know, the wrist you just point, you know, with the hands. Or you have just to, with your face, you have to remind them something is wrong probably I guess. So I don't know. I never think about this. {laughs} But sometimes it's very important the expression of the face because whenever you see the expression and see that they're not happy, you know you'd better just also leave them for a while until the anger calms down." 1032