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Resilience in dementia: Perspectives of those living with dementia

by

Tawnya Schmidt

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Abstract

This study examined the concept of resilience and factors associated with it from the perspective of individuals living with dementia. Resilience is a process through which individuals demonstrate positive adaptation despite exposure to adverse life events, such as a diagnosis of dementia. How individuals with dementia describe resilience and the factors they identify as contributing to or interfering with resilience were determined using semi-structured interviews. Measures of quality of life and wellness provided additional information about the concept of resilience. The study identified three major factors associated with resilience: ‘active and purposeful living’, ‘perspective’, and ‘resources.’ Resilience is anticipated to be clinically useful as a means of identifying areas of strength and weakness for individuals living with dementia in order to guide intervention efforts to support more resilient outcomes. This study provides an initial basis of identifying these clinically relevant factors that promote or impede resilience in this population.

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Introduction

Resilience is a process through which individuals demonstrate positive adaptation despite experiencing adverse life events and is commonly described in resilience literature simply as an individual 'doing okay' when exposed to events or situations that have potentially negative outcomes. The origins of resilience research are rooted in the field of social work (Garmezy, 1974; Anthony, 1974; Rutter, 1979; Werner & Smith, 1982). Although originally viewed as a rare or extraordinary personality trait, resilience is now understood to be a dynamic process that varies both between and within individuals. In the resilience literature, factors that promote resilience are described as protective factors and those that deter resilience are described as vulnerability factors. Three levels of influence for protective and vulnerability factors have been identified in the resilience literature including individual, family, and community or societal.

Although resilience studies to date have primarily focused on childhood adaptation in the face of adversity, the concept of resilience is one that can be applied across the lifespan. Luthar, Cicchetti, and Becker (2000) argue that resilience research across the lifespan has great value, however, few studies to date have focused on resilience in individuals at older ages. Resilience can be examined for specific populations, such as individuals who have had a stroke or been diagnosed with dementia, as a means of understanding how individuals cope with these significant life events with negative outcomes.

Resilience is an area of research with significant potential in the field of rehabilitation sciences as it defines 'doing okay' as behaviours that result in adaptive functioning, even in the face of immutable adverse life events, such as a diagnosis of dementia. Neuro-cognitive disorders, such as dementia, represent evidence of significant cognitive decline from a previous level of functioning in one or more domains (complex attention, executive function, learning and memory, language, perceptual motor, or social cognition), which interfere with independence in everyday activities and cannot be explained by delirium or other psychiatric disorders (American Psychiatric Association, 2013). These impairments significantly affect how individuals with dementia function in their daily lives. Previous studies (Harris, 2008) have determined that individuals with dementia can continue to live meaningful lives and demonstrate resilience following their diagnosis.

The current study examines the concept of resilience for individuals living with dementia. Resilience will be examined from the perspective of individuals with mild to moderate dementia in order to determine what constitutes resilience for them and to begin the process of identifying factors that promote or impede resilience for individuals living with dementia.

Resilience

Resilience research has its foundations in the work of Garmezy (1974), Anthony (1974), Rutter (1979), and Werner and Smith (1982). The majority of research in resilience has been focused on children in order to identify key factors that promote or deter resilience for at-risk youth. Garmezy’s 1973 Project Competence examined how children developed well despite risk status or exposure to adversity including poverty, parental mental illness, or other stressful life experiences (Masten & Powell, 2003). The project focused on competency, adversity, and resilience. Despite their exposure to risk and adversity, there were children in these situations who demonstrated “psychosocial competence…defined in terms of a track record of effective performance in developmental tasks that are salient for people of a given age, society or context, and historical time” (Masten & Powell, 2003, p. 5), including adequate academic, social, and conduct competence. These observations formed the basis of further investigations into the factors that contributed to an individual’s ability to respond well to adversity. Werner and Smith’s (1982) groundbreaking longitudinal studies on children in Hawaii followed a set of participants from birth to midlife who were at high risk for social and academic problems. This work prompted further research that examined other factors associated with resilience at various stages of child development. For example, Rutter (1993) examined children who demonstrated resilience in high stress environments and who had parents with mental illness. These studies examined the factors associated with positive outcomes for children in adverse situations. Interestingly, although resilience researchers studied children with diverse backgrounds, many of the factors identified as promoting positive adaptation were consistent across groups.

In a review of resilience literature, Garmezy identified three levels of factors that contributed to positive adaptation in the face of adversity across studies; individual attributes, family qualities, and supportive systems outside the family (1974). The concept of resilience was acknowledged to have the potential to influence social policy and prevention programs. Luthar and Cicchetti (2000) emphasize the importance of prevention through the promotion of resilience for at-risk individuals, rather than remediation.

Resilience Defined. Resilience can be defined as "a dynamic process wherein individuals display positive adaptation despite experiences of significant adversity or trauma" (Luthar & Cicchetti, 2000, p. 858). According to Masten (2001), the demonstration of resilience depends on two fundamental judgments common in the resilience literature: (i) that there is a significant threat to development and (ii) that the developmental outcome is "good or OK" (Masten, 2001, p. 228). Although initially viewed as an extraordinary or rare quality, resilience is now understood as positive human adaptation, which is the result of normal functioning of the human adaptive system (Masten, 2001). These human adaptation systems are ones that have evolved, biologically and culturally, allowing humans to change and function despite exposure to adverse life events. Further, human adaptational systems continue to develop throughout the lifespan (Masten & Powell, 2003). Masten (2001) referred to the concept of resilience as "ordinary magic" (p. 227) as resilience is a relatively common process. Resilience is optimistic in that it is within reach of the ordinary person, arising from ordinary adaptation as opposed to extreme change or extraordinary adaptation.

Resilience is a process individuals engage in rather than purely an inherent personal attribute (Masten & Powell, 2003). Initial investigations of positive adaptation in response to adverse life events suggested that resilience was exclusively a personal attribute or quality. However, viewing resilience as an internal trait may lead to inadvertent blaming of individuals for not demonstrating the inherent characteristics needed to be resilient (Luthar & Cicchetti, 2000). Resilience is now understood as a dynamic process that can vary between and within individuals. An individual can be resilient in one situation but not others, as well as in response to one adverse event but not another. Although there are components of the resilience process identified in previous literature that are internal to an individual, such as positive coping styles or attitude (Wiles, Wild, Kerse, and Allen, 2012; Hildon, Smith, Netuveli & Blane, 2008), focusing on the components of resilience that are modifiable processes lends itself to practical application, in that if components of resilience are behaviourally-based, others who are not demonstrating resilience could learn to behave in a more resilient way. The accessibility of resilience makes it a concept that is achievable by ordinary individuals who face adverse life situations.

Adversity and positive adaptation. Central to the definition of resilience are two assumed concepts: (i) adversity or risk, and (ii) positive adaptation in response to adverse life events. Adversity, in this case, refers to negative life circumstances that are frequently associated with adjustment difficulties or negative psychosocial outcomes (Luthar & Cicchetti, 2000). Situations of adversity or risk, terms used interchangeably in the resilience literature, can range from a single stressful life experience to multiple negative events over an extended period of time (Luthar, Cicchetti, & Becker, 2000). These events all have the potential to disrupt adaptive functioning (Harris, 2008). Examples of risk or adversity in the resilience literature are varied and included factors such as socioeconomic status, massive community trauma, low-birth weight, as well as health conditions such as dementia (Masten, 2001; Harris, 2008). Risk is also acknowledged to be a subjective or relative phenomenon (Wild, Wiles, & Allen, 2013). What might be a risk factor for one individual, at one specific time may not be a risk for the same individual at another time or could even be an asset to another individual.

Positive adaptation, according to Luthar and Zelazo (2003), is a response that is better than would be expected given the adverse event encountered. It can be defined as “behaviourally manifested social competence” (p. 858) in which an individual displays success at meeting societal expectations at a particular life stage (Luthar & Cicchetti, 2000). According to Rutter (1993), positive adaptation can be viewed as the positive end of a continuum of potential outcomes. In their longitudinal study, Werner and Smith (1992) identified one-third of children as ‘doing okay’ or demonstrating resilience; these were individuals who were exposed to four or more high-risk situations before the age of 2, such as poverty, perinatal stress, parental alcoholism, or mental illness. As children, they were classified as ‘doing okay’ because they got along well with their classmates and continued to be social, despite exposure to negative home environments (Werner & Smith, 1992). Consistent with Werner and Smith’s definition, Masten (2001) indicates that an individual demonstrates resilience when their outcome related to adverse life events is evaluated as “good or OK” (p. 228). Masten (2001) acknowledges that there is considerable debate in the resilience literature about “who should define resilience by what standards” (p. 228). However, it is generally understood that it is positive adaptation, in the face of adverse life events, that constitutes resilience.

Positive adaptation is a multidimensional concept that can be displayed in a variety of domains including educational, behavioural, and emotional (Luthar, Cicchetti, & Becker, 2000). Further, Luthar, Cicchetti, and Becker (2000) suggest that the nature of the adversity encountered should be considered when defining criteria for positive adaptation. Consistent with this suggestion, adaptation criteria have differed across studies. For example, for individuals exposed to severe or traumatic life events, the absence of negative psychosocial effects might be sufficient to be described as positive adaptation. However, for individuals with more moderate adverse life events, social aptitude or other related achievements might be a more appropriate measure.

Protective and vulnerability factors. Identifying protective factors that promote resilience and vulnerability factors that deter resilience is integral to understanding what may influence whether an individual is or is not resilient in a certain situation (Luthar & Cicchetti, 2000). Protective factors reduce the likelihood of negative behaviours following adversity, while vulnerability factors increase the likelihood of negative behaviours following adversity. If an individual has sufficient protective factors, the impact of an adverse event will likely be decreased (Masten, 2001). There are multiple levels of influence for protective and vulnerability factors, which include the individual, family, and community as well as how each of these levels interacts with the others (Luthar & Cicchetti, 2000). These three levels of influence have been identified in the literature as contributing to the demonstration of resilience (Luthar, Cicchetti, & Becker, 2000).

Understanding specific protective and vulnerability factors that moderate the effects of adversity for at-risk populations provides insight into effective interventions (Luthar & Cicchetti, 2000). For example, a positive relationship with an adult was identified as a protective factor for children in adverse conditions (Luthar and Cicchetti, 2000), which suggested that positive adult-child relationships might foster resilience in at-risk children. This understanding may be the basis for intervention programs directed at providing adult mentors for vulnerable youth. Similar intervention programs could be developed for adult populations at risk for non-resilient behaviours, such as individuals living with dementia, once the factors that promote or impede resilience are identified for these specific populations.

Resilience in Health Science and Aging Populations

Relatively few studies have examined the concept of resilience in aging populations (Hildon, Montgomery, Blane, Wiggins & Netuveli, 2010; Hildon et al., 2008; Harris, 2008). These studies have examined the concept of resilience in older adults with a variety of adverse life events including illness, relationship loss, or change in socioeconomic status, which are not uncommon in aging populations. Understanding resilience, and identifying protective and vulnerability factors that affect resilience in specific populations, has the potential to contribute to more focused rehabilitation efforts and community initiatives to foster resilience in adults facing adverse situations.

Wiles, Wild, Kerse, and Allen (2012) examined how older people understood and experienced the concept of resilience. The authors posited that resilience was (i) the ability to “bounce back” (p. 417) from adversity, (ii) that people could live with a disability or trauma and still be relatively healthy, and (iii) that there are many paths to “ageing well” (Wiles, Wild, Kerse, & Allen, 2012, p. 417). The investigation utilized focus groups and interviews in two New Zealand communities with 121 older individuals in order to determine how the participants understood resilience as well as how it applied to their current lives, specifically in regard to aging. Internal resources identified as contributing to resilience in this study included attitude, having a purpose and keeping busy, as well as counting blessings. External resources identified in this study included social resources, such as family and friends. The study by Wiles and colleagues (2012) also supported the ways that resilience can differ both between and among individuals, in that participants could face constraints in one area, but demonstrate resilience in another. For example, individuals could struggle in the area of financial well-being but demonstrate resilience in the area of social relationships. Wiles et al. (2012) emphasized the complexity of the notion of resilience as resilience was understood by study participants to be a “multidimensional, contextual and ongoing process” (Wiles et al., 2012, p. 423). This finding is consistent with the developmental literature on resilience.

Hildon, Smith, Netuveli, and Blane (2008) examined the concept of resilience in older adults recently exposed to adverse life events, using the CASP-19 quality of life scale, which examines the dimensions of control, autonomy, self-realization, and pleasure. These four dimensions are ones that constitute quality of life at older ages (Hildon, Smith, Netuveli, & Blane, 2008). Hildon et al. separated their sample into resilient and vulnerable outcome groups. Their study found that the vulnerable group was more likely to have greater or more compounding losses or adversity than their resilient counterparts. Social support and positive coping styles were central to positive outcomes in response to adverse life events for study participants.

In a follow-up study, Hildon and colleagues (2010) examined resilience in an older population in order to identify factors that were related to an increased quality of life as well as factors that were involved in mediating the negative effects of adversity. Resilience in this study was defined as better-than-average quality of life scores despite exposure to adverse life events. Adverse events in their study included deteriorating health, increase in stress, changing life circumstances, financial hardship, and a specific negative event such as bereavement. Their study found that social supports were especially critical during times of adversity and factors that positively influenced resilience included quality relationships, integration in the community, and a highly adaptive and developmental coping style.

Protective factors at all three levels of influence have been identified in the literature and include positive and adaptive coping styles (individual), high quality relationships (family), social resources and supports (family and community), as well as integration into the community (community) for older adults generally, however, do not specifically examine the concept of resilience for older adults living with dementia.

Resilience and Dementia

Dementia. Dementia is an umbrella term for a condition that consists of a number of symptoms including memory loss, changes in mood, behaviour, and communication abilities, which is severe enough to interfere with activities of daily life, occupation, and social interaction (Mahendra & Hopper, 2011). Neuro-cognitive disorders, such as dementia, interfere with independence in activities of daily living and are characterized by a significant cognitive decline from previous levels of functioning, unexplainable by delirium or other psychiatric disorders (American Psychiatric Association, 2013). Dementia is the most significant cause of disability for adults over the age of 65; there are currently approximately 500,000 Canadians living with dementia (Alzheimer's Society, 2010). Rates of age-related health conditions, including dementia, are expected to rise with the increase in aging populations. It is estimated that the percentage of those 65 and older will increase from 12.6% to 20.3% in North America by 2030 (Kinsella & Velkoff, 2001) and similarly, by 2038, the number of Canadians with dementia is expected to increase 2.3 times from the current level (Alzheimer's Society, 2010).

The condition of dementia causes general cognitive decline, which significantly affects how individuals with dementia function in their everyday lives. Individuals with dementia often initially have impairments of working and episodic memory that worsen as the disease progresses. In later stages of the disease, semantic and non-declarative memory may also be impaired (Mahendra

& Hopper, 2011). Impairments in working memory and episodic memory in the early stages of dementia may influence activities of daily living. For example, an individual with dementia might have trouble keeping appointments, organizing, or remembering their everyday activities, as well as difficulty learning new skills. In addition to memory impairments and personal factors that impact health in cases of dementia, environmental factors are especially salient for this population. Because of the cognitive underpinnings of dementia, patients may be less able to adapt to changes in their environments or everyday demands (Mahendra & Hopper, 2011). These difficulties may lead to a decrease in competence and a corresponding loss of independence, which can negatively affect daily functioning and whether or not an individual demonstrates resilience in the presence of dementia.

In the past, because of the progressive nature of dementia, most intervention efforts have been of a pharmacologic or palliative nature (Mahendra & Hopper, 2011). However, Mahendra and Hopper (2011) suggest that interventions directed at maintaining function and improving quality of life should be a primary focus. Recent research suggests that the functioning of individuals with Alzheimer's disease can be improved by utilizing intervention techniques that focus on spared memory skills as well as principles of learning and remembering shown to be effective for some individuals with dementia (Bayles & Kim, 2003). A focus on resilience could contribute to maintaining functioning and improving quality of life by reinforcing or bolstering protective factors and reducing the impact of vulnerability factors.

Studies of dementia and resilience. A critique of previous literature on the concept of resilience in older adults is that often studies do not include the individual with dementia as a direct participant (Wild et al., 2013). Cotrell and Schulz (1993) suggest that in much of the research on a form of dementia, Alzheimer's disease, "the afflicted person is viewed as a disease entity to be studied rather than someone who can directly contribute to our understanding of the illness and its course" (p. 205). However, a case study of two individuals with dementia (Harris, 2008) examined the role of resilience for individuals living with dementia. It was among the first studies to demonstrate that individuals with early stage dementia can be resilient (Harris, 2008). Harris (2008) defined resilience by the subjective description used frequently in the resilience literature of "doing okay" (p. 49), from the perspective of the individual with dementia, the care-partner of the individual with dementia, the referral source, and the researcher. This study examined why these two participants functioned well despite their diagnosis of dementia, which was considered to be an adverse event. Harris' (2008) study identified protective factors for the two study participants that included having a positive attitude, good problem solving and coping skills, positive self-concepts, the use of community resources, and positive long-term relationships with family. Vulnerability factors identified included other serious health issues, caregiver burden, denial, increased social isolation, as well as instability in financial situations or living arrangements.

Harris (2008) argues that the notion of resilience, as opposed to the notion of successful aging, is a more inclusive means of framing aging, as it can include individuals with dementia who continue to live meaningful lives following their diagnosis. Successful aging as conceptualized by Rowe and Kahn (1987) places aging on a continuum from ‘usual’ to ‘successful.’ The successful aging framework has three main tenets: (i) avoiding disease and disability, (ii) maintaining high mental and physical functioning, as well as (iii) remaining socially engaged (Rowe & Kahn, 1987). Successful aging, like resilience, occurs throughout the lifespan and in response to adverse life events (Hochhalter, Smith, & Ory, 2011). However, resilience presumes that even with adverse conditions, individuals can still function and cope. Resilience and its associated processes can contribute to the notion of successful aging. However, it is possible that an individual may be resilient, but not necessarily age successfully. As Harris (2008) argues, the three main tenets of successful aging are not accessible for individuals with deteriorating health or with the onset of a chronic disability, such as dementia. This population is one that has typically been excluded from discussions of successful aging because a dementia diagnosis, or other causes of functional decline and disability, is contradictory to the notion of successful aging. Although seemingly mutually exclusive, in that an individual living with dementia cannot age successfully by definition, Harris (2008) suggests that individuals with dementia can continue to live a meaningful life following their diagnosis (Harris, 2008).

Resilience provides a more inclusive definition of aging in which there is a possibility of achieving resilient states in dementia, as demonstrated in Harris’ (2008) study. In a review of risk and resilience related to individuals with dementia, Bailey and colleagues describe the focus of resilience as related to ‘successful ageing’, ‘positive ageing’, coping, and adjustment (Bailey, Clarke, Gibb, Haining, Wilkinson & Tiplady, 2013). Bailey et al. (2013) emphasize that resilience takes a strengths-based approach to living with dementia. Further, Wild and colleagues (2013) argue that resilience is inclusive and that it acknowledges how older individuals in particular “thrive in spite of and even at times *because* of their experience with these difficulties” (p. 142). Hildon et al. (2010) also that argue, “resilience overrides the idea that once health begins to deteriorate and disability sets in, aging successfully is no longer possible” (p. 37).

Resilience provides an opportunity to demonstrate positive outcomes despite dementia and other disabilities. Particularly, insight into the specific protective and vulnerability factors that contribute to resilience for individuals with dementia will guide future intervention. If common internal and external protective factors are identified within a specific population, such as individuals living with dementia, it may be possible to bolster the external modifiable factors and reduce the impact of vulnerability factors by focused intervention efforts.

Purpose and Goals of the Study

An important first step in resilience research is to identify factors that are linked to positive or negative outcomes in specific at-risk populations (Luthar & Cicchetti, 2000). Identifying and then bolstering factors associated with resilience may lead to an increased quality of life and optimized functioning in the face of dementia. Because of the limited application and understanding of resilience for individuals living with dementia, this study aims to fill this gap in the literature.

Therefore, the overall goals of this study are (i) to describe resilience as defined by participants with dementia, and (ii) to identify protective and vulnerability factors that influence resilience in this population from the perspectives of individuals living with dementia

Methodology

The effect of protective and vulnerability factors in resilience research has generally been examined from either a variable-focused or person-focused approach. The person-focused approach aims at identifying individuals who display resilience in order to determine the vulnerability and protective factors that influence resilience. The variable-focused approach examines the mechanisms of resilience; often once the protective and vulnerability factors have been identified for a specific population (Harris, 2008).

The use of a person-focused approach was appropriate for this study as it was an initial investigation into the construct of resilience for individuals with dementia and sought to both describe resilience as well as begin identifying the factors associated with resilience for this population. Resilience was initially described to study participants as ‘doing okay’ in relation to the presence of dementia. ‘Doing okay’ for this study was left purposefully vague as a means of allowing study participants the opportunity to provide their subjective understanding of what ‘doing okay’ means to them on a daily basis. Semi-structured interviews with individuals with dementia provided data that was analyzed using an interpretive description (ID) approach.

Through the use of interpretive description, this study determined how individuals living with dementia describe resilience as well as the factors they view as contributing positively or negatively to the demonstration of resilience. ID aims to identify themes and patterns within a clinical phenomenon in order to "generate an interpretive description capable of informing clinical understanding" (Thorne, Reimer-Kirkham, & O'Flynn Magee, 2004, p. 5). As a methodological approach, interpretive description examines the commonalities within a specific phenomenon, such as the experience of resilience in adults with dementia.

Interpretive description is an appropriate methodological approach for the current study as it aims to create a "coherent, conceptual description" (Thorne et al., 2004) of what resilience means for individuals with dementia. As compared to approaches such as phenomenology, which may be more theoretical in nature, interpretive description is directed at informing clinical understanding of specific relevant phenomenon (Thorne et al., 2004). Because there is very limited research on the concept of resilience in dementia, it is important to first understand the common factors within this population prior to measuring or quantifying the processes that underlie resilience for individuals with dementia.

Participants

Six individuals with dementia participated in this study. Participants self-selected in regard to eligibility for the study based on having a diagnosis of dementia and self-identification of demonstrating resilience or 'doing okay' at any point in the face of this diagnosis. Because resilience is understood as a process, 'doing okay' did not have to be something an individual consistently demonstrates.

If participants felt that they were ‘doing okay’ or coping at any point in their everyday lives, they were classified as demonstrating resilience.

Inclusion criteria. Participants were individuals with dementia; with type and severity not specified. Medical records were not requested from study participants to verify their diagnosis. Study participants were required to agree to be audio- and video-taped during the interview and participate in an individual interview without family members or care-partners present. Note that for this study, the term care-partner is utilized to denote any individual associated with and involved in caring for the person with dementia, including family, friends, and professionals. Care-partner, as opposed to the term care-giver is suggested by Bryden (2005) in order to represent equalized care relationships and ensures that “the person with dementia is at the centre of the relationship, not alone as an object to be looked at, as merely a care-recipient. Instead we [individuals with dementia] become an active partner in a circle of care” (p. 150).

Recruitment and Consent. For this study, purposive sampling was utilized in order to recruit participants who met the specified inclusion criteria. Following ethics approval through the University of Alberta Human Research Ethics board, participants were recruited through community support groups and organizations, such as the Alzheimer’s Society of Alberta and the Northwest Territories. Contacts at these organizations and groups were asked to provide the recruitment letter for the study to potential participants. The recruitment letter outlined the purpose of the study as well as the criteria for participation.

Individuals interested in participating in the study contacted Dr. Paslawski, my thesis supervisor, at a private University of Alberta phone-line and provided their contact information. I followed up to confirm their interest and eligibility, provide additional information if required, and arrange an interview time. All six participants chose to be interviewed in their homes. Each interview took approximately 90 minutes. As per University of Alberta Ethics guidelines, prior to data collection the consent form was reviewed with and signed by participants, and a copy given to them. I reviewed the consent form with the participants and study participants signed it prior to beginning the interview. A copy was given to each participant for his or her own records. Five of the six interviews were audio and video-recorded for verification purposes. One participant requested not to be video-recorded but consented to audio-recording. The interviews were transcribed verbatim, primarily using the audio-recording. Data were stored and handled following University of Alberta Research Ethics Board guidelines to protect the confidentiality of study participants.

Data Collection

The data collected for this study included basic demographic and descriptive information (age, marital status, level of education, occupation, working diagnosis of dementia, and age of diagnosis), as well as responses to semi-structured interview questions and standardized measures. The standardized measures completed by study participants included the Montreal Cognitive Assessment (MoCA, Nasreddine, Phillips, Bedirian, Charbonneau, Whitehead, Collin…Chertkow, 2005), World Health Organization Quality of Life – BREF

(WHOQOL- BREF, World Health Organization, 2004) scale and the Geriatric Depression Scale (GDS, Yesavage & Sheikh, 1986). These standardized measures are common screening tools, which provide additional information that provide context for study participants' descriptions of the concept of resilience.

The Montreal Cognitive Assessment is a rapid screening tool for mild cognitive dysfunction. This screen was used for the current study as a means of understanding study participants' basic level of cognitive impairment. Scores below 26 out of 30 are considered abnormal. It was anticipated that individuals with scores between 17-25, consistent with mild-moderate cognitive impairment, would have the cognitive-communication skills to participate in the interview. It is important to note that there are no severity rating scores for the MoCA beyond the cut-off of 26 out of 30 for abnormal.

The World Health Organization Quality of Life-BREF assessment is a well-established measure of quality of life. The WHOQOL-BREF scores are scaled in a positive direction; higher scores on this measure indicate a higher quality of life. For the current study, this assessment tool was used to examine the ways that quality of life (QOL) and resilience interact. It is notable that previous studies (Hildon et al., 2010; Hildon et al., 2008) have used better-than-expected scores on QOL tests as indicators of resilience. For the current study, this measure was not used as a means of determining whether or not a participant is resilient, but rather provided additional information on the concept of resilience for individuals living with dementia.

The Geriatric Depression Scale is a screening tool for detecting depression in older populations. Scores above 5 on the GDS may indicate depression. For the current study, the short version of the Geriatric Depression Scale (Yesavage & Sheikh, 1986) was used to determine the possible presence of depression, which may interact with the measure of quality of life as well as descriptions of resilience for study participants.

To establish rapport between interviewer and study participant, the semi-structured interview was performed prior to the standardized assessments. Placing the interview prior to the standardized measures was purposeful as a means of establishing rapport with study participants because all six study participants have had experience with memory and cognition tests as part of their dementia diagnosis; it was anticipated that participants might not have been as receptive to these measures without first establishing rapport with the interviewer through the semi-structured interviews.

Data for this study were primarily gathered through semi-structured interviews developed from previous projects examining the concept of resilience in adults with neurologic disorders as well as through discussion with a panel of experienced researchers (refer to Appendix A). Additionally, two factors, physical activity and spirituality, were probed in the current study as possible influences on resilience for individuals with dementia. Physical activity was highlighted as it has been identified in the literature as playing a role in improvements in mental health in aging (Daffner, 2010). Voelcker-Rehage, Godde, and Staudinger (2010) suggest that physical and motor fitness may contribute to positive cognitive functioning in older adults. Religious beliefs have also been previously identified as protective factors for individuals with dementia (Harris, 2008). The use of the term ‘religion’ over ‘spirituality’ was purposeful; Koenig (2011) proposes using religion, rather than spirituality, in health research because it is a more clear and distinct concept. Specific questions regarding religion were developed based on Koenig and Bussing (2010). All questions in the interview were centered on levels that have been previously identified as impacting resilience in the literature: individual, family, and community (Luthar & Cicchetti, 2000; Luthar, Cicchetti, & Becker, 2000).

Data Analysis

Transcript verification. I transcribed each interview verbatim based on the recommendation of Easton, McComish, and Greenberg (2000), in order to ensure transcript accuracy. Additionally, spot-checking by a second listener (Dr. Paslawski) was employed for accuracy purposes; following the recommendations of Easton et al. (2000) and Maclean, Meyer and Easton (2004), a sampling ratio of two or more minutes for every ten minutes of recording was used. Transcripts were verified with 95% agreement between Dr. Paslawski and myself. Qualitative data analysis software (NVivo) was used to assist in organizing themes in the data related to the research questions.

Method. Thematic analysis was employed to assess the data. Interviews were read several times and Dr. Paslawski and myself coded recurring comments, phrases, words, or concepts independently. Similar codes were then grouped into themes within interviews and across respondents. In the case of differences in coding, we discussed the data in order to reach consensus on what concepts were most salient to study participants (i.e. ones that came up multiple times in a single interview or across interviews). Sub-themes were then derived from these conceptual codes, and were operationally defined and agreed upon by both researchers, which ensured reliability of the coding system.

The major themes identified in the data analysis process were then conceptualized as 'major factors', which were comprised of the sub-themes, or 'sub-factors', that were identified as contributing to the concept of resilience for individuals with dementia. Factors that were described by study participants to operate as protective or vulnerability factors were outlined as the 'sub-factors' in this study and were then grouped together to form the 'major factors'.

Reliability and validity. For the current study, as suggested by Guion, Diehl and McDonald (2011), validity referred to the truth and certainty of findings, " 'true' in the sense that research findings accurately reflect the situation, and 'certain' in the sense that research findings are supported by the evidence" (p. 1). Lincoln and Guba (1985) assert that validity is sufficient to establish reliability in qualitative research. Therefore, reliability and validity in this study were established following Patton's (1999) recommendations of triangulation of data sources and analyst triangulation. Triangulation of data sources ensures validity of themes identified in the data, by taking into account perspectives of multiple individuals with dementia. Data triangulation occurred across the six individuals with dementia (Guion, Diehl, & McDonald, 2011). Analyst triangulation to ensure reliability was accomplished by Dr. Paslawski and I both analyzing the data in order to compare identified themes.

Results

Individuals who met the following criteria were included in the study: (i) they believed they were ‘doing okay’ in the presence of dementia, (ii) they agreed to be audio- and/or video-taped, and (iii) they were comfortable participating in the interview without family members or care-partners. Six participants met the inclusion criteria and participated in the study; four women and two men. The average age of participants was 72, with a range from 65-82. All participants were from Edmonton or surrounding area.

Analysis of the data from the six study participants revealed three major factors associated with resilience for individuals with dementia: ‘active and purposeful living,’ ‘perspective’, and ‘resources.’ Each of these major factors was comprised of several sub-factors that operated at one or more of the following levels: individual, family, and community. The protective factors, and their sub-factors, are not mutually exclusive. There is overlap and interaction between the sub-factors, however, each sub-factor encapsulates a central theme identified by study participants. Although several of the sub-factors appear similar, it is important to note that they were chosen as separate sub-factors as a means of highlighting the concepts most salient to the study participants. Additionally, there is likely some degree of influence and interaction of factors and sub-factors. Because the notion of resilience is one that is complex, with a variety of inter-related and interacting factors, the following description of factors is simplified.

The relationship between factors and sub-factors is likely more complex than represented here, however, exploring the interactions of those relationships is beyond the scope of this project.

Table 1 outlines the factors that were identified in this study:

Protective Factors	Sub-Factors
Active and Purposeful Living	Participation Physical Activity Social Interaction
Perspective	Attitude Acceptance Openness Independence
Resources	Education Family & Care-partner Support Strategies

Table 1. Summary of Protective Factors and Sub-Factors

Each sub-factor in this study exists on a continuum, operating as a protective factor on one end of the continuum and as a vulnerability factor on the other end. In the current study, most sub-factors were identified by study participants to be operating primarily as protective factors; however, a few sub-factors were identified as operating primarily as vulnerability factors. Whether each sub-factor was described by study participants mainly as a protective or a vulnerability factor will be stated as such in each sub-factor section. This continuum of protective and vulnerability sub-factors will be addressed in greater detail in the discussion. Participant quotes are utilized to illustrate sub-factor content. For ease of reading, interjections, repetitions, and pauses have been removed and participant quotes are italicized.

Active and Purposeful Living

‘Active and purposeful living’ is a major factor that refers to being engaged in a variety of everyday activities following a diagnosis of dementia. Participants identified filling their days with meaningful activities and having a purpose in their daily life as contributing to resilience. The factor of ‘active and purposeful living’ is comprised of the sub-factors ‘participation’, ‘physical activity’, and ‘social interaction.’

Participation. The sub-factor of ‘participation’ refers to becoming or staying busy in participants’ everyday lives. All six participants referenced being or staying active as something that helped them ‘do better’ following their diagnosis of dementia. Study participants primarily described ‘participation’ as a protective factor. Participation overlaps with the other two sub-factors of ‘active and purposeful living’, however it is broader than ‘physical activity’ and ‘social interaction’ as it includes activities that are not social or physical in nature and is therefore justified as a separate sub-factor.

Being ‘busy’ includes a variety of activities such as going to the gym, attending organized community social groups, or going on family outings, depending on the participant. For most participants, continuing to engage in activities that were central in their daily lives prior to being diagnosed with dementia was beneficial, in that there was a sense of continuity between life before and after dementia. When asked what helped her do better with dementia, one participant stated: "*Do your life, do the same thing that you've been doing before. Don't stop, activity is important.*" Another participant acknowledged that how she participated in her activities has shifted since the onset of her dementia, however the maintenance of these activities despite these changes was important. She stated:

> *I work out, I go to the gym, I still go out with people. I still go to friends. Things have changed, but I still go out. I can still go out, I can still go shopping when I feel like it. I've had to make adjustments; like I can't do those things on my own. But I haven't stopped.*

Being busy was used as a distraction from his disease for one study participant. When asked what advice he would give to someone recently diagnosed with dementia, he stated: "*They should try to keep busy. It takes you away from thinking about your Alzheimer's for a certain length of time.*"

The sub-factor of 'participation' operates at all three levels as it includes activities that can be completed individually (e.g. hobbies), within the family (e.g. family outings) as well as in the wider community (e.g. church groups).

Physical Activity. 'Physical activity', defined as engagement in physical exercise of any kind, was identified as the next sub-factor of 'active and purposeful living.' Because physical activity had been identified as improving mental health for older adults (Daffner, 2010), questions about physical activity were specifically asked of study participants. Physical activity was identified as a factor that contributed to resilience for all six participants and operated primarily as a protective factor for study participants. The types and frequency of physical activity varied across participants and included activities such as walking, going to the gym, cleaning a local community centre, or swimming.

For all study participants, physical activity was not something they began to do following their diagnosis of dementia, but rather was something they already did and continued to do following diagnosis, which was an important component of their adaptive functioning. One participant discussed the importance of square dancing and stated:

> *It's amazing how the brain works, because I couldn't go and teach somebody how to do it. I couldn't say you need this step, but once the music comes on and the steps come back in my brain, I can dance.*

Physical activity was identified to be important and significant in study participants' daily lives. For the participant who square-danced, even with her significant memory loss, she identified dancing as something that helped her 'do okay' following her diagnosis and she stated: "*I think that's what's kept me good.*" For another participant, physical activity was an especially important means of social interaction, as a means of engaging with other individuals at the local gym. The significance of physical activity for mood regulation was identified by a study participant who stated "*I really don't have too many bad moods, but usually if I get myself turned around a little bit, all I do is put my clothes on and go for a walk.*" Another participant solely attributed his resilience to physical activity, and that going for walks became even more integral to his daily life following his diagnosis of dementia. When asked whether physical activity helped him 'do okay', he claimed: "*It's the best thing I can think of.*" Physical activity was identified to serve a variety of purposes, however, regardless of the reason study participants engaged in exercise, the physical activity itself was central to their daily lives. The sub-factor of 'physical activity' operates at all three levels, as it can include physical activities done alone (e.g. going for walks independently), with family (e.g. weekly family swims) or in the community (e.g. going to a public gym).

Social Interaction. 'Social interaction' is defined as meaningful interaction between participants with dementia and other individuals in their everyday lives. These types of interactions can be formal, organized situations such as Alzheimer's support groups, or casual interactions such as brief conversations at the local gym. In four out of six interviews, social interactions were an element that contributed to resilience for participants. The sub-factor of 'social interaction' was identified by study participants to primarily operate as a protective factor.

The types of social interaction varied across participants. Three participants identified engagement with and staying in contact with friends as something that contributed to their resilience. By remaining in contact through phone conversations and lunch dates, these participants felt that their close friends played an important role in their adaptive functioning. Further, a variety of different types of social groups were mentioned by study participants, including sorority, church groups, and Alzheimer's support groups, as a means of social interaction and engaging with others. One participant noted that having a role within an organized group was helpful to her and she stated: "*I like that, because it makes me feel a part of [group name] cause we all have to do certain things.*" When describing the nature of her community group, one participant described it as "*a really fun place to be with great, great people.*" Her involvement in this group, and her relationship with the group members, was something she identified as helping her be resilient after receiving her diagnosis of dementia.

One participant noted that social interaction, although an important factor for her resilience, was something that was especially difficult with dementia. When asked what plays a role in helping her 'do okay', she stated that:

> *Interaction with people too. With this illness, it's really easy for me to stay in and I find you get a spot that you like. And it's really hard, as I like that one spot. Sometimes when you go out, I can't wait to get back to that one spot. But I haven't stopped doing, which would be easy to do. Really easy because you just want to stay in that spot and not make a mistake. I have to fight that to make myself still go out and interact.*

'Social interaction' operates at two levels: the family level (e.g. interactions with loved ones, such as family and friends) and the community level (e.g. interactions out in the community, such as with community or support groups).

Perspective

'Perspective' is the second major factor that refers to the approaches individuals with dementia take in regard to their diagnosis. Participants identified how they viewed their diagnosis of dementia as a factor that contributed to their resilience. The sub-factors of ‘perspective’ include ‘attitude’, ‘acceptance’, ‘openness’, and ‘independence.’

Attitude. The sub-factor of ‘attitude’ refers to becoming or staying positive in the face of a dementia diagnosis. Five out of six participants identified having a positive attitude or disposition generally, or specifically related to their diagnosis of dementia, as contributing to their resilience. The sub-factor of attitude includes being positive, being optimistic, reframing thoughts, and having a sense of humour, as well as maintaining or building self-esteem and confidence. Study participants primarily discussed ‘attitude’ as a protective factor.

Having a positive attitude was important to one participant who stated: “*I feel I’ve had a very good life. I don’t want you to feel that I’ve got this thing* [dementia] *hanging over me all the time.*” Participants identified being optimistic or ‘looking on the bright side’ as being helpful in their everyday lives. When asked what advice she would give to someone recently diagnosed with dementia, one participant stated: “*You just have to keep smiling, because that’s one of the biggest things. Don’t give up.*”

Other participants noted that positively reframing changes in ability following the onset of dementia was important. One participant stated, “*I went through ‘poor me’ and feeling sorry and depressed. Then I changed my thoughts - ‘I’m retired, ‘What would I do if I was retired?’* ” By changing her attitude about new limitations imposed by dementia, this participant felt she was able to look at dementia in a different, more empowering way.

Three participants explicitly referenced having a sense of humour, being able to joke, make light, and laugh about their diagnosis, as something that helped them ‘do better’ following their diagnosis of dementia. One participant noted that rather than being upset at her memory loss, she would tell others “*Oh I forgot, I’ve got dementia, I’ve got Alzheimer’s, that’s why I forgot! And I’ll make a joke about it.*”

Another participant noted that having a positive self-image, or having high self-esteem, especially following a dementia diagnosis was something that helped her be resilient. She stated:

> *I think it’s important to build self-esteem too. And it’s a hard one because when you’re doing stupid things - when you can’t add your money anymore, when you can’t make a sandwich, when you can’t drive your car anymore - you feel stupid.*

She noted that having a positive self-image and high self-esteem prior to the onset of dementia was something that was especially beneficial after her diagnosis. The sub-factor of ‘attitude’ operates at the individual level and relates to personal attitudes towards dementia and ways of approaching living with dementia.

Acceptance. ‘Acceptance’, defined as being accepting of one’s dementia diagnosis as well as the changes and limitations that accompany it, was another sub-factor of ‘perspective.’ Similar to the sub-factor of ‘attitude’, ‘acceptance’ is related to how an individual approaches living with dementia. It is notable that the sub-factor of ‘acceptance’ is strongly related to the sub-factor of ‘attitude’, however ‘acceptance’ is justified as an independent sub-factor, as it specifically refers to coming to terms with the diagnosis of dementia, rather than a general positive attitude towards living with dementia. ‘Acceptance’ refers specifically to an individual’s ability to be okay with their diagnosis of dementia, without anger or resentment. ‘Acceptance’ was described by study participants to function primarily as a protective factor.

Accepting the dementia diagnosis was an element that contributed to resilience for four out of six study participants. One participant stated that: “*Acceptance would be a big part of this. Having to accept my limitations and be okay with it.*” Multiple participants discussed the question ‘why me?’ in regard to their dementia diagnosis, and the process through which they began to accept their diagnosis of dementia. One participant noted that: “*I’ve never said ’why me?’ I’ve just said to myself ‘This is me now, I’ve got to make the best of this I can.’*” Another participant stated:

> *I was angry at God. I really was. And sometimes I’d say, ‘why me God?’ and then I’d say ‘why not?’ You have to look at it from that angle too; there are hundreds of people who have Alzheimer’s.*

The immutability and permanence of dementia was also identified as something that prompted acceptance. One participant said:

> *I was so acceptant of this* [dementia] *because I knew when they say it, that’s it. It can’t be fixed. And what are you gonna do about it? I mean you can sit there and go back to bed. Or you can get off your dot and do something.*

The sub-factor of ‘acceptance’ includes accepting help or support. This refers to the ways in which people with dementia or their family members began to accept their diagnosis and with it began accepting support from others, such as friends, family, and neighbors. When asked what advice she would give to someone recently diagnosed with dementia, one participant said: “*To be able to accept help and not hate yourself for it. I think that’s what’s helped me too, is that I ask for help.*” Although accepting help was noted to be beneficial, another participant observed that there is a difficulty asking for help, by stating that: “*I’ve got lots of people who would say ‘I’ll take you somewhere’, but when you’ve been independent it’s really hard to ask somebody.*” Additionally, several participants noted that their care-partners or loved ones’ acceptance was also something that facilitated their resilience, because when their loved ones were accepting and supportive of their diagnosis, study participants felt more supported. ‘Acceptance’ operates at the levels of the individual and the family. It involves coming to terms with the diagnosis and accepting support for both the individual with dementia (individual) and their family or loved ones (family).

Openness. ‘Openness’ refers to sharing the diagnoses of dementia with other individuals in one’s life. ‘Openness’ is strongly related to ‘acceptance’, as often the process of acceptance precedes that of openness. However ‘openness’ refers specifically to sharing the diagnosis of dementia, and therefore is justified as a separate sub-factor of ‘perspective.’ ‘Openness’ was identified as something that positively contributed to well-being and operated as a protective factor by four out of six study participants.

Study participants saw openness as a way of decreasing embarrassment and increasing understanding of their dementia, especially in public situations. Different participants had varying degrees of openness, which was related to their personal decisions about who to share their diagnosis with, as well as input from their trusted family members or loved ones. One participant noted that she shares her diagnosis at the grocery store and stated: "*I tell people ahead of time so if I make a mistake, I don't feel silly.*" While another participant noted that it was important to tell close 'trusted' friends, however this individual was not comfortable sharing with more casual acquaintances, such as individuals at the grocery store.

Several participants noted that by sharing the news of their diagnosis with others, there was a wider range of support that was available should they need it, and openness also increased general awareness about their condition. In one case, a participant explained the influence his care-partner had on sharing his diagnosis. He explained:

> *Let me tell you what we did first. We told as many people as possible – good friends and even marginal friends if there was a good chance that we would meet up in different circumstances. I say that nobody said 'Oh, that's* [name]*, he's away with the fairies.*

By sharing his diagnosis with others, he stated that his care-partner was able to advocate for him more readily and increase support provided for both of them. Additionally, because of this openness, he felt more comfortable with his current level of functioning and found that people were more understanding once they were aware of his diagnosis of dementia.

Further, three people discussed dementia as a ‘hidden illness’ in that it is not discernable as a visible disability, which increased the need to be open and honest with others. One participant stated: “*What’s really hard about people with early dementia is I look well. People aren’t there saying ‘Can I help you?’ so you have to advocate or your family has to advocate for you.*” Because dementia does not have the same visible symptoms as other chronic conditions, and often there are variable levels of cognitive functioning, participants commented on how these factors influenced their daily lives. One participant stated: “*It’s a hard disease, because one minute you’re good and one minute you’re bad. Or one day, you’re perfect and nobody would have a clue there’s something wrong with you.*” This ‘invisibility’ of dementia prompted increased openness as identified by study participants. ‘Openness’ operates at the individual and family levels, as the decision to share the news of a dementia diagnosis is personal (individual), however, family members or care-partners also were identified to play a role in the decision-making process (family).

Independence. The final sub-factor in ‘perspective’ refers to ‘independence’, which is defined as the ability to complete activities or tasks without assistance from others. In four out of six interviews, participants made statements about ‘independence.’ Study participants identified the ability to be independent as something that facilitated their resilience, and that a loss of independence, common for individuals with dementia (Andersen, Wittrup-Jensen, Lolk, Andersen, & Kragh-Sorensen, 2004) was a barrier to their everyday functioning. This loss of freedom, and having to rely on others, was identified primarily as a barrier to resilience or a vulnerability factor for study participants. Because of the significant cognitive changes that accompany dementia, individuals in this study identified a decreased independence and an inability or difficulty doing things that they previously had done independently as impeding their resilience.

Several study participants noted that though they are still functioning in their everyday environments, *how* they are functioning or what they do now is markedly different since the onset of dementia. For example, one participant when asked 'what makes it harder to do okay' stated:

> *Well that's a hard question for the simple reason that what I'm doing now is so different from what I did all these years as a* [profession]. *So I'm really treading new paths. I'm faced with incidents that have rarely, or never, appeared before.*

Specifically, the inability to drive was noted by three participants as a significant barrier to their everyday functioning. One participant stated: "*Not being able to drive, not being able to just open the door and go. Freedom…freedom is gone to a certain extent and that's what really bothered me.*" Further, difficulties taking public transportation or lack of access to reliable and affordable transportation compounded the loss of independence felt by study participants related to their inability to drive.

Other participants noted the need for increased support to do daily tasks, such as grocery shopping, and that their loss of independence for these tasks negatively affected how they felt in those situations. A participant mentioned that, "*My biggest thing with my family is that I always, always wish I could do it myself because I hate being a burden.*" Although she said that family members repeatedly assured her that she was not a burden, this participant still felt that her inability to be as independent as she was prior to dementia was something that impeded her resilience. 'Independence' operates at all three levels: the ability to be independent is related to how individuals feel about themselves (individual), the ways family support fosters or interferes with independence (family), and how access to community resources, such as transportation, promote or impede independence (community).

Resources

'Resources' is a major factor that pertains to external supports that contribute to an individual's resilience following a dementia diagnosis. Participants identified ways of adapting, problem-solving, or accessing supports as a means of coping with everyday life and how it has changed since the onset of dementia. The sub-factors of 'resources' include 'education', 'family and care-partner support', and 'strategies.'

Education. 'Education' refers to the process of becoming informed about dementia by actively searching out information regarding the disease itself, how everyday life may change, and what the future outlook of the disease is.

Four out of six study participants noted that knowing about dementia was something that was beneficial to them, and that self-education was something that helped them cope following their diagnosis; therefore, this sub-factor was identified primarily as a protective factor. Self-education took a variety of forms that included support groups at the Alzheimer's society, reading books about dementia, as well as using the Internet as a means of education. Several participants noted that knowing they had dementia made it easier, however, they also acknowledged the importance of not letting their diagnosis overtake their life. One participant stated: "*I read as much as I can about Alzheimer's, but I don't want to get clogged with it because looking through a book is not going to give me any cure.*" Another participant noted that education decreased the fear associated with the future, and when asked 'what helps her be okay' she stated: "*I think knowledge – I sought out help with the Alzheimer's society. I'm not afraid of dementia.*" Further, public education and increased awareness was also identified as something that would assist individuals living with dementia. Two study participants commented on a lack of awareness about dementia and that increased awareness did, or would have, helped them 'do better' after their diagnosis. Study participants identified a lack of awareness within the general public, the medical community, as well as at a personal level. When asked what would have been beneficial following her diagnosis a participant stated:

> *Other people knowing about dementia: family and friends. People don't know. People know what Alzheimer's is, and of course, they think the*

> *worst. Some people don't understand the beginning stages of dementia or Alzheimer's. People are afraid of it. So I think knowledge.*

Four study participants also commented on the Alzheimer's Society support groups as something that played an integral role in their functioning following their diagnosis of dementia. The support groups were identified as having a variety of roles for individuals with dementia; attending meetings at the Alzheimer's society were a way of learning about the disease, its progression and everyday strategies, as well as a way of socializing with others, being active, and getting out in the community. 'Education' operates at all three levels and involves directly educating the individual with dementia (individual), family members and care-partners (family), as well as broader public and community awareness (community).

Family and Care-partner Support. The sub-factor of **'**family and care-partner support' refers to the different supports that loved ones or care-partners provide to individuals with dementia. All six study participants commented on the integral role their family members, loved ones, or care-partners, played in contributing to their resilience. 'Family and care-partner support' is another sub-factor that primarily was identified to be a protective factor for study participants. The role of the care-partner and family members included a variety of different support types, depending on the participant and their relationships with their loved ones. Different supports identified by study participants included providing emotional regulation, reminders compensating for memory loss (e.g. the name of an acquaintance in a public setting), transportation, assistance in public domains (e.g. at the grocery store), taking on additional household responsibilities as well as keeping the individual with dementia company.

One participant commented on the role of his care-partner, and the specific way she provides him with support, stating:

> *She helps me a lot, but there's some times she says nothing. And I appreciate that - she doesn't always step in. It's just the fact that she has recognized and responded to my need, but not in such excess that it's a bit embarrassing.*

Several participants identified this notion of respectful and graded support. Having family and care-partner support significantly contributed to resilience for study participants and several participants commented on how much they appreciated having their loved ones take on the care-partner role and how effective they felt their care-partners were in that capacity. One participant noted that she could rely on her family, which helped her function in her every day life. She noted that: "*Anything I need, they talk to me. They either come right away if they can, or they come as soon as they can. They always, always answer my calls.*" Another participant stated, in regard to her care-partner: "*I really rely on him.*" 'Family and care-partner support' operates at the family level, as care-partners and loved ones are the individuals who provide support and care to study participants (family). It is also strongly related to community resources, and operates at the community level (community).

Strategies. 'Strategies' is the final sub-factor of 'resources' and refers to ways of adjusting, compensating, or adapting to changing needs and abilities following a diagnosis of dementia. This sub-factor refers to the kinds of supports that helped or would have helped participants function following their diagnosis. Primarily, study participants identified the sub-factor of ‘strategies’ as a protective factor.

Environmental modifications were identified as important strategies to support resilience for individuals with dementia. Four participants discussed sensitivity to noise, crowds or visual distractions as barriers, that they mitigated by changing their environment to improve functioning. These kinds of environmental changes included moving into a smaller home, changing how groceries were bought, reducing noise and clutter, and having easier access to activities within the home.

Devices or reminders, to compensate for memory loss, were identified as strategies to help with everyday functioning. These devices included iPads, other calendar, or reminder systems (e.g. alarms reminding participants to make lunch), as well as writing notes or making lists. Other strategies identified included increasing or maintaining communication with loved ones, especially care-partners. When asked what helps her ‘do okay’, one participated noted:

> *Being able to communicate, and that’s hard with dementia, because when I’m tired, the communication isn’t there. So it changes. I’ve been okay up to now, but that can be a real problem for me when I won’t be able to communicate.*

For this participant, being able to express herself was difficult, but communication operated as an important strategy to get her wants and needs recognized and met.

Several participants commented on a role-shift with care-partners that occurred following the diagnosis of dementia. Changes in household responsibilities such as paying bills, buying groceries, or cooking meals often occurred, and acceptance of those changes by the person with dementia was important. One participant explained it as "*You adapt, you buy groceries a little differently. Things have changed, my husband does the groceries, he has to do the cooking and being okay with that has helped me.*" One participant noted that having support with meals and daily chores would be beneficial, but that costs of such services were an impediment to accessing them.

This sub-factor operates at all three levels. 'Strategies' can be implemented individually (e.g. using devices for reminders). Additionally, the sub-factor of 'strategies' can operate at the familial level through environmental modifications and role shifts (family), as well as at the broader community level by providing affordable, available access to needed supports, such as meals and transportation (community).

Standardized Measures

In additional to semi-structured interview questions, data were collected through demographic questions and three standardized measures. Table 2 outlines the results of these additional measures:

Participant Gender	Number of Years Post-Dementia Diagnosis	Montreal Cognitive Assessment (MoCA) Score	Geriatric Depression Scale (GDS) Score	World Health Organization Quality of Life BREF Score			
				Domain 1	Domain 2	Domain 3	Domain 4
female	9	14	6	38	44	69	56
male	5	18	0	56	69	75	88
female	<1	15	1	69	69	100	88
female	<1	18	7	56	56	56	63
female	1.5	12	2	24	20	12	35
male	3	19	2	69	81	44	88

Table 2. Results of Standardized Measures Administered

The number of years since participants were diagnosed with dementia ranged from less than 1 to 9 years. Scores on the Montreal Cognitive Assessment were between 12-19; scores below 26 out of 30 on the MoCA are considered abnormal. Participants' scores on the Geriatric Depression Scale (GDS) ranged from 0-7; scores above 5 on the GDS may indicate depression. The World Health Organization Quality of Life-BREF measure indicated a range of scores across participants (Domain 1 – Physical Health: 24-69; Domain 2 – Psychological: 20-81; Domain 3 – Social Relationships: 12-100; Domain 4 – Environment: 35-88).

The results of this study suggest three major factors related to resilience for individuals living with dementia: 'active and purposeful living', 'perspective', and 'resources.' Each major factor was comprised of several sub-factors that were identified across interviews. Each sub-factors operates at one or more of the following levels: individual, family, and community, as well as along a continuum serving as factors that promote resilience (protective) or impede resilience (vulnerability). Sub-factors were discussed as either primarily protective factors or vulnerability factors as identified by study participants. The following section will discuss these findings, in relation to the research questions, previous literature, and clinical implications.

Discussion

This study examined the concept of resilience for individuals living with dementia and identified factors associated with resilience following a dementia diagnosis. Several factors determined from the current study were consistent with those found in previous literature; however, this study also identified and described three factors not previously discussed in the literature to date, that may also play a role in resilience for individuals living with dementia; ‘physical activity’, ‘openness’, and ‘independence.’

Describing Resilience

The first research goal of this study aimed to describe resilience as defined by participants with dementia. For study participants, resilience appeared to be a process of maintenance, in that participants felt that their resilience was related to a degree of continuity between life before and after their diagnosis of dementia. Even though their life had changed to varying extents, most participants noted that a sense of normalcy and similarity to their life prior to the diagnosis of dementia was central to ‘being okay’ after the diagnosis. Further, maintenance of daily life activities was central to their positive adaptation. What changed for most participants was *how* they did these daily life activities, rather than *what* they did. Consistent with this finding, in a recent review of resilience literature, Bailey and colleagues suggest that resilience for individuals with dementia “can encompass the ability to continue with established roles and activities that (re)affirm a sense of self and build on a lifelong accumulation of social, knowledge, psychological and material assets” (p. 394), which further emphasizes the importance of continuity between life before and after dementia identified in the current study.

Additionally, resilience, as described by participants in this study, was considered to be a behaviour in addition to a mental state. Two sub-factors (‘attitude’ and ‘acceptance’) identified by study participants are primarily internal to the individual and therefore arguably mental states. However, other sub-factors were described by study participants to be more external and behaviourally-based. Participants demonstrated resilience in their actions and resilience was something participants actively did. For example, going for a walk or attending a support group were the physical manifestations of their resilience. It was through their actions, and the kinds of activities they did on a daily basis, that study participants felt they were able to be resilient.

Protective and Vulnerability Factors

The second research goal of this study was to identify the protective and vulnerability factors that influence the process of resilience for individuals living with dementia. Three major factors were identified as promoting resilience for this population: ‘active and purposeful living’, ‘perspective’, and ‘resources.’ The sub-factors identified in each major factor represent a continuum, with both positive and negative poles, and were identified by study participants to operate as either primarily positive (protective factors) or negative (vulnerability factors) in the current study. Each sub-factor was identified or could be anticipated to operate as both a protective factor at one end of the continuum and a vulnerability factor on the other. In the current study, although discussed primarily as protective factors by participants, the following sub-themes were also identified by some of the study participants as vulnerability factors: ‘social interaction’, ‘attitude’, ‘acceptance’, ‘independence’, ‘education’, ‘family and care-partner support’, and ‘strategies.’ This illustrates the continuum from protective to vulnerability that these factors may operate on. For example, ‘attitude’ operates as a protective factor in that having a positive attitude contributes to resilience. However, two study participants noted that frustration or negative emotions related to the onset of dementia made it more difficult to for them to ‘be okay.’ Worry about letting others down, concern over negative stereotypes of people with dementia, and anxiety of making mistakes in public were all identified as vulnerability factors at the negative end of the ‘attitude’ sub-factor continuum. Figure 1 demonstrates the protective and vulnerability factor continuum for the sub-factor of attitude:

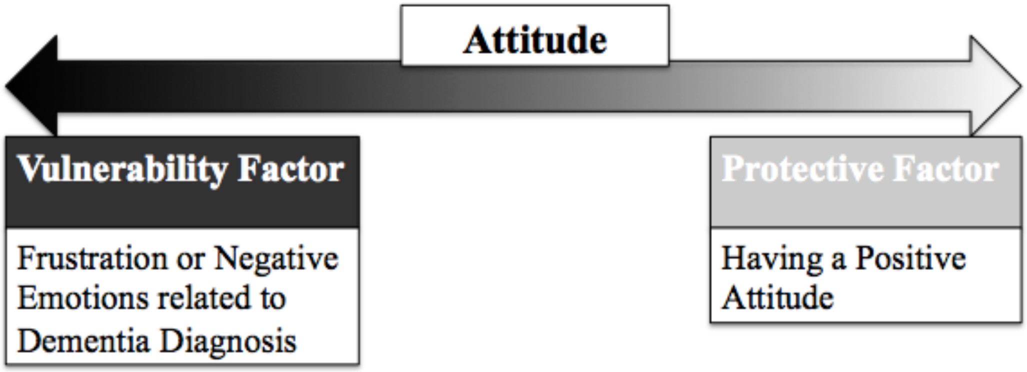

Figure 1. Illustration of Protective and Vulnerability Continuum.

Similarly, ‘family and care-partner support’, although primarily identified as a protective factor in the current study, can also operate as a barrier to resilience. Two study participants identified familial tension as something that made it harder to function in the face of their diagnosis demonstrating the negative end of the ‘family and care-partner support’ continuum.

The other sub-factors (‘participation’, ‘physical activity’, ‘openness’) were not explicitly mentioned as vulnerability factors by current study participants, however these sub-factors could be anticipated to operate as such based on what was identified by study participants to be a protective factor. For example, ‘openness’ was discussed primarily as something that helped individuals function following the diagnosis of their dementia, however, it is anticipated that a lack of openness might impede functioning. If an individual is not open about their diagnosis of dementia (i.e. at the vulnerability end of the ‘openness’ continuum), it is possible they may not be able to access resources or supports that promote resilience, such as community support groups or familial support.

Many of the sub-factors identified in this study are supported by previous findings in the literature. The sub-factor of ‘participation’ identified in the current study relates to the protective factor of *productivity* as identified by Harris (2008) in a case study of two individuals living with dementia. Glymour, Weuve, Fay, Glass, and Berkman (2007) identified *social integration* as a protective factor for stroke patient’s cognitive recovery; this parallels the sub-factor of ‘social interaction’ in the current study. The sub-factor of ‘attitude’ corresponds with several factors identified by Harris (2008) including: *positive attitude*, a *fighting* *spirit* and *positive self-concept*. Harris (2008) also suggested that *acceptance of changing self* was a protective factor, which mirrors the sub-factor of 'acceptance' in the current study. All three sub-factors of the major factor 'resources' in the current study were also supported in the literature (Harris, 2008): 'education' (*community resources), '*family and care-partner support' (*social support networks, long-term supportive marriage*) and 'strategies' (*coping strategies, problem solving skills*). The overlap of sub-factors identified in both the current study and the literature suggest that these factors are ones likely to be involved in the demonstration of resilience for individuals living with dementia.

Important findings in this study were three factors not previously identified in the literature, 'physical activity', 'openness', and 'independence' that were found to be important in bolstering resilience for participants in the current study.

All six study participants identified the sub-factor of 'physical activity' as a protective factor that helped them 'do okay' after their dementia diagnosis. Interestingly, this finding underscores the importance of healthy habits prior to the identification of illness, as all six study participants continued the physical activities they had established prior to their dementia diagnosis following their diagnosis. Physical activity was not something that became a part of their lives following their diagnosis, but rather was a something they were already doing in their daily lives. It suggests a prevention approach, in that it is much easier to maintain a healthy, physically active lifestyle, which may contribute to resilience, if that lifestyle was already incorporated into daily life before dementia, as opposed to establishing one following a diagnosis of dementia in order to bolster resilience.

'Openness' is another sub-factor not previously identified in the literature on the concept of resilience in dementia. Being open and honest about a dementia diagnosis is a message stressed by the Alzheimer's Association. Because study participants were recruited through this community organization, the role of openness as a sub-factor may be influenced by the study participants' experience with this organization. It is important to note that four out of six study participants identified telling others about their diagnosis as something that contributed to their resilience. This finding validates the Alzheimer's Association's emphasis on openness, as it was believed by study participants to be helpful in their daily lives and contribute to their resilience.

'Independence' was the final sub-factor identified in the current study that has not explicitly been linked with the concept of resilience for individuals with dementia. Previous studies (Andersen et al., 2004) have suggested that dependency for activities of daily living was a significant factor in measures of quality of life for individuals living with dementia. However, 'independence' in relation to resilience has not been discussed for this population. Several of the study participants noted that their biggest impediment to resilience was their loss of independence as a result of their dementia diagnosis.

Religion was found to be a factor for one participant in Harris (2008). Based on this finding, questions were developed for the current study to probe the role of religion related to resilience in this population. Despite being specifically probed, religion was not identified as a major factor or sub-factor in the current study. Three study participants referred to religion or spirituality as something that played a role in their everyday lives, however only one study participant claimed that religion was something that positively contributed to her resilience. The concept of religion as related to resilience was not found to be meaningful for current study participants; it may have played a role in their everyday lives, but was not identified to positively contribute to their demonstration of resilience.

Clinical Implications

Resilience can be applied in clinical settings. As an initial investigation into resilience and factors that contribute to it for individuals living with dementia, this study demonstrates that there are a wide range of protective and vulnerability factors that operate at the individual, family, and community levels. In a review of resilience literature related to dementia, Bailey and colleagues (2013) suggest that further investigations into the "interplay between person and environment in managing risk and resilience" for individuals with dementia are essential (p. 397). The current study points to the ways that resilience or positive adaptation is influenced by these external factors. Although 'attitude' and 'acceptance' could be considered to be internal states, the other sub-factors identified in this study highlight the notion that there are multiple, modifiable factors playing out at a number of levels (individual, family, community). Because some of these factors, operating at multiple levels, are both behaviourally-based and modifiable, the opportunity to alter these factors to positively contribute to resilience following the diagnosis of dementia is plausible.

The following tables demonstrate the levels each sub-factor operates on based on data from the current study:

	Active and Purposeful Living		
	Participation	Physical Activity	Social Interaction
Individual	+	+	
Family	+	+	+
Community	+	+	+

Table 3. Major Factor: ‘Active and Purposeful Living’ at Each Level.

	Perspective			
	Attitude	Acceptance	Openness	Independence
Individual	+	+	+	+
Family		+	+	+
Community				+

Table 4. Major Factor: ‘Perspective’ at Each Level.

	Resources		
	Education	Family and Care-Partner Support	Strategies
Individual	+		+
Family	+	+	+
Community	+	+	+

Table 5. Major Factor: ‘Resources’ at Each Level.

The concept of resilience, although in its early stages of development and application to the adult population may prove to be a useful clinical tool for bolstering resilience, especially for individuals living with dementia who are not currently demonstrating behaviours consistent with resilience. By understanding the factors that positively contribute to resilience, the notion of resilience could be used to identify areas of strength and weakness for goal-setting purposes for individual clients. Bailey and colleagues (2013) suggest asking "What resources does the person living with dementia have and how might they inform notions of risk?" as a means of understanding not just what the individual with dementia needs, but also the resources they already have (p. 395). For example, the tables illustrated above could be used for each individual with dementia; the presence or absence of each sub-factor, at each level may facilitate identification of areas an individual already has sufficient support, and areas that require additional effort or intervention to bolster resilience with regard to that factor.

Speech-language pathologists, as rehabilitation professionals, have an integral role in working with individuals with cognitive-communication impairments, including dementia. Speech-language pathologists are trained to facilitate communication and therefore facilitate discussions of resilience directly with individuals living with dementia. These first-hand discussions may be inherently more challenging given the cognitive-communication deficits characteristic of dementia. Therefore, speech-language pathologists are especially suited to conduct research that includes individuals living with dementia. Research that seeks to understand resilience from the perspective of individuals affected by dementia and to identify the factors that promote or impede resilience can directly influence intervention. In addition, because communication affects many aspects of resilience, it is a valid area of focus for speech-language pathologists in the clinical setting. Having an increased understanding of resilience in dementia may ensure that our intervention efforts as speech-language pathologists are directed at appropriate targets and treatment goals to promote resilience.

The defining characteristic of resilience for individuals living with dementia as suggested in the current study is that of maintenance, or continuity, between life before and after dementia. Assuming this bears out with further research, this finding provides insight and direction regarding the kinds of interventions and supports that would be beneficial for individuals diagnosed with dementia. These interventions and supports could include means of making life after dementia similar to life before dementia, by increasing accessibility and affordability of transportation for individuals with dementia, for example. Related to intervention efforts, as support from loved ones and care-partners was identified as a protective factor, arguably it is equally important to provide support and care to those care-partners as a means of benefitting both the individual with dementia and the people who care for them.

Originally, this study sought to examine the concept of resilience in individuals with mild dementia; however, participants had much lower scores on the MoCA than initially expected, which indicates that participants may have had more moderate dementia. The score range of 17-25 was initially anticipated to be the range that would to ensure study participants would have the cognitive-communication ability to participant in the semi-structured interview. However, even with what would be considered more significant cognitive impairment, all of the interviews provided useful and meaningful data, even if study participants scored below 17 on the MoCA and were therefore included in the study. The current study was actually able to examine the concept of resilience for both participants with mild and more moderate dementia. This finding suggests that a low score on a brief cognitive screening such as the Montreal Cognitive Assessment may not be indicative of an individuals cognitive-communication ability to share his or her experiences of living with dementia.

From a resilience perspective, it is also interesting to note that even with this level of cognitive impairment, study participants still felt they were resilient. This suggests that individuals with abnormal scores (lower than 26), as suggested by a brief screen such as the MoCA, can ‘do okay’ and function in their everyday lives following a diagnosis of dementia.

Two study participants had scores on the Geriatric Depression Screening scale above 5. According to this measure, any score greater than or equal to 5 may indicate depression. This finding is notable as it demonstrates that even individuals who may be depressed can still consider themselves to be resilient. As resilience was described primarily as a process or behaviour, rather than exclusively a static internal trait, ‘doing okay’ at any time, would classify as being resilient. This suggests that even in the face of depression, in addition or perhaps related to a diagnosis of dementia, resilience is still a concept that is achievable for this population. This finding demonstrates that resilience is not exclusive of depression; as individuals may be depressed and still be resilient.

Participants’ scores on the World Health Organization Quality of Life-BREF measure indicated a vast range of scores across participants, some of which fell within a normal range compared to individuals with no cognitive impairments or chronic illnesses (Hawthorne, Herrman, & Murphy, 2006). However, it is important to note that many of the scores on the individual domain measures on the WHOQOL-BREF were significantly below the average. Even with what would be considered ‘low’ quality of life scores, study participants still considered themselves to be resilient. This is especially interesting because in previous studies on resilience in older adults, the measure of resilience was better-than-expected quality of life scores. The finding that participants in the current study described themselves as resilient, even with low quality of life scores suggests that resilience is not directly associated with quality of life, and although these factors may be related, resilience and quality of life do not presuppose each other. More research is required to address this relationship.

It should be noted that all three additional measures are used primarily as screening tools to indicate cognitive impairment, depression, and quality of life. Therefore, these assessments are not comprehensive measures of these factors. However, it is surprising that even with what would be considered low scores on these measures, study participants identified themselves to be demonstrating resilience in their everyday lives. The results from both the semi-structured interviews and the standardized measures provides evidence that resilience is both an inclusive and optimistic position from which to examine living with dementia. Even individuals who appear to be significantly cognitively impaired, depressed, and have low quality of life scores, can still be resilient.

Working with individuals with dementia as the primary research participants, rather than relying on care-partners or other professionals, was a central component of this research study. By viewing individuals with dementia as able to contribute to our understanding of resilience and specifically interviewing individuals with dementia, this study was able to identify the factors that contribute to resilience using the first-hand knowledge of individuals living with dementia. Further, this study also demonstrated that even individuals with more significant cognitive impairment could still provide meaningful data that contributes to this knowledge base. This finding challenges the assumption that data collected from individuals with cognitive impairment are inaccessible and unreliable (Cotrell & Schulz, 1993).

Limitations and Challenges of the Study

As an initial investigation into resilience for individuals with dementia, this study employed a qualitative methodological approach. By using qualitative methods, rich information on resilience was obtained. However, there were some limitations to this study related to procedure and others related to the population studied.

Procedurally, although inclusion criteria for the study specified that participants must have dementia, diagnosis and medical history were not confirmed. Because type and severity were not specified, it is possible that study participants had varying types and severities of dementia. Different types of dementia may present and progress differently; therefore the factors associated with dementia may not be consistent across dementia types. Participants were invited to participate in the study if they felt they had demonstrated resilience in the face of their diagnosis. However, several participants noted that their primary reason for participating in the study was to help others, not necessarily because they felt they were demonstrating resilience in the face of their diagnosis. Therefore, it is possible that study participants agreed to participate on the basis of being helpful to others rather than self-selection based on whether they truly felt they had demonstrated resilience. However, because recruitment for the study occurred through the Alzheimer's society, study participants were already individuals actively taking part in support groups and accessing community resources, which arguably illustrates a degree of resilience. Study participants also described and identified themselves to be resilient in the semi-structured interview. Finally, the data gathered in this study were not verified with study participants and varying degrees of cognitive impairments across participants may have influenced the accuracy of the data obtained. However, due to the degenerative nature of dementia, verification may not have been possible in the same way as it would be possible in other populations.

Suggestions for Further Research

This study was a preliminary investigation into the notion of resilience for individuals with dementia. As an initial in-depth investigation, this study suggested several factors that may contribute to resilience for this population. Validating that these factors, identified in the current study, in fact, promote resilience for individuals with dementia would be an important next step. This study specifically focused on identifying factors that promoted resilience for individuals with dementia; however, a broader study could investigate factors that impede resilience in this population by examining both individuals who demonstrate resilience and those that do not in order to examine what differentiates these two groups. Further, having a more concrete understanding of the factors that contribute to positive adaptation for individuals with dementia can influence the development of intervention and support programs that promote resilience.

There were several factors identified by Harris (2008) that were not found to be factors in the current study, which included having a *positive role model, early father daughter relationships*, as well as a *person-centered environment*. Although our study did not find these factors to be salient with current study participants, it warrants further investigation as these factors have been previously found to be relevant for resilience in individuals living with dementia. Similarly, our findings suggest that religion may not play a role in resilience although this was a factor in Harris (2008). There are a variety of considerations that may influence the finding that religion was not salient for current study participants, including how questions regarding religion were worded, the small sample size, as well as cultural, geographic or age differences between participants. Therefore, there are many plausible reasons religion was not found to be relevant for current study participants, and does not suggest that religion will not play a role in resilience for other individuals living with dementia. The relation of religion to resilience requires further exploration.

This study used three standardized measures to provide additional information on cognitive abilities (MoCA), depression (GDS) as well as overall quality of life (WHOQOL-BREF). In addition to these three measures, it would be interesting to use a dementia severity rating scale as a means of understanding the relationship between severity of dementia and the various factors identified in playing a role in resilience as well as how these factors may operate differently depending on dementia severity. Additionally, it would be interesting to use measures of functional status or impairment to determine if these more closely align with self-identification of resilience in future studies.

A final area warranting future research would be to interview both individuals living with dementia as well as their care-partners. By gaining both perspectives, a deeper understanding of the concept of resilience for individuals living with dementia may be gained.

Summary

Using data gathered from semi-structured qualitative interviews and qualitative thematic analysis, this study both described resilience as well as suggested protective and vulnerability factors associated with resilience from the perspective of individuals living with dementia. This study identified three major factors associated with resilience for individuals with dementia: ‘active and purposeful living’, ‘perspective’, and ‘resources.’ The factors found in this study build on those previously identified in the literature, and suggest additional factors that may impact resilience in this population.

The concept of resilience, as described in the current study, corresponds to maintenance or a degree of continuity between life before and after a diagnosis of dementia. There are several clinical implications of resilience for this population, which include increasing this sense of continuity between life before and after dementia as well as bolstering the multiple, modifiable factors identified as promoting positive adaptation for study participants. This study emphasized the importance of first-hand perspectives of individuals living with dementia as well as the inclusivity and optimism inherent in the notion of resilience. The current study provides an initial basis for future investigations into the concept of resilience as applied to individuals living with dementia.

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Appendix A

Interview Questions

1. What made you sign up for this study?
    a. Are you doing okay?
    b. If so, why are you doing okay
        i. At home?
        ii. At work?
        iii. With family?
        iv. With friends?
        v. Out in the community?
    c. What does it mean to you to be resilient/be doing okay?
2. What helps you do okay?
    a. [Individual] – How are things with you personally?
    b. [Family] – How are things with your family?
    c. [Community] – How are things in the wider community?
3. What makes it hard for you to do okay?
    a. [Individual] – personally?
    b. [Family] – in your family?
    c. [Community] – in the wider community?
4. What would have helped you do better after your diagnosis of dementia?
    a. What would help you now?

5. What advice would you give to someone that may be able to assist them with overcoming hurdles, such as a dementia diagnosis?
6. Are you religious or spiritual? Tell me about that.
    a. Do you think religion played a role in doing okay?
        i. How often do you attend church or other religious meetings?
        ii. How often do you spend time in private religious activities, such as prayer, meditation, or Bible study?
        iii. Do you feel like you experience the presence of the divine in your life?
        iv. Do your religious beliefs lie behind your approach to life?
        v. Do you try to carry your religion over into all other dealings in life?
7. Are you physically active? Tell me about that.
    a. Do you think physical activity was important to you once you learned you had dementia?
    b. Do you think it plays a role in helping you be okay?
8. Is there anything else you would like to tell me (about doing okay with dementia?