Resilience in Dementia: Perspectives of Individuals with Dementia and Their Care Partners

by

Kelsey F. Earle

A thesis submitted in partial fulfillment of the requirements for the degree of

Master of Science

in

Speech-Language Pathology

Department of Communication Sciences and Disorders

University of Alberta

© Kelsey F. Earle, 2015

Abstract

This study examined the protective and vulnerability factors operating in the lives of individuals with dementia and their care partners. Semi-structured interviews were conducted with two participants with dementia and five care partner participants. Screening measures were also completed with the participants with dementia to assess cognition, mental health, quality of life, communication, and relative saliency of factors previously identified in the literature. Factors identified by participants with dementia were: ‘Communication’, ‘Family and Friends’, ‘Perspective and Attitude’, and ‘Quality of Care’. Factors identified by care partner participants were: ‘Communication’, ‘Understanding Dementia’, ‘Relationship’, ‘Quality of Care’, and ‘Care of Self’. Based on these factors, this study also identified the possibility of clinical intervention by speech-language pathologists and other health professionals that may help to support or foster resilient behaviour in this population.

Preface

This thesis is an original work submitted by Kelsey F. Earle. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name "Resilience in Dementia-Perspectives on living with dementia" No. 00051564, October 28th, 2014.

Acknowledgements

"Frodo wouldn't have got far without Sam"

(Tolkien, 1982)

I would like to extend my thanks to all of the people who have lent their support and encouragement to me throughout this thesis journey. Firstly, I would like to thank my thesis supervisor, Dr. Teresa Paslawski, for her continual support and guidance throughout this process. Thank you for always having my back.

I would also like to thank the members of my committee, Dr. Tammy Hopper, Dr. Wendy Duggleby, and Dr. Carol Boliek for their interest in and support of this project. Their perspicacious questions and thoughtful commentary helped me to learn and grow as a researcher and student.

My heartfelt thanks go out to the participants of this study. It was a privilege for me to hear their stories, and this study would not have been possible without their willingness to share their experiences.

Finally, I would like to thank my friends and family for their support over the last three years. This has been an exciting and challenging journey, and I wouldn't have gotten very far without such an amazing group of people at my back. Thank you for your understanding and patience.

Table of Contents

Abstract .... *ii*
Preface .... *iii*
Acknowledgements .... *iv*
List of Tables .... *viii*
Chapter 1: Literature Review 1
  Introduction 1
  Resilience 2
  Resilience in Adult Populations 4
  Dementia 5
  Resilience and Dementia 7
    Resilience in care partners. 7
    Individuals with dementia. 8
  Research Questions 9
Chapter 2: Methodology 10
  Position of the Researcher 11
  Method 11
    Participants. 11
      Inclusion criteria. 11
    Recruitment. 11
    Data collection. 12
    Screening measures. 12
    Semi-Structured Interviews. 13
    Consent. 13
    Session location. 14
    Protection of confidentiality. 14
    Data analysis. 14
      Transcript analysis. 14
      Reliability and validity. 15
Chapter 3: Results 16
  Demographic information 16
  Screening Measures 16

Factors questionnaire 17
Interview Data: Individuals with Dementia 18
  Communication. 19
    Difficulty with expression 19
    Support in communication. 20
  Family and friends. 20
  Perspective and attitude. 20
  Quality of care. 20
    Activity and social group. 20
    Exercise. 21
    Choice and autonomy 21
Interview Data: Care Partners 21
  Communication. 23
  Understanding dementia. 23
    Quality of information 24
    Translation of knowledge into practice 24
    Person vs. disease. 25
  Relationship. 26
    Stable and responsive community. 26
    Connection with the individual with dementia. 27
    Faith. 27
  Quality of care. 28
    Appropriate level of care. 28
    Appropriate interaction 29
  Care of self. 30
    Expectations of self. 30
    Perspective. 30

Chapter 4: Discussion 32

  Interpretation of Screening Measures 32

  Interactions Between Factors 33

    Individuals with dementia. 33

    Care partners. 34

      Understanding dementia. 34

      Quality of care. 36

      Communication. 37

    Care partners and individuals with dementia. 37

      Communication. 37

      Quality of care. 38

      The role of perception. 38

  Areas of Similarity and Difference with Previous Research 40

    Individuals with dementia. 40

    Care partners. 41

      Communication. 41

      Understanding dementia. 42

      Relationship. 42

      Quality of care. 43

      Perspective. 43

      Culture and language. 43

  Implications for Clinical Practice 44

  Limitations and Directions for Future Research 47

    Factors affecting resilience. 49

  Conclusion 51

References 53

Appendix A 60

Appendix B 61

Appendix C 63

List of Tables

Table 3.1: *Demographic Information*

Table 3.2: *Screening Measures*

Table 3.3: *Factors Questionnaire*

Table 3.4: *Factors and Sub-Factors: Individuals with Dementia*

Table 3.5: *Factors and Sub-Factors: Care Partners*

List of Figures

Figure 4.1: *The Role of Perception*

Figure 4.2: *Implications for Clinical Practice*

Chapter 1: Literature Review

Introduction

Resilience is a dynamic pattern of behaviours that protect humans from succumbing to the negative effects of adversity. Early work in the field of developmental psychology found that, in groups of vulnerable children at risk for negative psychosocial outcomes due to the presence of adverse life circumstances, some individuals were able to grow and develop typically and avoid negative outcomes, namely psychopathological conditions (Werner & Smith, 1982). Subsequent examination of resilience led to further study of how it operates in other populations (Masten & Powell, 2003). Though resilience was originally viewed as a unique and immutable personality trait present in a select few individuals (Garmezy, 1974; Werner & Smith, 1982), more recent studies have defined it as a dynamic and fluid pattern of behaviours. It was also found that resilience is not rare, but quite common, leading Masten (2001) to refer to it as "ordinary magic" (p. 227), as it is frequently observed but still remarkable. Resilient behaviour patterns, however, do not exist in a vacuum, but rather are influenced by a multitude of factors. Some factors support or foster resilient patterns of behaviour and are referred to as protective factors, while others inhibit or disrupt resilient behaviour patterns and are referred to as vulnerability factors (Rutter, 1985). Protective and vulnerability factors have been shown to operate at multiple levels, from the individual to the family through to the community (Luthar, Ciccetti, & Becker, 2000). In addition, protective and vulnerability factors can often be conceptualized as positive and negative extremes on a continuum of the quality they represent (Richardson, 2002). The effect that these factors have on the development of resilience has been shown to be a process that takes place across the lifespan, from childhood to the end of life (Gilgun, 1999).

The aim of this study was to examine the ways in which resilience is experienced and understood by individuals with dementia and their care partners, and to identify the protective and vulnerability factors that operate in the lives of these individuals. In spite of the widespread loss of cognitive function that is the hallmark of dementia (Alzheimer's Society of Canada, 2013), individuals with mild, moderate, and severe dementia have been shown to demonstrate resilient behaviour patterns (Harris, 2008), and are still able to maintain hope in the context of their condition (Wolverson, Clarke, & Moniz-Cook, 2010). A more detailed understanding of protective and vulnerability factors and their influence on the lived experience of adults with dementia may assist health professionals in a variety of fields in providing care that will support the maintenance and development of resilient behaviour patterns and minimize the effects of vulnerability factors.

Resilience

In his meta-review of literature in the field of resilience, Richardson (2002) classified the study of resilience into three distinct waves. The “first wave” (p. 308) of resilience research, which included the foundational work of Garmezy (1974), Anthony (1974), Rutter (1985), and Werner and Smith (1982) in the field of developmental psychology, was concerned with trying to discover the personality traits that enabled some individuals to respond more positively to adversity than others. Specifically, these early studies examined the positive developmental outcomes seen in children in diverse contexts who were at risk of negative psychosocial outcomes due to the presence of various risk factors in their lives. Richardson also identified a “second wave” (p. 308) of resilience literature, which defined resilience as a process rather than a set of personality traits, and a “third wave” (p. 308) that examined resilience as a postmodern construct. In addition, he noted that research into resilience is consistent with the shift towards the study and application of positive psychology in the field of counselling psychology, which focuses on examining mental processes and healing by identifying an individual’s strengths and competencies and supporting the growth and maintenance of those strengths as a means of treating illness. This approach is directly in contradiction with the previous medical model in psychology, which focused on the identification of weakness and disability (Richardson, 2002; Snyder & Lopez, 2005). In addition, the study of resilience has also focused on the identification of competence and the exploration of individual behaviours which promote positive response to adversity, and which can inform the development of prevention strategies and policies (Masten & Powell, 2003).

Resilience has been commonly defined as a positive outcome in spite of the presence of adversity. The essential components of a definition of resilience, therefore are: i) the presence of adversity and, ii) a positive outcome (Masten, 2001). In the early resilience literature, those with resilient outcomes were viewed as individuals who possessed a unique set of personality traits from birth which enabled them to flourish despite significant risks to their development (Garmezy, 1974; Werner & Smith, 1982). More recent literature has discovered quite the contrary, namely that resilience is a human response to adverse circumstances that can be demonstrated by any individual in a given circumstance. This is a shift in thinking, as it indicates that fostering resilience relies on capacities that are inherent to human nature, not strange and exceptional traits that only a lucky few possess. In addition, it has been found that resilience is not a finite quality that an individual either has or does not have. Resilience varies within and across individuals, in the sense that an individual may show resilient behaviour patterns in some areas of their lives, but not in others (Luthar et al., 2000). In addition, resilience varies across time, with individuals demonstrating resilient behaviour patterns in a given situation at some points in time and not at others (Bonanno & Diminich, 2013).

Resilient behaviour patterns are affected by the presence or absence of protective and vulnerability factors. Protective factors, according to Rutter (1985), are those that somehow moderate or alleviate the effect of an event which predisposes an individual to negative outcomes. Vulnerability factors, on the other hand, are those that open an individual up to greater risk for negative outcomes, or increase the effect of predisposing risk factors (Rutter, 1985). Protective and vulnerability factors are often closely related, and can be seen as corresponding to the positive and negative poles on a continuum of a particular quality to which they both relate. ‘Having a supportive spouse’ and ‘living alone’, for example, could each be seen as the positive and negative poles on a continuum of ‘supportive relationships in the home environment’ (Richardson, 2002). In addition, the effects of protective and vulnerability factors are not limited to the individual, but operate across many levels, including family and sociocultural environment (Luthar et al., 2000) and their effects may persist and fluctuate across the lifespan (Luthar et al., 2000; Gilgun, 1999).

Though the study of resilience has most often been applied to children and young adults (Rutter, 1985; Luthar et al., 2000; Masten, 2001), there has been a growing move to utilize the distinct perspective provided by this approach to examine responses to adverse circumstances in older adults. Past research has examined the nature of resilience in adulthood by pairing it with other perspectives such as reserve capacity (Staudinger, Marsiske, & Baltes, 1993), successful aging (Wagnild, 2003, Lamond et al., 2008), and quality of life (Hildon, Montgomery, Blane, Wiggins, & Netuveli, 2009). In the context of these other perspectives, it must be noted that, though resilience is in many ways compatible with these perspectives, it is not synonymous with them. In the case of reserve capacity, which can be defined as “the internal and external resources” (pg. 542) an individual can bring to bear on a situation at a given time (Staudinger et al., 1993), there is a good deal of compatibility with resilience. Reserve capacity, like resilience, highlights the possibility for positive adjustment during the aging process, and is a shift in thinking from the focus on decline in aging research. In this context, however, a successful outcome that indicates resilience in cognition is considered to be the maintenance of cognition, or a response to intervention which results in the “performance on the trained tests to levels approximating that displayed by the same subjects 14 years earlier” (Staudinger et al., 1993, p. 548). The same is true of the perspective of successful aging, which defines success in aging as the freedom from disease and other negative health outcomes (Wagnild, 2003, Lamond et al., 2008). In other words, resilience in aging is not getting old which, as Bonnano (2012) points out, is comparable to defining health as the absence of disease. Quality of life also has much in common with resilience, including a focus on the positive capabilities of individuals, but it departs from resilience in one critical way - resilience, though the way it is conceived by individuals can be affected by quality of life, is not contingent on having a positive self-concept of life, or a high quality of life. Indeed, Nygren and colleagues (2005) found that scores on a resilience measure had no correlation with perceived physical and mental health.

Resilience in Adult Populations

In the study of resilience in adults, the experience of adults with dementia is often overlooked (Easley & Schaller, 2003; Felten, 2000; Hildon, Smith, Netuveli, & Blane, 2008; Lamond et al., 2008; Wells, 2010) or directly excluded by when examined from specific perspectives (Hildon et al., 2009; Nygren et al., 2005; Staudinger et al., 1993; Wagnild, 2003). Though, as mentioned above, there is considerable overlap between resilience and other perspectives, such as quality of life and successful aging, the differences in perspective result in very different ways of conceptualizing and examining resilience. These differing definitions frequently do not allow for the possibility that individuals with dementia could demonstrate resilience, as they demonstrate the negative health outcome of having dementia.

Examining the life experience in adults solely through the lens of resilience, however, does allow for the inclusion of populations that are not necessarily free from negative health outcomes, such as those with neurodegenerative conditions (Hildon et al., 2008; Wells, 2010, Easley &Schaller, 2003; Felten, 2000; Nygren et al., 2005). Much of the work in this area also forms part of a body of research that has only recently begun to examine the experience of resilience from the patient perspective as understood and communicated by the patients themselves (Cotrell & Schultz, 1993), an approach that provides a unique perspective on the possible factors that influence individuals' levels of positive outcomes. Several factors have been identified as contributing to resilient behaviour patterns in adults, including previous experiences with hardship (Felten, 2000), family connection (Easley & Schaller, 2003), and emotional well-being (Lamond et al., 2008).

Dementia

Dementia is a general term that is used to describe a collection of neurodegenerative conditions which result in the gradual loss of a variety of cognitive functions (Alzheimer's Society of Canada, 2013). Incidence and prevalence of dementia are relatively similar across geographic regions; both increase as a function of the age of the population considered, and are highest in those over the age of 95 (Fratiglioni, De Ronchi, & Aguëro-Torres, 1999). If current Canadian estimates of incidence and prevalence remain stable, it is estimated that the proportion of the population diagnosed with dementia will continue to rise in the coming years (Canadian Medical Association, 1994). Among the many neurodegenerative conditions that result in dementia, Alzheimer's disease is the most common, accounting for approximately 64% of dementia diagnoses in Canada (Alzheimer's Society of Canada, 2013). The cause of Alzheimer's disease is unknown and, to date, there is no cure (Giannopoulos, Joshi, & Pratico, 2014). The disease progresses through early, middle, and late stages, and is characterized by gradual loss of memory and other cognitive functions such as judgement, reasoning, speech, and language (Alzheimer's Society of Canada, 2013).

The majority of studies on the nature and experience of Alzheimer's disease to date have focused on how care partners[1] of individuals with dementia experience and understand the disease and its impact (Balfour, 2014; Cherry et al., 2013; Cotrell & Schultz, 1993; Donellan, Bennett, & Soulsby, 2014; Duggleby, Schroeder, & Nekolaichuk, 2013; Duggleby, Williams, Wright, & Bollinger, 2009; Flynn & Mulcahey, 2013; O'Dwyver, Moyle, & Van Wyk, 2013; McCann, Bamberg, & McCann, 2015; Quinn, Clare, Pearce, & van Dijkhuizen, 2008). Though the research in this area has arisen from multiple perspectives and disciplines, much of this work has parallels with work in the area of resilience. In their study of the lived experience of care

---

[1] In this study, the term 'care partner' is used to identify any individual associated with or involved in the care of an individual with dementia. It is used in preference over the term 'care giver', as it recognizes the autonomy of the individual with dementia (Bryden, 2005).

partners of individuals with early onset dementia, Quinn and colleagues (2008) conducted interviews with care partners and identified four themes relating to their experience. These themes included difficulty understanding the disease, “changes in the relationship” (p. 772), coping strategies, and the “emotional strains” (p.774) of care giving. In their work exploring the hope experience of care partners of individuals with dementia, Duggleby and colleagues (2009) found that “fading hope” (p. 517) was a concern for care partners, and that care partners engaged in various behaviour patterns that helped them in “renewing everyday hope” (p. 517). In a later study interviewing care partners about their hope experience while caring for an individual with dementia in a long term care facility, Duggleby and colleagues (2013) found that a connection to the individual with dementia was as an integral part of the hope experience for care partners. Flynn and Mulcahey (2013) investigated the experience of care partners of individuals with early onset dementia from the perspective of care-giver burden, and found several factors that contributed to the physical, emotional, social, and financial aspects of burden. Though these four studies examine the experience of care partners of individuals with dementia through different lenses, they all use qualitative methods to explore the experience of care partners and discover ways to help them in their role. Flynn and Mulcahey (2013)’s work on burden can be seen as similar in many ways to the discussion of resilience, as factors that increase care-giver burden may also make it more difficult for care partners to demonstrate a resilient pattern of behaviour. The work in the area of hope also has many parallels with resilience, as hope is fluid and changes over time. This perspective allows for an examination of the experiences that help care partners to keep going, as well as those that make their role more difficult. Hope may differ from resilience in that it invokes a future that is “better” or “different from the reality of what is” (Duggleby et al., 2013, p. 4).

Qualitative researchers in a variety of fields have found that individuals with dementia, when they are willing to participate in research, are able to do so, and provide valuable information, independent of their cognitive state (Snyder, 2001; Wolverson et al., 2010; Schmidt & Paslawski, in press). In their 2010 qualitative study on the experience of hope in early stage dementia, Wolverson and colleagues (2010) found that the participants who volunteered for their study were able to provide information on a variety of themes, including personal meaning, resources, and potential barriers and facilitators to hope. Schmidt and Paslawski (in press) also found that adults participating in a qualitative study on resilience who demonstrated relatively severe cognitive impairment were able to interact with the researchers and provide meaningful information about the subject matter in question. In addition, despite the widespread loss of cognitive function that is the hallmark of dementia, Hopper, Bayles and Kim (2001) found that the nature of these losses is not predictable and consistent across the progression of the disease. In fact, at each stage there are many aspects of cognition that are preserved, such as procedural memory and ability to perform basic activities of daily living (ADLs). Many processes, such as the ability to understand and interpret the ways language is used socially (receptive pragmatics), as well as many nonverbal communicative behaviours such as smiling, waving, and shaking hands were preserved even until the late stage of the disease (Hopper et al., 2001).

Resilience and Dementia

The study of resilience in the context of dementia has been fairly limited and it has followed a trajectory similar to those of its component parts. That is to say, it first emerged from other perspectives such as successful aging and hope, was studied in care partners, and is now more recently being examined from the perspective of individuals with dementia themselves.

Resilience in care partners. In a study examining factors of risk and resilience in the context of suicidal ideation in care partners of individuals with dementia, O'Dwyver and colleagues (2013) found that several factors affected care partners' experiences of suicidal ideation. O'Dwyver and colleagues (2013) termed these factors "risk" (p. 756) and "resilience" (p. 757) factors, which can be seen as parallel to protective and vulnerability factors in the sense that "risk factors" characterized those who "experienced suicidal thoughts" (p. 756) and were classified as not demonstrating resilience, and "resilience factors" were factors that "foster[ed] carer's ability to cope with […] the challenges of caring" (p. 757). In an interpretative phenomenological analysis of care partners' experience, McCann and colleagues (2015) explored the factors that allow care partners to "develop the resilience to sustain their caring role" (p. 204). Both studies found multiple personal and environmental factors that affected care partners' ability to maintain their mental health (O'Dwyver et al., 2013) or their role as a care partner (McCann et al., 2015) Cherry et al. (2013) conducted a systematic review of the literature of care partners of individuals with dementia and, using Windle (2011)'s definition of resilience, attempted to identify factors that contributed to care partners' resilience. Windle (2011) defines resilience as "a significant adversity/risk, the presence of assets or resources to offset the effects of the adversity, and positive adaptation to or the avoidance of a negative outcome" (p. 163). Accordingly, Cherry et al. (2013) identified factors that affected care partners' ability to avoid negative outcomes associated with their caring role, such as depression and anxiety. Using a similar definition, Donellan et al. (2014) interviewed care partners of individuals with dementia and found a variety of factors that allowed them to classify care partners as resilient or not resilient. They characterized a resilient care partner as one who "stays positive and actively maintained their relationship" (p. 932). Unlike the current study, however, the above definitions of resilience do not take into consideration that a care partner could be 'doing okay' even in the context of negative outcomes such as depression and anxiety, or the loss of a relationship with the individual with dementia.

Individuals with dementia. Harris (2008) addressed the question of whether or not individuals with dementia could demonstrate resilient behaviour patterns. Working through the lens of successful aging, Harris (2008) attempted to challenge the paradigm which suggests that resilience or success in aging consisted of the absence of disease. Harris (2008) examined the cases of two individuals with dementia and found that they could, in fact, be considered to be demonstrating resilience, based on the criteria that they were 'doing okay' in the face of dementia, which constituted an adverse circumstance (Harris, 2008). Though the factors that supported resilience were different in each case, both individuals were deemed to be resilient in the face of dementia. Since this initial proof of principle, there has been research focused both on the resilience of care partners of individuals with dementia (Cherry et al., 2013) and resilience as experienced by individuals with dementia themselves (Gilmour, Gibson, & Campbell, 2003; Bailey et al., 2013; Wolverson et al., 2010; MacKinlay, 2012; Angus & Bowen-Osbourne, 2014; Schmidt & Paslawski, in press). This body of literature is quite diverse, approaching the question of resilience from such perspectives as risk management (Gilmour et al., 2003; Bailey et al., 2013), hope (Wolverson et al., 2010), narrative theory (Angus & Bowen-Osbourne, 2014), and narrative theology (MacKinlay, 2012), however, there is a recognition in these studies that certain individual, social, and environmental factors help individuals with dementia to 'do okay'. There is also a recognized need for a more detailed understanding of how exactly individuals with dementia experience resilience and its operation in their lives, and what factors support or inhibit its development (Harris, 2008).

Research Questions

The study of resilience in individuals with dementia has shown that there are a variety of factors that contribute to resilient behaviour patterns in their daily lives. It has also demonstrated that patients with dementia have a unique perspective on the experience of living with the disease and the factors which support or inhibit their ability to exhibit resilient behaviour patterns following a diagnoses of dementia. Further research is required in order to identify the protective and vulnerability factors operating in the lives of individuals with dementia.

This study sought to answer the following questions:

1. What are the protective and vulnerability factors contributing to the resilience of adults with dementia?
2. What are the protective and vulnerability factors contributing to the resilience of adult care partners of individuals with dementia?

Chapter 2: Methodology

In resilience research, the examination of protective and vulnerability factors is typically undertaken from either a variable-focused or a person-focused perspective. Variable-focused research is driven by the detailed examination of the mechanics of resilience and how previously identified protective and vulnerability factors affect long-term outcomes, such as the development of psychopathologies. Person-focused research, on the other hand, is concerned with the identification of individuals with resilience and the attempt to establish which protective and vulnerability factors operate in the lives of those individuals in particular. The person-focused approach was chosen for this study, principally due to the lack of clear understanding about the exact nature of resilience in this population and the protective and vulnerability factors that may or may not be at play. A variable focused component was also included, in order to examine the relative salience of factors that have been identified in previous research, and to gain as complete an understanding of these experiences as possible. In the interest of maintaining an open definition of resilient patterns of behaviour, this study defined resilience as 'doing okay in the face of adversity', consistent with the definition found in Masten and Coatsworth (1998). Data were collected using semi-structured interviews of individuals with dementia and their care partners. Standardized screening tools to assess cognition, communication, depression and quality of life, as well as a short questionnaire assessing the relative importance of factors that have been previously identified in the literature as having an effect on the experience of resilience were also administered to individuals with dementia. Interview data were analysed using an interpretive description technique to identify factors that affect resilience. These data were compared with previous research in this area including a rating of relative salience of factors previously identified in the literature as having an effect on resilience.

The use of interpretive description allowed this study to ascertain the nature of resilience as experienced by individuals with dementia and their care partners, as well as the factors that they identify as supporting or inhibiting resilience in their everyday lives. Interpretive description is a process aimed at generating "a coherent report that depicts and links common elements of a clinical phenomenon" as well as "a mental heuristic that makes that new understanding accessible" (Thorne, 2008, p. 168). It is a methodological approach that is concerned primarily with finding and understanding the common experiences of individuals within a given population, such as resilience among individuals with dementia. Interpretive description is appropriate for this study, not only because of its focus on common factors, but also because of its unique clinical focus. Not only does it attempt to generate a coherent 'mental heuristic', but the heuristic generated from that process must also be "accessible to the *practitioner* [emphasis added] target audience" (Thorne, 2008, p. 168).

Position of the Researcher

Due to the qualitative nature of this examination of resilience, it is essential that I identify my position as a researcher and the ways in which my own life experiences and opinions may have shaped the outcomes of this study. The lived experience of dementia as I have seen it in my personal life and volunteer experience holds a deep interest for me, particularly the ways in which some individuals are able to 'do okay' in the face of such incredible adversity, while others are not. Throughout the course of this study, I have also come to believe that examining the experience of individuals with dementia and their care partners through the lens of resilience is an extremely valuable course of study. It is my hope that the results of this study can be used to affect necessary clinical and social change that can help to foster and support resilience in this population.

Method

Participants. Two individuals with dementia and five care partners were recruited for this study. This study was concerned primarily with the experience of resilience as a dynamic process that may fluctuate from one day or one situation to another. As such, participants were recruited solely on the basis of their dementia diagnosis, or their role as a care partner of an individual with dementia. Even if an individual does not, at present, believe themselves to be resilient, they are able to provide information of the factors that may be at play in their lives at other times (Schmidt & Paslawski, in press).

Inclusion criteria. In order to be included in this study, participants needed to have a diagnosis of dementia, or be a care partner of an individual with dementia. Study participants were required to agree to be audio- and video-taped during the interview and to participate in the interview without a family member or care partner present.

Recruitment. Convenience sampling was used to recruit participants that met the inclusion criteria. Following ethics approval from the University of Alberta Human Research Ethics Board, participants were recruited through the Edmonton Federation of Community Leagues. The recruitment letter outlined the purpose for the study as well as the inclusion criteria. Notification of this study and its inclusion criteria was included in the community newsletters of various neighborhoods in the university area, as identified from the City of Edmonton's list of registered community leagues (Edmonton Federation of Community Leagues, 2008).

Individuals interested in participating in the study were instructed by the recruitment letter to contact Dr. Paslawski, my thesis supervisor, on her private University of Alberta phone line and leave their contact information. I followed up with interested participants in order to confirm their interest and eligibility, provide additional information if required, and to set up an interview time. The two participants with dementia in this study, as well as three care partners, were recruited by word of mouth. Two of the individuals with dementia connected to the care partners were excluded from the study; one was unavailable due to geographical distance, and the other was excluded due to concerns about capacity to consent to participation

Data collection. The data collected from individuals with dementia in this study included basic demographic information (age, gender, marital status, level of education, working diagnosis of dementia), semi-structured interview responses, and standardized measures pertaining to participants' level of cognitive impairment, depression, and quality of life. In addition, participants with dementia were asked to complete a short questionnaire rating the relative importance of factors previously identified in the research as having an effect on semi-structured interview responses only.

Screening measures. The Montreal Cognitive Assessment (MoCA; Nasreddine et al., 2005) is a rapid screening tool for mild cognitive impairment, and was used as a means of understanding study participants' basic level of cognitive impairment. Scores below 26 out of 30 are considered abnormal on this measure. The World Health Organization Quality of Life – BREF (WHO QOL- BREF; World Health Organization, 2004) is a well-established and widely used assessment of quality of life. For the purposes of this study, this assessment was used to provide context in which to interpret how quality of life interacted with participant responses regarding resilience. The Geriatric Depression Scale (GDS; Yesavage & Sheikh, 1986) is a screening tool to detect depression in older adults. In this study, the shorter version of the GDS was used to determine the possible presence of depression, which may affect an individual's perception of their own ability to demonstrate a resilient behaviour pattern. The Arizona Battery of Communication Disorders of Dementia (ABCD; Bayles & Tomoeda, 1991) is an assessment tool designed to evaluate the communicative competence of individuals with dementia. This study used the Object Description Subtest of the ABCD to evaluate individuals with dementia's ability to use language to describe a concrete object (i.e. a nail). Knowledge of communicative competence, particularly in this area, helped to provide context to an individual with dementia's responses to interview questions.

A short questionnaire outlining factors previously identified in the literature as having an effect on resilient behaviour patterns in this population (Harris, 2008; Schmidt & Paslawski, in press) was also included (see Appendix B). Participants were asked to rate whether or not each factor contributed to their ability to demonstrate a resilient behaviour pattern. The factor of 'communication' was included in the questionnaire, as it has been previously identified as a concern for care partners of individuals with dementia in long-term care facilities in the context of hope (Duggleby, 2011), and which is of interest from a speech-language pathology perspective.

Data for this study was primarily gathered through semi-structured interviews (Appendix A) developed from previous projects examining resilience in adults with dementia and following review by a panel of experienced researchers. Questions in the interview were organized by levels that were identified in the literature as having an influence on resilience: individual, family, and community (Luthar et al., 2000).

Semi-Structured Interviews. The interviews with individuals with dementia lasted approximately 50 minutes, and the administration of the screening measures lasted approximately 40 minutes, for a total session length of approximately 90 minutes. The interviews with care partners lasted approximately 45 minutes. Data collection for each participant was completed in one session, with breaks as required. If necessary, due to fatigue or other factors causing the participant to wish to discontinue temporarily, it would have been possible to reschedule for a follow up session at a convenient time as close as possible to the original session date, but this was not required.

The interviews were video- and audio-recorded for the purposes of verification, and transcribed verbatim. During transcription, all identifying information was removed and pseudonyms and ID numbers were used to maintain confidentiality.

Consent. The consent form was reviewed with the participants prior to beginning each interview, and care partners of participants with dementia signed the consent form for each of the participants with dementia in order to ensure informed consent. Signed consent forms were stored in a locked cabinet at the University of Alberta, and a copy was given to each participant for their records.

Session location. Participants were given the option of having the session conducted in their homes or at the University of Alberta, wherever was most convenient for them. Four of the care partner participants chose to conduct the session at the University of Alberta and one chose to conduct the interview in their home. Both participants with dementia chose to conduct the session at their residence.

Protection of confidentiality. An ID number was assigned to each research participant. A master list with names and associated ID numbers was stored separately from other data related to the study in order to ensure confidentiality. All study data, including transcripts, used pseudonyms and ID numbers. The audio- and video-recordings of the interviews were only accessible to Dr. Paslawski and myself. The data were stored in a locked cabinet in the Department of Communication Sciences and Disorders at the University of Alberta, separate from the master lists, and will be destroyed in five years, in accordance with University of Alberta Human Research Ethics Board requirements.

Data analysis.

Transcript verification. Each interview was transcribed verbatim, based on the recommendations of Easton, McComish, and Greenberg (2000). Following the recommendations of Easton and colleagues (2000) and Maclean, Meyer, and Estable (2004), spot-checking by a second listener was employed for the purpose of accuracy using a sampling ratio of two or more minutes for every ten minutes of recording.

Transcript analysis. Thematic analysis was used to assess the interview data. Each interview was read several times and recurring comments, phrases, words, or concepts were coded and grouped into themes within interviews and across respondents. After themes were identified, they were then ordered into themes and subthemes independently by Dr. Paslawski and myself. In the case of differences in coding, or in the classification of themes and sub-themes, we discussed the data in order to reach a consensus on how best to represent the items in question. Themes derived from the data were operationally defined and agreed upon by both researchers, which ensured reliability of the coding system.

Reliability and validity. Of the seven processes for ensuring validity and trustworthiness of data outline by Holloway and Brown (2012), this study employs source and analyst triangulation, contextualization, and epistemological reflexivity. Following Patton's (1999) recommendation, triangulation of data sources ensured validity of themes identified in the data by taking into account the perspectives of multiple individuals with dementia and care partners. Analyst triangulation to ensure reliability was accomplished by two researchers analyzing the data in order to compare identified themes. Contextualization was ensured by utilizing screening measures in addition to the semi-structured interview. In addition, field notes outlining my impressions of the interview process were taken following every interview, and informed the data analysis process. Epistemological reflexivity was ensured by repeated questioning of the extent to which interpretations of the data had a solid base in the interview transcript and could in fact be known. Due to the progressive nature of dementia, member checking was not utilized in this study as a means of establishing validity.

Chapter 3: Results

The results of this study include demographic information and screening measures of quality of life, mental health, cognitive functioning, and communicative competence collected from two participants with dementia. In addition to the screening measures, themes were identified from semi-structured interviews conducted with individuals with dementia and their care partners. Themes were refined into factors and sub-factors.

Demographic information

Table 3.1 shows the demographics of the two participants with dementia in this study. The participants with dementia were aged 88 and 93 years. Both participants were female and living alone in a long term care facility. Both participants had been married; participant 1 was widowed, and participant 2 was separated from her husband. Participant 1 had received a grade twelve education, and participant 2 had received a grade eleven education as well as an additional college certificate.

Table 3.1

Demographic Information

Participant	Gender	Age	Marital Status	Education
1	Female	93;1	Married, husband deceased	Grade 12
2	Female	80;8	Single	Grade 11 and College Certificate

Screening Measures

The screening measures administered to the participants with dementia in this study screened quality of life using the World Health Organization Quality of Life (BREF) scale (WHOQOL-BREF; World Health Organization, 2004), mental health using the Geriatric Depression Scale (GDS; Yesavage & Sheikh, 1986), cognitive functioning using the Montreal Cognitive Assessment (MoCA; Nasreddine et al., 2005) and communicative competence using the Object Description Subtest of the Arizona Battery of Communication Disorders of Dementia (ABCD; Bayles & Tomoeda, 1991). A questionnaire assessing the relative salience of factors previously identified in the literature was also administered. Table 3.2 shows the results of these measures.

Table 3.2

Screening Measures

Participant	Montreal Cognitive Assessment (MoCA) Score	Geriatric Depression Scale (GDS) Score	Arizona Battery for Communication Disorders of Dementia (ABCD) Object Description Subtest Score	World Health Organization Quality of Life BREF Scores			
				Domain 1	Domain 2	Domain 3	Domain 4
1	6	7	5	63	69	69	88
2	6	9	2	44	50	69	56

Table 3.2: Cognition. *Both participants scored 6 on the Montreal Cognitive Assessment (MoCA). Scores above 26 on the MoCA indicate normal cognitive functioning.* ***Mental health.*** *Scores between 0-9 on the Geriatric Depression Scale (GDS) are considered normal.* ***Communication.*** *The average raw score obtained by typically functioning adults on the Object Description Subtest of the Arizona Battery for Communication Disorders of Dementia (ABCD) is 9.2 (2.2). The average raw score obtained by individuals with Mild Alzheimer's Disease on this subtest is 7.5 (3.1), and the average raw score obtained by individuals with Moderate Alzheimer's Disease is 4.2 (2.2).* ***Quality of life.*** *The World Health Organization Quality of Life-BREF (WHOQOL-BREF) yields a scaled score in each of the four domains of Physical Health (Domain 1), Psychological Health (Domain 2), Social Relationships (Domain 3), and Environment (Domain 4). Scores are scaled in a positive direction, with a maximum score of 100 in each domain. Higher scores on this measure indicate a higher quality of life.*

Both participants scored below the cut off of 26 on the MoCA, indicating that they both had cognitive functioning consistent with a diagnosis of dementia. Scores on the GDS indicated that both participants were within the range of normal on this measure of depression. Scores on the WHOQOL-BREF indicated that one participant believed they had a fairly high quality of life, while the other participant had a much lower quality of life.

Factors Questionnaire

When asked whether factors previously identified in the literature helped them ‘do okay’, the participants with dementia responded that 'keeping busy', 'being physically active', 'maintaining a positive attitude', 'accepting your diagnosis', 'being open about your diagnosis', 'being independent', and 'having information about dementia' all helped them to ‘do okay’. One participant said that 'having social connections' helped her to ‘do okay’, and the other said that they 'maybe' helped her. Table 3.3 shows participant responses regarding the relative salience of factors.

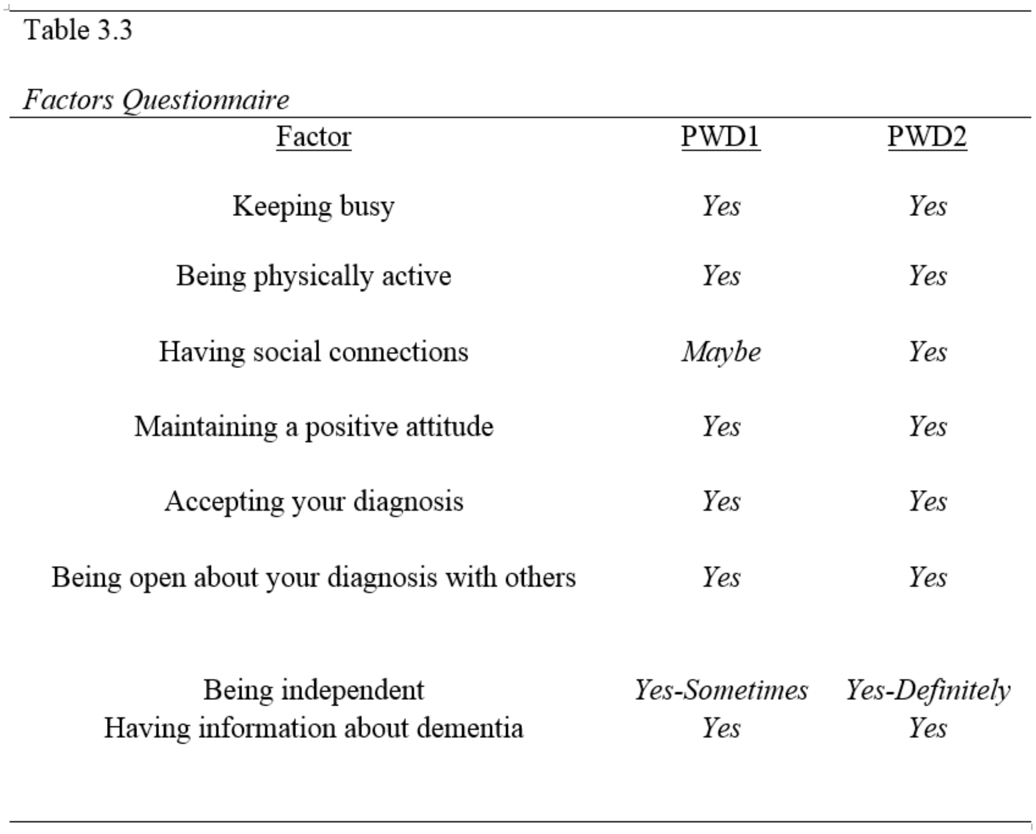

Table 3.3

Factors Questionnaire

Factor	PWD1	PWD2
Keeping busy	*Yes*	*Yes*
Being physically active	*Yes*	*Yes*
Having social connections	*Maybe*	*Yes*
Maintaining a positive attitude	*Yes*	*Yes*
Accepting your diagnosis	*Yes*	*Yes*
Being open about your diagnosis with others	*Yes*	*Yes*
Being independent	*Yes-Sometimes*	*Yes-Definitely*
Having information about dementia	*Yes*	*Yes*

Interview Data: Individuals with Dementia

The interview data from the participants with dementia revealed four main factors that affected resilience for these individuals. The main factors were ‘communication’, ‘family and friends’, ‘perspective and attitude’, and ‘quality of care’. The main factor of ‘quality of care’ was comprised of several sub-factors. These main factors and sub-factors operated at the levels of individual, family, and community. There is considerable interaction and overlap between these factors, but each one represents a main theme that was identified by participants. Protective factors, which support or enhance resilience, were those that participants identified as helping them to ‘do okay’. Vulnerability factors, which inhibit resilience, were those identified by participants as making it harder to ‘do okay’. Though the factors and sub-factors identified have the capacity to act as either protective or vulnerability factors, most factors and sub-factors were identified as operating predominantly as either a protective or vulnerability factor. An indication of the primary operation of each factor is provided in its description. Factors were not ranked in any particular order of importance. Table 3.4 illustrates the factors and sub-factors identified by individuals with dementia.

Table 3.4

Factors and Sub-Factors: Individuals with Dementia

Factor	Sub-Factors
Communication	*Difficulty with Expression* *Support in Communication*
Family and Friends	-
Perspective and Attitude	-
Quality of Care	*Activity and Social Group* *Exercise* *Choice and Autonomy*

Each of these factors and sub-factors may be considered as points on a continuum from protective to vulnerability. An indication of the primary function of each factor as identified by study participants is given in the descriptions. Participant quotes are used to help illustrate the essence of each sub-factor described below. For ease of reading, participant quotes have been italicized and all interjections, hesitations, and repetitions have been removed, so long as they did not change the meaning of the utterance.

Communication. 'Communication' was a predominant factor for one of the participants with dementia. 'Communication' refers to the act of transmitting a thought, idea, feeling, or emotion from one person to another. This factor was comprised of the sub-factors 'difficulty with expression' and 'support in communication'.

Difficulty with expression. This sub-factor, 'difficulty with expression', refers to any challenges an individual with dementia may have with verbally expressing their thoughts, ideas, feelings, or emotions to others. One participant identified difficulty in expressing herself in words as a vulnerability factor. Due to her difficulties in keeping track of the words she wanted to say, she struggled to express what she was thinking and feeling. She reported that this led to feelings of frustration, and made it more difficult to demonstrate a resilient pattern of behaviour:

> *But I have a hard time explaining a lot of things. If I'm trying to tell a story, and all of a sudden in the middle of it, I can't say what it is that I want, I don't know how to answer the questions they're telling me.*

Support in communication. This sub-factor, 'support in communication', refers to any attempts by others to assist the individual with dementia in verbally expressing their thoughts, ideas, feelings, or emotions. One participant identified support in communication from others as both a protective and a vulnerability factor. When family was present and able to speak on her behalf, or assist her in conversation, that was protective: *"Then mostly, if they're good friends or family, they fill in for me, lots of times."*

However, when others attempted to request clarification by asking questions, she was often unable to answer, and supports became a vulnerability factor:

> *...if I'm just snorting around and trying to say something, I might as well be quiet, cause I'll just get worse questions, and it depends on the questions. Sometimes, some are a lot harder than others. And it'll turn into another question, or else, forget about it.*

Family and friends. This factor, 'family and friends', was identified by both participants as affecting resilience in dementia. 'Family and friends' here refers to interaction and spending time with relatives and friends. For both participants, the 'family and friends' operated primarily as a protective factor when it was present, and a vulnerability factor when it was not: *"...the girls come lots, they really make that nice. The only thing is, they cut 'em [the visits] short."*

Perspective and attitude. The factor of 'perspective and attitude' refers to the general outlook that individuals with dementia have with respect to their condition and their reality. Despite differences in perspective and attitude between the two participants, both identified this factor as a protective one. For one participant, her self-identification as someone who was "*not a give up person*", as well as her desire to get well and "*try as much as [she] can*" were protective factors. For the other participant, it was her ability to take a wider perspective that was protective. Though she recognized that others were doing better than she was, she also recognized that there were others who were worse: *"...everybody I talk to seems to be in the same position, and I'm either worse or better from that section."*

Quality of care. The factor of 'quality of care' refers to the individual with dementia's perception of the standard of care they are receiving. The sub-factors identified by these participants were 'activity and social group', 'exercise', and 'choice and autonomy'.

Activity and social group. The sub-factor of 'activity and social group' refers to the opportunities presented to the individual with dementia to engage in meaningful activity, either independently or in a group setting. Both participants identified ‘activity and social group’ as a vulnerability sub-factor. They both spoke of spending time alone with nothing to do, or of a lack of activities to participate in: *"…but the whole day all to myself, for instance, is pretty boring. Well, not really boring either, it's [pause] not good, that's different than boring."* In addition, one participant identified the lack of social group in her facility as a vulnerability sub-factor:

> *…when I was home I could do more things, I was mixed up with more different friends and any bits that were things that I used to be in, even games and stuff like that…I can't do those things any more. I can, but I don't have the right crowd to do that in.*

Exercise. The sub-factor of ‘exercise’ refers to the opportunities presented to the individual with dementia to engage in physical activity. This sub-factor was identified by one participant as a vulnerability sub-factor, due to its absence. She felt that if she were able to walk around more, that this would be protective:

> *Well, if I could get out of this building, it would be easier. And try more. I loved walking, and I used to do a lot of walking…and when that went away…I could do less and less…and that made it harder.*

Choice and autonomy. The sub-factor of ‘choice and autonomy’ refers to the individual with dementia’s ability to make decisions about their lives and have others respect those decisions. This sub-factor was highlighted by one participant as a vulnerability sub-factor. This participant identified having others respect their choices and wishes as something that had happened in the past and would be protective if it were also happening now: “*Like, if I said, 'leave me alone', they left me alone, but they'd say 'what do you feel like today?', and I'd tell them. And they would believe me."*

Interview Data: Care Partners

Analysis of the interview data collected from the five care partners of individuals with dementia revealed five factors affecting resilience in dementia. These factors were ‘communication’, ‘understanding dementia’, ‘relationship’, ‘quality of care’, and ‘care of self’. Each of these major factors, with the exception of ‘communication’ was comprised of several sub-factors that operated at one or more levels, including individual, family, and community. These factors are not entirely mutually exclusive, however each sub-factor represents a prominent theme identified by study participants. Though the terminology used to describe these factors and sub-factors may appear to be quite similar, the descriptors were chosen to reflect the areas of nuance and distinction among the themes identified by the care partner participants.

Of the five care partners interviewed in this study, three were adult children of an individual with dementia, one was a sibling of an individual with dementia, and the other was a close friend and acting power of attorney of an individual with dementia. Due to the close relationships between care partner participants and individuals with dementia, care partner participants identified some factors that affected their own resilience as well as the resilience of the individual with dementia. In some cases, the perceived effects on the resilience of the individual with dementia in turn affected the resilience of the care partner participants. Where factors and sub-factors were identified by care partner participants as operating in this way, it has been noted in the description. Factors were not ranked in any particular order of importance. Table 3.5 displays the factors and sub-factors that were identified in this study.

Table 3.5

Factors and Sub-Factors: Care Partners

Factors	Sub-Factors
Communication	-
Understanding Dementia	*Quality of Information* *Translation of Knowledge to Practice* *Person vs. Disease*
Relationship	*Stable and Responsive Community* *Connection With the Individual With Dementia* *Faith*
Quality of Care	*Appropriate Level of Care* *Appropriate Interaction*
Care of Self	*Expectations of Self* *Perspective*

As in the previous section, each of these factors and sub-factors may be considered as points on a continuum from protective to vulnerability. An indication of the primary function of each factor as identified by study participants is given in the descriptions. Participant quotes were used to help illustrate the essence of each sub-factor described below. For ease of reading, participant quotes have been italicized and all interjections, hesitations, and repetitions have been removed so long as they did not change the meaning of the utterance.

Communication. The factor of 'communication' refers to any instance in which the care partner is attempting to transmit thoughts, ideas, feelings, or emotions to the individual with dementia, or vice versa. Participants identified communication as a vulnerability factor. Word-finding issues were identified as challenge when the individual with dementia was attempting to communicate. Sometimes this was a source of humour, but it could also make conversation difficult:

> *...she's lost a lot of her language, and she realizes she's using the wrong word, may start with the right alphabetical letter, and she'll say broom for bag...[after her perm] she had these little curls on her forehead, and she said 'these little, these little wieners up here', well [sister] and I just started laughing...*

Topic maintenance was also highlighted by participants as something that made it more difficult for the individual with dementia to communicate:

> *...if we're talking about this topic, and we do that for five minutes, then we go to this topic, and five minutes or so later, we go back to this first one, I'm getting a different story, it's not what we talked about the first time.*

Care partners also identified concerns in how to communicate with the individual with dementia. Some participants spoke of difficulty in knowing how to handle word-finding errors or poor topic maintenance, or how to respond to errors in memory retrieval, particularly when those issues surrounded a difficult conversation:

> *...every once in a while, she'll say 'am I in a place like dad was in? So what I need to know is, do I tell my mom, 'yeah, this is exactly the same thing' and break her heart, or do I change the subject, or what do I do?*

Another participant described her efforts to communicate her future intentions to her mother, despite her mother's difficulty holding on to such concepts:

> *...just making sure that I'm there, and phoning when I can't be there, and making it up, making that time up, and making sure that my mom knows that, even though she may forget, but somewhere in there, she remembers.*

Understanding dementia. The factor of 'understanding dementia' refers to the access to accurate information about dementia, as well as the ability to put such knowledge into practice in order to effect positive change in the lives of individuals with dementia and their care partners. This factor was comprised of 'quality of information', 'translation of knowledge into practice', and 'person vs. disease.'

Quality of information. The sub-factor of 'quality of information' refers to the ability of care partners and others to have access to reliable and accurate information about dementia, including its symptoms and progression. Participants identified ‘quality of information’ as both a protective and vulnerability sub-factor. The presence of reliable and accurate information that had been provided or verified by a health care professional was considered protective. Previous experience with dementia, and good quality information helped one participant to feel that they knew what was coming next, and that it helped them to feel better prepared:

> *…we went to an information thing, which was put on by the Alzheimer's Society, so we got a lot of information…we try to inform ourselves…so it wasn't like 'oh my gosh, what are we going to do?'. …we just knew this was coming with her…we knew what to do.*

The inability to identify which pieces of information were reliable and accurate, and which were not, served as a vulnerability sub-factor for another participant:

> *…we have so much information available…and we're all online…but we're doing it on our own, and it's like anything else, is it accurate?...I don't mind going and doing the work, I don't at all, but I'd really like to know that I'm going to the right sources…*

In addition, the absence of timely and accurate information from reliable sources about what to expect next in the progression of the disease and what impact the disease would have on an individual with dementia's living situation was identified as a vulnerability sub-factor. It contributed to difficulty in identifying strategies to deal with present behaviours: *"I don't know anything about dementia, except what I read on Google…I just don't understand her problem, except for the fact that she's in need of assistance."*

Translation of knowledge into practice. The sub-factor of 'translation of knowledge into practice' refers to the process by which accurate and reliable knowledge about dementia is used to inform larger practice decisions about programming and scheduling in care facilities, as well as practical day-to-day decisions made by care staff, and expectations of the behaviour of individuals with dementia in care facilities. Participants highlighted ‘translation of knowledge into practice’ as a vulnerability sub-factor; they felt that available knowledge was not always used by care staff to inform care decisions and expectations of the individual with dementia. As a result, participants felt the need to advocate for the individual with dementia:

> *...it's not reassuring to know that the people who are looking after these poor people are not educated...They've supposedly taken a course, but...the things they say, you think, 'no person with dementia could know that, so why would you be asking them that?'*

The need to advocate, while it was viewed by one participant as "*moving in a good direction*," was a source of stress for another participant, as she felt that she did not have the time or energy to advocate as effectively for her mother as she felt she needed to: "*...if I had time to write to the ombudsmen, Alberta Health Services, to write letters, to be a little more politically active, and I just can't, because I don't have the energy. Right now, my energy's with my mom."*

Person vs. disease. This sub-factor, 'person vs. disease', refers to the ability of care partners to discern which aspects of the behaviour of an individual with dementia are a result of their own thoughts, feelings, and personality, and which are the result of their dementia. This sub-factor was identified by all five care partners as a vulnerability factor. The difficulty in knowing which words or behaviours were accurate reflections of the individual with dementia's thoughts and feelings, and which were not, made it more difficult for the care partner to demonstrate a resilient behaviour pattern. In some cases, care partners struggled to deal with anger or hurtful comments directed towards them by the individual with dementia:

> *...this very gentle loving woman is now sometimes really angry, and...when it's directed at me, I know it's the disease, but it's really hard to have her say unkind things. You think you could just separate that, but when it's directed at you it's hard.*

In other cases, care partners were trying to understand and deal with challenging social behaviours that they believed could not be appropriately addressed because they were part of the individual with dementia's personality: *"...I guess the answer would be nothing, just leave her alone, don't see her. Or maybe go every day. They're both wrong, you know. It's just the way she is."* Another individual found it helpful to conceptualize challenging behaviours in the context of the disease in order to help understand the individual with dementia:

> *...he was annoying his wife to no end because, let's say, over the breakfast table, he would line up all the boxes; cereal, butter, jam, whatever, so their labels faced him. ...and I said, 'no, no, no, it seems to me that he is losing track of the world, and this is something he can do to put some order back into it'.*

Relationship. The factor of 'relationship' refers to the complex network of social and spiritual connections that exist in the lives of care partners and individuals with dementia. Care partner participants identified several different types of relationships that contributed to resilience in dementia. The sub-factors included in 'relationship' were 'stable and responsive community', 'connection with the individual with dementia', and 'faith'.

Stable and responsive community. The sub-factor of 'stable and responsive community' refers to the collection of individuals involved in the lives of care partners who provide support to them in their interactions with the individual with dementia. When these networks supported resilience, they provided ongoing support and adapted to fit the changing needs of care partners and individuals with dementia throughout the progression of the disease. Participants identified family support and outside support networks (e.g. church groups, other care partners, etc.) as the elements of a stable and responsive community.

Family support for care partners came either from siblings supporting one another in the care of a parent with dementia, the support of a care partner's own nuclear family in the care of the individual with dementia, or both. Support from the care partner's own nuclear family was identified by participants in this study as a protective sub-factor. In the cases where siblings were working together to care for a parent with dementia, participants identified this support system as operating as both a protective and a vulnerability sub-factor. When the sibling network was able to work as a team to provide care, it was protective: *"... [siblings] are very supportive of me. Very supportive of me."* However, when members of that care team were at odds about how to provide care, or about the appropriate level of involvement in care, this network became a vulnerability sub-factor:

> *... [older sibling] doesn't see it as her responsibility to do the day to day stuff. ...so she was taken off the [contact] list, and...I basically told her, 'you start participating, you get back on the list'. So that hasn't happened.*

Most participants identified outside support networks as consisting of individuals with shared experience, such as family members of other residents in a long term care facility. Relationships built on shared experience acted as a protective sub-factor for care partners by reducing feelings of isolation:

> *I'm watching all these other residents and their families, and people coming to visit, and trying really hard to engage with the other residents who are in there, and other families and so on, that's a really good thing, is to have a cadre of people who get it…*

For other participants, outside support came from other community connections or from professionals who were able to advise them in financial and legal matters that were bound up in their care of the individual with dementia.

Connection with the individual with dementia. All of the care partner participants in this study had some kind of close, long-term relationship with an individual with dementia. The quality of connection experienced in this relationship in the context of dementia was a sub-factor identified by participants as one that affected their resilience. All participants had experienced a change in their connection to the individual with dementia as the illness progressed. Each of the participants noted a kind of loss: *"My mom is my mom, but…part of her is gone, you know what I mean?"*

Whether the connection with the individual with dementia was a protective or vulnerability sub-factor for care partner participants depended on how that connection had been maintained. Some participants were able to foster and maintain a close personal connection to the individual with dementia, and felt that they still had a good relationship with them: "*She's always really happy to see me, I'm always delighted to see her, you know, we have a really loving relationship, and we always have had."* For others, the loss associated with dementia had severed connection, and caused the relationship with the individual with dementia to deteriorate: *"I guess what I'm saying is there's no relationship, really. There used to be."*

Faith. The sub-factor of 'faith' was identified by three participants as impacting their resilience, or that of the individual with dementia. Faith was described either as a relationship with others of the same faith, as a personal relationship with a deity, or both. It operated as a protective or a vulnerability sub-factor, depending on the nature of the relationship. For some participants, the connection to a higher power, and to a faith community was a protective sub-factor: *"Well, I really have a strong faith, which really, I draw on that."* For another participant, her own faith was also a protective factor for her, yet she believed that her mother's personal relationship with a deity was a vulnerability factor for her mother and, consequently, for her:

> *I've thought about talking to her about [going to heaven], in fact I did once, she was crying, she was really upset, and I said, 'Why don't you talk to God?', and she said 'He's not that kind of guy', and I said, 'oh, okay'. I have to remember that she's Catholic.*

This complex factor interaction will be expanded upon in the discussion of interactions between factors.

Quality of care. All of the participants in this study were connected to an individual with dementia who was receiving care in a facility that was not their home. The factor 'quality of care' refers to the nature of care and interaction that care partner participants felt the individual with dementia was receiving in a care facility. Participants highlighted a variety of aspects of the quality of care that the individual with dementia was receiving in their place of residence as factors that affected their resilience as well as that of the individual with dementia. The sub-factors of 'quality of care' included 'appropriate level of care', and 'appropriate interaction'.

Appropriate level of care. The sub-factor of 'appropriate level of care' was identified by care partner participants as care that was efficiently allocated and administered in a way that respected the dignity and personhood of the individual with dementia, taking their unique needs, history, and personal characteristics into account. This acted as a vulnerability sub-factor when participants felt that the needs of their family member with dementia were not being addressed in such a manner.

For some participants, options available for housing the individual with dementia and the process for deciding which facility to place an individual in were highlighted as vulnerability sub-factors:

> *...if I wouldn't go and live there, how could I possibly say yes? And their directive is 'you must take the first available position...[or] you'll have to go back into the queue.' ...I'm not going to put her someplace bad just because it's the only place you say is available.' We have better ways.*

Some participants felt that resources were allocated in a very rigid manner, with little room for modification: *"The model that [is used] is...'here's an institution', and they stuff people in and make them fit..."*

One participant felt that treating all residents of a care facility with dignity and respect would be protective for both the care partner and the individual with dementia, and that a lack of dignity was incompatible with resilience:

> *...it's just personalizing and giving these people their dignity, instead of robbing it at every corner, which stings, I think, and goes back to resilience. How can you be resilient if you feel like your dignity's being smacked every five seconds? Those two are not compatible.*

Related to the concept of dignity was the idea of allowing the individual with dementia to contribute where they were able, which some care partner participants felt would help the individual with dementia to feel as though they were contributing in some way: *"...but she needs to feel like she's still useful. So that makes her feel better, if she feels like she can still contribute, right?"*

Personalized care that takes the individual's history and pre-morbid personality into account was also identified as impacting the resilience of care partners and individuals with dementia. When care staff did not know about the interests and personality of the individual with dementia, care partner participants felt they were less able to provide activities of interest, or to look for the roots of problematic behaviour and interactions: *"...let's see if we can get to the source of what's distressing her so much. She's usually not belligerent, so if she is, why don't we check and see what that is, instead of bulldozing?"*

Appropriate interaction. The sub-factor of ‘appropriate interaction’ was described as the extent to which the social interaction and activities made available to an individual with dementia were appropriate for their needs. Independent of the diverse needs of individuals with dementia, care partner participants identified ‘appropriate interaction’ as a vulnerability sub-factor, both for themselves and for the individuals with dementia. One participant felt that her mother was not necessarily comfortable engaging in group activities and, as such, would benefit from a more supported one-on-one or small group context where the activity was explained to her:

> *...they want her to participate in some group activity and they just say, 'do you want to go and do this craft?’ Well, for her, craft, when it comes into her brain, might be 'I don't know what a craft is', 'I'm afraid of this', or 'what if I look stupid and I don't know how to do it?’ It’s like they don't take that into consideration when she says, 'no, I don't want to do it'.*

Another individual believed her mother was more outgoing and would benefit from increased social interaction of any kind: *"...somebody coming to see her, that's the important thing, is just* *to have that time off the floor, somebody to do stuff with, go outside, you know, that kind of thing…"* These care partners felt that the individual with dementia was not receiving a level of interaction and activity that was appropriate to their needs.

Care of self. The final factor, 'care of self', refers to care partners' capacity to ensure that they are mentally and physically well while they are caring for the individual with dementia. For many participants, the act of caring for the individual with dementia was a mentally and physically exhausting task, and the majority of participants recognized the need for self-care strategies of some kind. The factor 'care of self' is broken down into the sub-factors of 'expectations of self' and 'perspective'.

Expectations of self. The sub-factor 'expectations of self' refers to the expectations care partners have of the ways in which they should be active in the care of the individual with dementia. Participants identified having appropriate expectations of self as a protective sub-factor. Participants also identified the need to remind themselves that expectations of self were personal, variable, and not related to the abilities of others:

> *…everybody doesn't have the same level of capability of dealing with it, so if you're anxious about it, it's a true emotion, don't beat yourself up about that, if you can't go and see them…if you're not that person, do not feel guilty about that. We have to look after ourselves too.*

In contrast, when participants felt that their own expectations, or those of others, for their involvement in the care of the individual with dementia were too high, 'expectations of self' operated as a vulnerability sub-factor: *"If I'm really tired, I probably shouldn't go visit her. 'Cuz it's draining. It is. And I kind of feel like I need to be upbeat with her, because she really picks up on nuances."*

Perspective. The sub-factor of 'perspective' refers to care partners' ability to identify and alter their perception of a situation. Due to changes in the individual with dementia and some of the challenging behaviours that result, care partners identified the need to step outside of a situation and remind themselves to think differently about it: *"So, it's like that part of my relationship with my mom has ended, and I'm the caregiver, so I concentrate on that."* When care partners were able to do this, the altered perspective was protective. In addition, care partner participants identified attitude as a protective sub-factor. For example, one participant said *"...you've got to keep a sense of humour, so that's a big deal..."* Maintaining a broad perspective and the ability to stay positive were reported as protective sub-factors.

This study identifies four main factors that affect the resilience experience of people with dementia: 'communication', 'family and friends', 'perspective and attitude', and 'quality of care' as well as five factors that affect the resilience of care partners of individuals with dementia and their perception of the resilience of the individual with dementia: 'communication', 'information and education about dementia', 'relationship', 'quality of care' and 'care of self'. These factors are comprised of multiple sub-factors, all of which operate at a variety of levels, including individual, family, and community. In addition, each factor and sub-factor operates as a continuum, with one end of the continuum representing protective factors which support the creation and maintenance of resilience and the other end representing vulnerability factors which have an adverse effect on the creation and maintenance of resilience. Factors and sub-factors have been discussed primarily as protective or vulnerability factors, according to the way in which they were defined by study participants. The following section will discuss the complex interaction that connects these findings, as well as their relation to previous literature, clinical practice, and future avenues of research.

Chapter 4: Discussion

Interpretation of Screening Measures

The two participants with dementia in this study demonstrated impaired language abilities as evidenced by their scores on the Arizona Battery of Communication Disorders of Dementia (ABCD; Bayles & Tomoeda, 1991). One participant scored 1.9 standard deviations below the mean for typical adults on the ABCD, and the other was 3.3 standard deviations below. In spite of these results, however, both participants were able to complete the data collection session in its entirety and provided valuable information about what it meant to them to be 'doing okay' and how things could be better for them. This observation is consistent with the literature regarding the value and feasibility of asking individuals with dementia to speak about their experience (Snyder, 2001; Wolverson et al., 2010; Schmidt & Paslawski, in press). It also provides a rationale for speech-language pathologists (SLPs) to be involved in this work, as our training and perspective allows us to assist individuals with communication disorders, such as those related to dementia, in sharing their experience.

It is interesting to note that, of the two participants with dementia in this study, the individual that scored lowest on all screening measures was also the participant who was the most positive in her interview. She spoke most about "*trying*", and felt she was "*doing okay"*. The ability to be 'doing okay' even in the context of a lower quality of life supports the conclusion that, while related, quality of life and resilience are different concepts. The presence of one does not necessarily imply the presence of the other, or vice versa. It is also of note that, though the first participant scored significantly higher on the ABCD, communication difficulties were most salient in her interview. If the scores on the ABCD subtest were considered in isolation, they would indicate that this is a strength of hers relative to the other participant. This difference indicates that an objective measure of an individual's functioning relative to their peers in a particular area is not always indicative of their personal experience or what they feel is making it harder for them to demonstrate a resilient behaviour pattern.

When asked about factors identified in previous research as contributing to resilience, both participants with dementia indicated that all of the factors identified in previous research operated as protective factors in their lives. The only possible exception is 'social connection', which one participant identified as 'maybe' being a protective factor. These results may suggest that factors identified in previous literature play a role in resilience, even if they were not mentioned in an interview setting. They also indicate a need for further investigation into the areas of discrepancy between interview and questionnaire data. In cases where participants did not speak about a particular factor, yet identified it as a protective factor in the questionnaire, it would be of use to know why this discrepancy occurred and if it is significant. It is possible, for example, that individuals with dementia responded positively to the questions out of a desire to be agreeable. It is also possible that, in spite of the efforts made to ensure comprehension, individuals with dementia did not understand what they were being asked, and so answered positively.

These screening results reinforce the importance of asking individuals with dementia specifically about their experience with resilience in dementia. While the screening results give an idea of an individual's functioning in a particular area, they do not allow for conclusions to be drawn about an individual's resilience or about the protective and vulnerability factors that may be at play in the lives of individuals with dementia. When taken together with the interview results, however, these screening results can help create a more complete picture of the resilience of individuals with dementia and the ways in which their levels of functioning in different areas influence their perception of what it means for them to 'do okay'.

Interactions Between Factors

The factors and sub-factors identified by participants in this study are not mutually exclusive entities. It is recognized that each factor has the potential to influence, and be influenced by, other factors. In some cases, the connections between factors were explicitly stated by study participants. It must be stated, however, that these connections are formed through inferences drawn from the data collected.

Individuals with dementia. 'Communication' was a major theme in the data collected from participants with dementia. It influenced other factors, and was influenced in turn. 'Perspective/attitude' influenced the way both participants with dementia spoke about communication. While they both highlighted communication concerns, each of them dealt very differently with those concerns, according to their perceptions of what was causing the difficulty and what might be an appropriate way to respond. One participant with dementia, for example, identified herself as someone who was very stubborn. Accordingly, her discussion of communication difficulties was peripheral to her discussion of her desire to walk. She spoke of a need to have care staff understand her, but did not express this as a fault in her own communication abilities, and she expressed a desire to keep trying. In contrast, the other participant with dementia expressed frustration around her own abilities to communicate and attributed the difficulty to something that was lacking in herself. She felt it was better to simply be quiet and stop trying, rather than to persist and have more questions as a result.

One individual with dementia identified ‘family and friends’ as impacting ‘communication’. For this participant, ‘communication’ was both a protective and a vulnerability factor. The presence of family and friends affected communication for this individual both in a positive and a negative way. Having family interpret or fill in for her made it easier to communicate, but the presence of family also required communication interactions to take place and led to the need for clarification questions, which were difficult for this participant and highlighted her communication difficulty.

Individuals with dementia also identified ‘communication’ as impacting ‘quality of care’. One participant with dementia mentioned specifically that she felt her quality of care would be improved if she could effectively communicate to others her desire to walk, and have them understand her. She also noted that it was better when doctors took her at her word and "*believed"* her. Both of these instances can be seen as examples of difficulties with communication affecting the care this individual perceived she was receiving.

These results indicate that, though the network of protective and vulnerability factors in the lives of individuals with dementia is complex, communication was central. The ways in which protective and vulnerability factors operate in the lives of these individuals are closely tied to their ability to transmit their thoughts and feelings to others.

Care partners. Three of the care partner participants in this study were adult children of an individual with dementia, one was a sibling of an individual with dementia who was geographically removed, and one was a close friend and power of attorney for an individual with dementia. In analysing the data collected from care partner interviews, it became clear that the resilience of care partners was quite complex. Care partner participants identified a number of interactions between factors, as well as interactions between their own resilience and their perception of the resilience of the individual with dementia.

Understanding dementia. ‘Understanding dementia’ was identified as impacting ‘communication’, ‘relationship’, ‘care of self’, and ‘quality of care’. Perhaps unsurprisingly, given that communication impairment is a central characteristic of dementia, care partner participants highlighted difficulties in communicating with the individual with dementia as a vulnerability factor. Many of the situations that were highlighted as examples by care partners stemmed from not understanding why an individual with dementia was exhibiting particular communication behaviours, what to do when those behaviours arose, or how to have conversations about important life events and experiences in the context of communication difficulties. While the difficulties participants experienced in these situations can be seen as related to ‘communication’, they are also a result of the care partners’ understanding about what changes to expect in an individual with dementia’s communicative abilities throughout the progression of the disease. They were also related to how much the individual with dementia was able to understand, as well as how their reduced cognitive capacity changed their ability to understand and use language socially (pragmatics), particularly in difficult conversations.

‘Understanding dementia’ was also at play in maintaining or adjusting expectations of how a relationship with the individual with dementia was going to look as the disease progressed. Specifically, knowing which behaviours were a result of the dementia and which resulted from the individual with dementia's true thoughts and feelings affected how care partner participants mediated their changing relationship with the individual with dementia. Care partner participants who demonstrated a more complete understanding of dementia spoke of knowing that a particular behaviour pattern was not characteristic of the individual with dementia and seemed more able to keep such behaviours from damaging their relationship with that individual. Care partner participants who did not demonstrate as complete an understanding of dementia seemed to attribute dementia symptoms more to an individual's personality, and noted that these behaviours had led to a deterioration of the relationship. This deterioration not only compromised the sub-factor ‘connection with the individual with dementia’, but it may also have affected ‘stable and responsive community’, preventing such a community from developing around the care partner and the individual with dementia.

‘Understanding dementia’ also impacted ‘quality of care’. Several care partner participants expressed concerns about the individual with dementia receiving appropriate levels of care and interaction from staff in care facilities. Part of this concern stemmed specifically from care staff lacking knowledge about the individual with dementia as a person. However, it was also in part affected by how well staff and families both understood the strengths and challenges individuals with dementia typically exhibit and the kind of care that would best optimize strengths and mitigate challenges. In particular, some of the difficulties that care partners identified under 'quality of care' were a result of how well care staff and care partners understood the communication abilities of individuals with dementia. Some participants, for example, noted a lack of education surrounding areas of communication in which individuals with dementia typically struggle and ways in which staff members can support individuals with dementia when communication breaks down.

'Understanding dementia' impacted 'care of self'. Care partners spoke of wanting to know what was coming next in the progression of dementia so that they could prepare. Care partners also shared that a more complete understanding of dementia would help mitigate their fears about the future. These fears related both to the health and well-being of the individual with dementia as well as the care partner's own health, including as the probability of developing dementia themselves. Again, 'understanding dementia' also encompassed an understanding of the particular communication challenges typically seen in dementia. Particularly, a more detailed understanding of the communication strengths and challenges in dementia would better enable staff and care partners to make care decisions that met the needs of the individual with dementia, and to effectively communicate those decisions in a way that the individual with dementia could understand, to the extent that understanding is possible. Such an adjustment in care could lead care partners to perceive that the individual is receiving adequate care and impact care partners' resilience by allowing them to feel that their involvement in the care of the individual with dementia is matched to the level of extra care the individual with dementia requires.

Quality of care. Care partner participants identified 'quality of care' as impacting 'care of self' and 'relationship'. When care partners spoke of their own expectations about their role in caring for the individual with dementia, there was often a juxtaposition between realizing that they were doing everything they were able to do while maintaining their own health, and yet feeling as though the care the individual with dementia was receiving was neither sufficient for their needs, nor tailored to their individual characteristics, strengths, and challenges. Perhaps unsurprisingly, the need for advocacy was directly related to 'quality of care'. When care partners felt that quality of care was insufficient, this increased their desire to advocate for the individual with dementia. When care partners were unable to advocate as effectively as they wished, this impacted their ability to maintain expectations of their own involvement in care for the individual with dementia that were commensurate with their abilities. This gap between expectations and ability had an adverse effect on ‘care of self’.

‘Quality of care’ also impacted ‘relationship’. Specifically, the sub-factor ‘appropriate interaction’ influenced the sub-factor ‘stable and responsive community’. Care partners felt that, when dignity had been preserved and the individual with dementia was engaged in meaningful activity, this contributed to the maintenance of community and connection.

Communication. ‘Communication’ impacted ‘relationship’, particularly the sub-factor of ‘connection to the individual with dementia’. Several care partner participants identified difficulties in communicating with the individual with dementia as affecting the quality of connection they had with that individual. Knowing how to have important conversations and knowing how to deal with socially inappropriate or confusing communicative behaviours and bridge communication gaps affected how well care partners were able to maintain a connection with the individual with dementia. It also influenced the extent to which the community surrounding both parties was able to be responsive to the changes that occurred in communication and support the maintenance of relationships.

These results indicate that, though the relationships and interactions between various factors identified by care partners were complex, ‘understanding dementia’, ‘quality of care’ and ‘communication’ had an effect on the operation of other factors. ‘Understanding dementia’ had by far the most diffuse influence on other factors, and appears to be a crucial factor in care partners’ resilience. It impacts ‘communication’, ‘care of self’, ‘quality of care’, and ‘relationship’. Additionally, through its impact on ‘quality of care’ and ‘communication’, ‘understanding dementia’ has an additional compounded impact on ‘relationship’

Care partners and individuals with dementia. In addition to the interactions within the factors identified by each group of participants, there were also connections between the factors identified by participants with dementia and those identified by care partner participants. The factors identified by care partners and individuals with dementia were not mutually exclusive, nor was the influence of individual factors limited to care partners or individuals with dementia. This section highlights the interaction across groups.

Communication. Both care partners and individuals with dementia indicated that difficulty with communication was a vulnerability factor. The sub-factor of difficulty with expression identified by participants with dementia can be seen as contributing to the difficulty that care partner participants experienced in communicating with the individual with dementia. In addition, the concern care partners expressed about how to respond to atypical communication behaviours or about having difficult conversations can be seen to impact the sub-factor of 'support in communication', in that this concern stemmed from a lack of appropriate strategies to support the communication of individuals with dementia, which may have affected the individuals with dementia's perception of whether 'support in communication' was a protective or vulnerability factor.

Quality of care. A connection can also be observed between 'appropriate interaction' identified by care partners and 'attitude and perspective' identified by individuals with dementia, in that the perspective or attitude of the individual with dementia will influence which kind of interaction would be considered most appropriate for them. For example, if an individual with dementia is high in extraversion, making them more "sociable and fun-loving" (Hermes, Hagemann, Naumann, & Walter, 2011, p. 367), then they may be more likely to desire large social gatherings and higher levels of social interaction than an individual with dementia who is higher in introversion.

The role of perception. At the outset of this project, the intention was to examine the factors that affected the resilience of individuals with dementia and their care partners, and possibly factors that affected both parties. In examining the data, however, it became clear that, in certain situations, certain factors had an after effect on the resilience of the care partner. That is to say that some factors could be argued to have first affected the resilience of the care partner and the individual with dementia. The care partner's perception of the subsequent change in the resilience of the individual with dementia in turn affected the resilience of the care partner. In the case of 'faith', for example, the relationship with a deity affected both the care partner and the individual with dementia. For one care partner, it was a protective factor, yet she felt that a relationship with a deity was a vulnerability factor for her mother, as it prevented her from seeking comfort from God in difficult times. This care partner's perception of faith as a vulnerability factor for her mother acted as a vulnerability factor for the care partner, regardless of its true operation in the life of the individual with dementia. This example is illustrated in Figure 1 below.

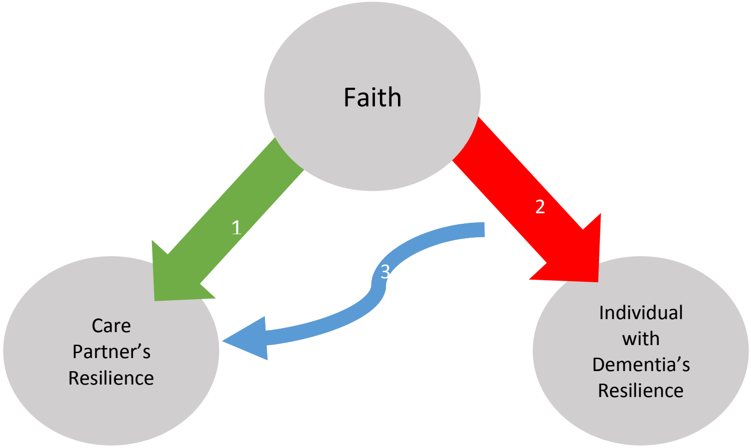

Figure 4.1: 1: *Faith as a protective factor for the care partner. 2: Faith as a vulnerability factor for the individual with dementia. 3: The care partner's perception of faith as a vulnerability factor for the individual with dementia in turn acting as a vulnerability factor for the care partner.*

Another example of this after effect can be seen in the case of 'family and friends'. The presence of family was a protective factor for both participants with dementia. All care partner participants indicated that they felt 'family and friends' was protective for the individual with dementia. This perception of what was protective for the individual with dementia in turn had an effect on the care partner's resilience. For example, one care partner expressed that she knew it was hard for her mother when she had to leave, and that her perception of the possible effect her presence or absence had on her mother's resilience in turn was a vulnerability factor for her. In this way, the care partner's perception of her mother's need for family and friends raised her expectations of her own involvement in her mother's care, which could affect this care partner's ability to care for herself. This interaction may be a result of the nature of the care partner relationship. This study investigated resilience specifically in the context of dementia, and because care partners and individuals with dementia are closely linked, when speaking of their own resilience in this context, care partners also spoke of the resilience of the individual with dementia. The care partner's perception of changes in the individual with dementia's resilience due to a given factor appeared to influence the resilience of the care partner, acting either as a protective or vulnerability factor in its own right. It appeared that a care partner's ability to demonstrate a resilient pattern of behaviour may be closely tied with their perception of the individual with dementia's ability to do the same. This complex relationship requires further investigation in order to reach more definite conclusions about the ways in which the perceived resilience of individuals with dementia has the capacity to affect the resilience of care partners.

Areas of Similarity and Difference with Previous Research

Individuals with dementia. Many of the factors and sub-factors identified by individuals with dementia in this study were quite similar to those identified in previous qualitative studies examining resilience in dementia from the perspective of the individual with dementia, though they often took on a different context, due in part to the nature of this sample. The sub-factors of 'choice and autonomy', 'exercise', and 'activity and social group', as well as the factors of 'family and friends' and 'perspective and attitude' are very similar to the factors of 'independence', 'participation', 'positive attitude', 'family and care partner support' found by Harris (2008) and Schmidt & Paslawski (in press), and 'physical activity' identified by Schmidt & Paslawski (in press). The main difference between these factors and sub-factors is the way in which participants identified them as operating in their lives. Participants in these two previous studies identified these factors as protective factors, with the exception of 'independence', which was identified as both. Participants in this study, however, identified all of these factors as operating as both protective and vulnerability factors, depending on the situation.

This difference may stem from the difference in participant living circumstances in each study population. The participants in Harris (2008) and Schmidt and Paslawski (in press) had a variety of living circumstances, but the majority of them were identified as living at home, or in the home of a care partner. The participants in this study differed from previous populations, in that they were both living in long term care facilities. This may indicate a difference in areas such as mobility or cognitive functioning which may have influenced the participants' perspective when considering factors such as 'exercise', 'activity and social group', and 'family friends', as individuals with dementia in this study were much more limited in their ability to be mobile, engage in physical activity, and maintain their social circles in the environment of a care facility. It may also influence the way in which the participants with dementia in this study spoke about the concept of independence. As they were no longer living in independent circumstances, their focus was more on having their choices and wishes respected, as opposed to remaining in independent circumstances for as long as possible. As a result, the participants with dementia in this study spoke of a desire to have more 'choice and autonomy' as opposed to a desire to maintain their independence for as long as possible. The discrepancies between these two groups again illustrate the ways in which resilience operates differently for different individuals; a protective or vulnerability factor in the life of one individual with dementia may not play the same role in the life of another individual.

Participants in this study, unlike participants in Harris (2008) and Schmidt and Paslawski (in press) identified ‘communication’ as a factor that affected resilience. Again, this may be a result of differences in participant characteristics. Participants in this study scored well below the typical adult average on the Object Description Subtest of the ABCD, indicating that they both had difficulty with word-finding. If participants in Harris (2008) and Schmidt and Paslawski (in press) were not experiencing the same degree of communication difficulties, it is possible that ‘communication’ was of less concern to them than to participants in the current study. The protective and vulnerability factors identified by individuals with dementia may vary depending on how far the disease has progressed, and what kinds of challenges individuals are facing in their lives as a result. Difference could also exist across different types of dementia. For example, fronto-temporal lobar dementia (FTLD) and early-onset Alzheimer’s disease can affect individuals at similar stages in their life, but result in very different experiences. An individual with FTLD, which includes progressive changes in personality and judgment as well as memory and language (Mahendra & Hopper, 2013) could have a significantly different perspective on their situation than an individual with early onset dementia who does not experience the same kinds of personality and judgment changes.

Care partners. While there has been very little qualitative research investigating the ways in which resilience operates in the lives of care partners of individuals with dementia (Schmidt & Paslawski, in press; Donnellan et al., 2014), many of the factors identified by care partners in this study have parallels in other fields. The following section outlines these parallels, as well as the differences between the current study and qualitative research with care partners in other fields.

Communication. Communication has been highlighted as an area of stress and concern by care partners in research into hope (Duggleby, 2011) and couple relationships (Balfour, 2014). In video exploring how to live with hope in the context of dementia, care partners identified communication and connection with the individual, “any little thing that lets you know [they are] still in there” as something that gave hope (Duggleby, 2011, 6:34). Balfour (2014) describes an intervention working with couples where one spouse has dementia and the other does not, and describes communication as an important aspect of maintaining relationship. Care partners in this study expanded on this theme, and described ‘communication’, particularly difficulty knowing how to respond to communicative difficulties or how to have difficult conversations, as a vulnerability factor.

Understanding dementia. The role of information and understanding in the lives of care partners has been somewhat unclear. Care partners in this study desired more information about dementia and felt that a greater understanding of the disease and its progression would be protective for them. However, the availability of quality information, and the translation of that knowledge into practice were both vulnerability factors for care partner participants in this study. Consistent with Quinn and colleagues (2008)’s findings, care partners specifically identified ‘person vs. disease’, not knowing which behaviours were symptoms of dementia and which were part of the individual with dementia’s personality, as being a vulnerability factor.

Relationship. Many studies with care partners have highlighted the importance of relationship in the lives of care partners and individuals with dementia (Balfour, 2014; Duggleby, 2013; Flynn and Mulcahey, 2013; O’Dwyer et al., 2013; Quinn et al., 2008; Cherry et al., 2013; McCann et al., 2015). Consistent with this diverse literature that points to the importance of relationship in the lives of care partners, care partner participants in this study identified ‘relationship’ and its sub factors of ‘stable and responsive community’, ‘connection with the individual with dementia’ and ‘faith’ as affecting their resilience. It is interesting to note Cherry et al. (2013)’s assertion that care partners speak about relationship and connection differently depending on their pre-morbid relationship with the individual with dementia (e.g. child, sibling, spouse). The differences between the results of this study and previous literature may be related to the fact that three of the five care partner participants in this study were adult child care partners, one was a sibling, and the other was a close friend with power of attorney. Care partner participants in this study, for example, did not speak of a loss of equality of relationship with the individual with dementia, but of a role reversal.

It is significant, however, that despite these differences, care partners in the previous literature as well as in this study speak of the importance of maintaining a connection with the individual with dementia. The identification of this factor in a wide variety of fields would suggest that finding ways to help care partners maintain connection with the individual with dementia would have a significant effect on the care partner experience.

Quality of care. Caldwell, Low, & Brodaty (2014) found that the kind of care an individual with dementia would be receiving factored into care partners' decision to place an individual with dementia in a long term care facility. This supports the conclusion that care partners are concerned about the kind of care that individuals with dementia are receiving in long term care facilities. Care partner participants in this study expressed a more detailed perspective of 'quality of care'. This may, in part, be due to the fact that all of the participants in this study were care partners of individuals with dementia who were in a long term care facility and, accordingly, had a different perspective. If an individual with dementia is already in a care facility, then it would be reasonable to assume that a care partner's perspective would shift from making a decision about placement to the outcomes of the decision they made. Participants in this study identified 'appropriate levels of care' and 'appropriate interaction' as vulnerability sub-factors of 'quality of care'. This indicates that, not only does quality of care factor into transitions in care for care partners, but it continues to affect their resilience even after the choice is made to place in individual with dementia in a long term care facility.

Perspective. Findings from research into hope indicate that 'perspective' plays a central role in the renewal of everyday hope for care partners of individuals with dementia (Duggleby et al., 2009). This is comparable to care partner participants' identification of 'perspective' as a protective factor in this study. In addition, care partner participants in this study identified 'expectations of self', specifically a disconnect between expectations and ability, as a vulnerability factor.

Culture and language. In addition to the factors outlined above, one care partner participant identified the role of culture and language barriers between care staff and individuals with dementia as a vulnerability factor. In particular, she indicated that differences in culture and language, when not recognized and dealt with accordingly, served as a barrier for understanding and good quality of care:

> *"...a lot of [staff] are [from a] different culture, so when the elderly are asking questions from their culture, from how they were brought up, they don't have a clue what they're talking about and they just answer any old thing. Or there's a language barrier."*

Research from Australia by Nichols, Horner, and Fyfe (2015) also indicates that cultural and linguistic differences between individuals with dementia and care staff present a difficulty, though they examined this issue from the perspective of care staff.

Implications for Clinical Practice

In outlining the clinical implications of this study, it is useful to consider the role of SLPs in fostering resilience in this population. According to Speech Pathology and Audiology Canada (SAC), SLPs are “autonomous professionals who have expertise in typical development and disorders of *communication* [emphasis added] and swallowing, as well as assessment and intervention for these areas” (Speech Pathology and Audiology Canada, 2015, p. 1). SLPs are uniquely placed to assist individuals with dementia and their care partners in navigating the inevitable communicative decline inherent in dementia. The specialized knowledge that speech-language pathologists possess in the area of communication, particularly the ability to help individuals communicate using alternative means such as drawing, gesture, or writing keywords (strategies for accessible communication, Communication Disabilities Access Canada, 2013) and exposure to individuals with language and communication difficulties, enable researchers in this profession to implement strategies that allow participants to express themselves more completely and provide meaningful information regarding their personal experiences (Schmidt & Paslawski, in press). In addition, these same strategies allow SLPs to address many of the concerns raised by participants in this study by directly targeting communication deficits in individual patients and providing strategies to help care partners and staff offset the effects of changes in the ability to use language socially. These strategies may focus around abilities such as recounting narratives, understanding of social language conventions, and using language to organize activities of daily living, all of which were identified by the care partner participants in this study as impacting resilience. SLPs are able to assist care partners in keeping the lines of communication open with the individual with dementia for as long as possible and potentially positively influencing their ability to demonstrate a resilient behaviour pattern.

Outside the central role as communication experts, the Alberta College of Speech-Language Pathologists and Audiologists (ACSLPA, 2015) has proposed six other roles that SLPs have in practice. These include the roles of Collaborator, Scholar, Communicator, and Advocate, among others. SLP practice in these roles has the potential to effect change in many of the factors identified by participants in this study. Figure 2 illustrates the potential ‘trickle-down’ effect that SLP intervention could have on the factors identified by participants in this study.

As Collaborators, SLPs have a responsibility to “provide speech-language pathology expertise in collaborative practice” (ACSLPA, 2015, p. 2), as Communicators, SLPs have the responsibility to “use language appropriate to the communicative situation [and] modify communication to minimize barriers due to diversity” (ACSLPA, 2015, p. 2). As Scholars, SLPs have the responsibility to “critically appraise research and other evidence in order to address client, service, or practice questions, share knowledge related to communication [and] develop and implement responsive teaching strategies” in order to facilitate “the learning of others” (ACSLPA, 2015, p. 3). This is to say that SLPs have a responsibility to share their expertise regarding communication difficulties with other professionals and staff, and to help teach others to apply appropriate communication strategies to offset those difficulties in everyday practice. These roles, when filled, impact the factor of ‘understanding dementia’ identified by care partner participants in this study. Specifically, SLPs can ensure that evidence-based information regarding communication difficulties in dementia is shared with other professionals and clients, impacting the sub-factor of ‘quality of information’. SLPs can also help teach others how to use strategies in communication with individuals with dementia to facilitate understanding, impacting the sub-factor of ‘translation of knowledge into practice’. The broad impact that ‘understanding dementia’ had on other factors and sub-factors in this study would make it an ideal target of clinical intervention, due to its potential to effect wide change in the lives of individuals with dementia and their care partners.

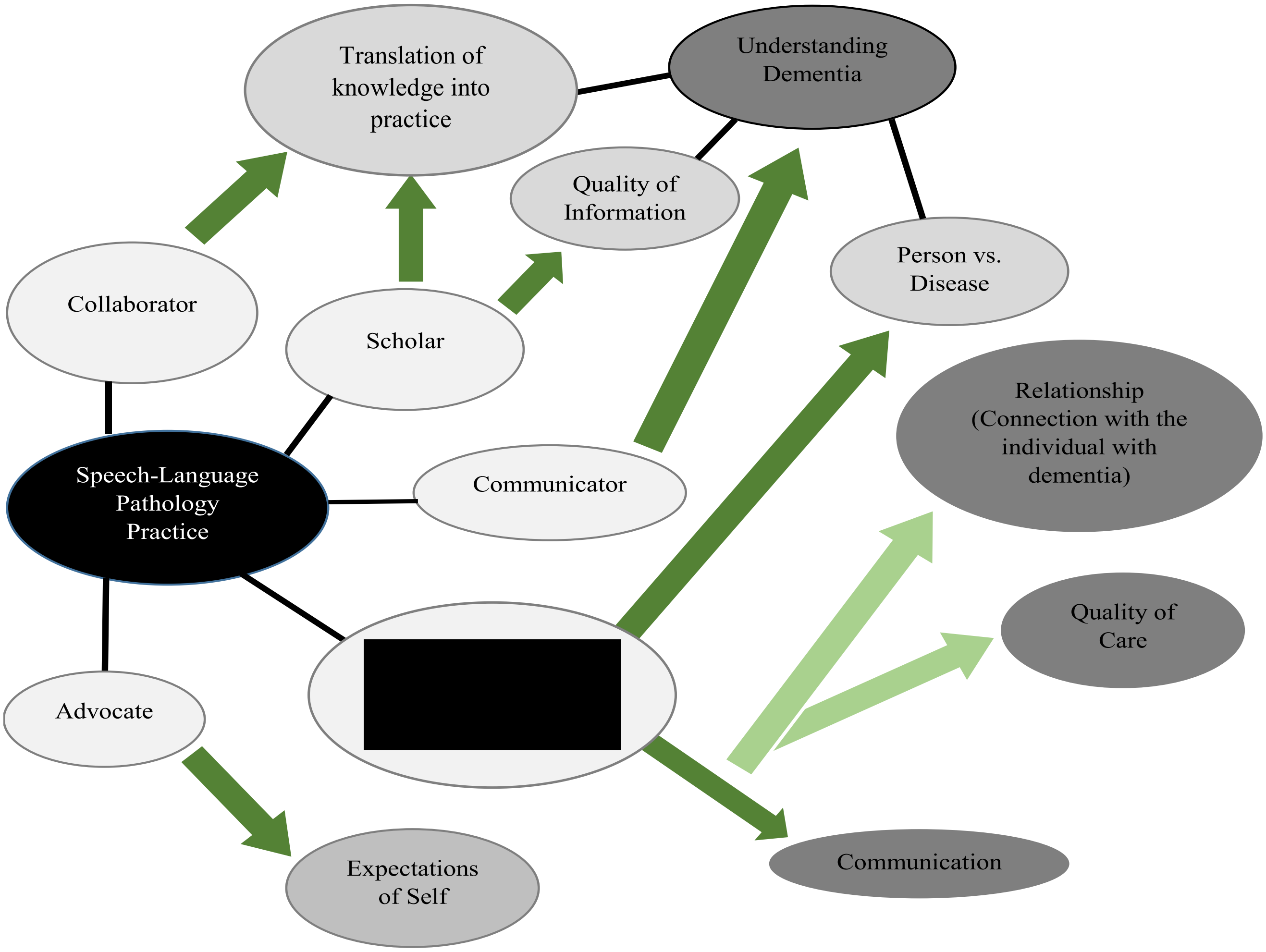

Figure 4.2: *Potential impact of speech-language pathology. If SLPs fulfill five of the seven roles outlined in the proposed ACSLPA competencies (shown in off-white), they have the potential to influence several factors(shown in dark grey) and sub-factors (shown in light grey) identified by care partners in this study. Note: Oval size in this diagram does not indicate the importance or salience of a given factor. Size was determined by spacing needs only.*

In addition to the roles outlined above, it is proposed that SLPs also fill the role of Advocate, to “identify and address client access barriers to services and resources, [and] advocate for services based on emerging trends and anticipated future needs of clients.” (ACSLPA, 2015, p. 3). While direct SLP intervention with a client or patient does not have an effect on policy decisions regarding long-term care facility staffing and design, our specialized training gives us a unique perspective that allows us to advocate for the needs of individuals with dementia and their care partners. It also allows us to educate colleagues, policy makers, and the public about the needs of individuals with dementia, and to work as part of a team to provide creative solutions to the unique logistical challenges identified by individuals with dementia and their care partners.

On a level of more immediate impact in the lives of individuals, participants in this study identified a number of protective and vulnerability factors that fall directly within the SLP's Central Role as communication experts. As professionals, SLPs have a role to play in helping to address these concerns by reducing the effect of these vulnerability factors and supporting protective factors through our direct clinical intervention.

Limitations and Directions for Future Research

This study's methods allowed for an exploration of the protective and vulnerability factors associated with resilience in dementia. However, there were some limitations to this study relating to procedures and to the population studied. Many of these limitations also allowed for the identification of several possible avenues of future research.

Due to convenience sampling, the sample size of this study size was quite small. As a result, the data collected in this study, particularly as it relates to individuals with dementia, may not represent the experience of all individuals with dementia or their care partners. In addition, there was considerable diversity in the relationships between care partner participants and individuals with dementia. Many of the individuals with dementia being cared for by care partner participants in this study were unavailable, either due to physical distance or lack of interest. The heterogeneity of the sample population in this study limits the conclusions that can be drawn about the ways in which resilience operates in the lives of individuals in specific types of relationships (e. g. siblings vs. adult children). While this heterogeneity may have prevented the identification of potential themes related to specific situations (e.g. being power of attorney for a friend with dementia vs. caring for a parent in a nursing home), this sample also reflects the diversity and complexity of relationships. Despite this, themes were still observed within the data of the care partner participants and between their data and that of the individuals with dementia. Future research may consider a more homogeneous sample with regard to the relationship between the care partner and the individual with dementia, as well as an even pairing of care partners and individuals with dementia. A more homogeneous sample would allow for more inferences to be drawn about the kinds of protective and vulnerability factors operating in the lives of individuals within a particular relationship category.

No demographic information was collected and no screening measures were conducted with care partner participants. This does not allow any conclusions to be drawn about the ways in which demographic factors or quality of life may inform the interview data collected from care partner participants. In particular, information about the level of education, family status (eg. married, with or without children), and current occupation of care partners would be of value in interpreting interview data. If, for example, a care partner is working a full time job and supporting a family of their own, does this affect their discussion of resilience? If an individual were to have a higher level of education, would that give them added benefit in such areas as 'understanding dementia'?

This study did not collect any medical information about dementia diagnosis. This may have affected the ways in which individuals with dementia spoke about resilience, as different types of dementia present with different progressions and have different communication difficulties associated with them. Future research in this area may specify the type of dementia and/or collect diagnostic information, as this would help ensure that protective and vulnerability factors identified by these individuals relate to a similar type of dementia.

Though it was not within the bounds of this study, the use of video data in conjunction with a system such as the Emotions Facial Action Coding System (Rosenberg, 2015) to analyse facial expression during semi-structured interviews may be valuable. Particularly in the case of individuals with dementia, where non-verbal forms of communication are often preserved into the later stages of the disease (Hopper, Bayles, & Kim, 2001), an examination of these aspects may help to inform participants' interview data and allow for a deeper understanding of participants' statements.

A further investigation of the discrepancy between factors that individuals with dementia identified as protective on the factors questionnaire and the data provided in interviews would also be valuable. If participants identified a factor as protective, but did not discuss it in the interview, how does that factor affect their resilience? Are there particular reasons why participants might not have mentioned particular factors in an interview setting? It is possible that this discrepancy is a result of the difference in cognitive load between an identification task (questionnaire) and a more difficult generative task (interview). However, a more detailed conversation about these factors would help to clarify the role of particular factors as it relates to resilience in dementia.

Factors affecting resilience. A more in-depth examination of the ways in which particular factors interact, would also help shed further light on the ways different protective and vulnerability factors affect resilience in dementia. The data collected in this study, for instance, suggested a possible interaction between ‘relationship’ and ‘care of self’ that may have implications for clinical practice in multiple disciplines. Given the possible complexity of this relationship, an exploration of how ‘relationship’ and ‘care of self’ interact and might be supported by a variety of professionals, including SLPs, nurses, and psychologists could be of high clinical value. In addition, the ways in which the fluctuating resilience of an individual with dementia, and the care partners’ perception of that fluctuation, affects the resilience of care partners would be a fascinating avenue for further research. How exactly does this interaction occur? Does the fluctuating resilience of the care partner affect the resilience of the individual with dementia in similar ways?

In considering how participants identified factors contributing to resilience, it became clear that where a participant placed a factor on the continuum from protective to vulnerability was influenced by their values. Values, according to Connor and Becker (1975), are “global beliefs about desirable end states underlying attitudinal and behavioural processes” (p. 551). That is, values affect one’s perception of what a good outcome will be. It would be understandable, then, that a care partner’s sense of what a desirable outcome would look like might influence how they saw a given factor as operating in their lives. In the case of ‘quality of care’, for example, a care partner’s perception of what kind of care the individual with dementia requires is driven in part by what they feel is more desirable in a given situation, such as whether personal security is more desirable than autonomy of the individual. It would be interesting to examine the ways in which value systems influence an individual’s resilience in the context of dementia.

In examining the connections between factors, it was also noted that knowledge, power, and control may influence resilience in dementia. If, as Foucault hypothesized, knowledge is the root of power (Polifroni, 2010), there are many possible ways in which power and control might influence resilience as it was discussed by participants in this study. This possibility is particularly apparent in relation to the factors of ‘communication’ and ‘information about dementia’. In situations where the care partner was responsible for important aspects of the individual with dementia’s life, such as power of attorney, it was observed that the care partner has the ability to control the flow of information between the individual with dementia, care staff, friends, family, and other care partners, and that this ability has the potential to be abused, to the detriment of the individual with dementia, or other care partners. One participant, for example, mentioned that a sibling had been removed from the facility contact list. Such a removal restricts the flow of information, and has the potential to be used in a punitive manner. If knowledge is the root of power, and is not shared with an individual with dementia or other care partners, those individuals are then rendered powerless. Power and control were also observed to be at play in a similar way in the interactions between care partners and health care professionals. Given the long history of research in the area of knowledge, power, and control (Polifroni, 2010), the specific cognitive and communication deficits associated with dementia, and the current discussion about mental capacity assessment in dementia (Moye, Marson, & Edelstein, 2013; Haberstroh et al., 2014, Kirschner, 2013), an examination of the interaction between power and resilience has the potential to be both fascinating and valuable.

The role of 'culture and language' in the resilience of individuals with dementia and their care partners may also be a valuable avenue of future inquiry. Though the factor of 'culture and language' was only salient for one participant in the current study, it is intriguing to consider the ways in which this factor may be influencing the resilience of care partners and individuals with dementia when cultural and linguistic differences are taken together with the pragmatic nature of communication deficits common in dementia. When an individual with dementia is experiencing difficulties with social uses of language, such as gauging appropriateness and politeness, cultural and linguistic differences could make communication with care staff of a differing cultural background more difficult.

A more detailed exploration of the factor of 'understanding dementia' would also be a beneficial focus of study. Given its broad impact on other factors and sub-factors in this study, intervention targeting this factor has the potential to affect the resilience of individuals with dementia and their care partners in a variety of ways. It is clear from the results of this study that, at some level, efforts to educate individuals with dementia and their care partners about what they can expect from a dementia diagnosis are not having the desired impact. A next step could be to examine why this is the case. An outline of the barriers and facilitators to understanding in this population could provide a more focused direction for possible clinical interventions and wider institutional policies regarding dementia education.

While the design of this study and the nature of the sample limited some of the inferences that can be drawn about resilience from the perspective of individuals with dementia and their care partners, it identified several factors and sub-factors that that operate in the lives of these individuals. It was able to identify several possible interactions between factors, as well as possible avenues for future research.

Conclusion

This study collected data from two individuals with dementia and five care partners. Through a thematic analysis of the interview data collected and contextualized using measures of communication, cognition, mental health, quality of life, as well as the relative salience of factors previously identified in the literature, this study identified several protective and vulnerability factors that impact the resilience of individuals with dementia and their care partners. The factors identified by individuals with dementia include ‘communication’, ‘family and friends’, ‘perspective and attitude’, and ‘quality of care’. Those identified by care partners include ‘communication’, ‘understanding dementia’, ‘relationship’, ‘quality of care’, and ‘care of self’. The operation of these factors and their sub-factors is quite complex. Each factor impacting resilience in this population affects and is affected by other factors. Due to the close nature of the relationship between individuals with dementia and care partners, factors identified by participants with dementia influence factors identified by care partners, and vice versa. In spite of the complexity and intricacy of these relationships between factors, this study also identified several ways in which the intervention of SLPS and other professionals could help to support protective factors and alleviate the effects of vulnerability factors. Intervention of clinical professionals, such as SLPs, specifically in the areas of ‘understanding dementia’, and ‘communication’ has the potential to create positive change in the lives of individuals with dementia and their care partners. The results of this study also highlight that asking individuals with dementia and their care partners about their resilience is essential. Screening measures that indicate an individual’s functional level compared to that of their peers is not always an accurate measure of what an individual believes helps them to demonstrate a resilient behaviour pattern. This study identified several possible avenues of research that may continue the exploration of resilience and the ways in which clinicians can support resilient behaviour patterns in individuals with dementia and their care partners. Taken as a whole, the results of this study indicate that an examination of the perspectives of individuals with dementia and their care partners through the lens of resilience is a valuable area of research. Moreover, there is a potential for clinical intervention by speech-language pathologists and other professionals that can affect positive change in the lives of these individuals by supporting their ability to ‘do okay’ in the context of dementia.

References

Alberta College of Speech-Language Pathologists and Audiologists (2015). Proposed Competency Profiles for SLP. Retrieved from: http://acslpa.ab.ca/download/college/Proposed%20Competency%20Profiles%20-%20SLP%20APRIL%202011.pdf

Alzheimer's Society of Canada (2013). About Dementia. Retrieved from: http://www.alzheimer.ca/en/About-dementia/Dementias/What-is-dementia

Angus, J., & Bowen-Osborne, S. (2014). A self-narrative of life-long disability: A reflection on resilience and living with dementia. *Dementia, 13*(2), 147-159. doi:10.1177/1471301212455121

Anthony, E.J. (1974). The syndrome of the psychologically invulnerable child. In E.J. Anthony & C. Koupernick (Eds.), The child and his family: Yearbook of the international association for child psychiatry and allied professions. (Volume 3, pp. 3-10). New York, NY: John Wiley and Sons.

Bailey, C., Clarke, C. L., Gibb, C., Haining, S., Wilkinson, H., & Tiplady, S. (2013). Risky and resilient life with dementia: Review of and reflections on the literature. *Health, Risk & Society, 15*(5), 390-401. doi:10.1080/13698575.2013.821460

Balfour, A. (2014). Developing therapeutic couple work in dementia care- the living together with dementia project. *Psychoanalytic Psychotherapy, 28* (3), 304-320.

Bonanno, G.A. (2012). Uses and abuses of the resilience construct: Loss, trauma, and health-related adversities. *Social Science and Medicine, 74*, 753-756.

Bonanno, G.A., & Diminch, E.D. (2013). Annual research review: Positive adjustment to adversity - trajectories of minimal-impact resilience and emergent resilience. *Journal of Child Psychology and Psychiatry, 54*(4), 378-401.

Bryden, C. (2005). Dancing with dementia: My story of living positively with dementia. London, UK: Jessica Kingsley Publishers.

Canadian Medical Association (1994). Canadian study of health and aging: Study methods and prevalence of dementia. *CMAJ: Canadian Medical Association Journal = Journal De L'Association Medicale Canadienne, 150*(6), 899-913. Retrieved from http://login.ezproxy.library.ualberta.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=cmedm&AN=8131123&site=eds-live&scope=site

Caldwell, L., Low, L.F., & Brodaty, H. (2014). Caregiver's experience of the decision-making process for placing a person with dementia into a nursing home: Comparing caregivers from Chinese ethnic minority with those from English speaking backgrounds. *International Psychogeriatrics, 26* (3), 413-424.

Cherry, M. G., Salmon, P., Dickson, J. M., Powell, D., Sikdar, S., & Ablett, J. (2013). Factors influencing the resilience of carers of individuals with dementia. *Reviews in Clinical Gerontology, 23*(4), 251-266. doi:10.1017/S0959259813000130

Connor, P. E., & Becker, B.W. (1975). Values and organization: Suggestions for research. *Academy of Management Journal, 18* (3), 550.

Cotrell, V. & Schulz, R. (1993). The perspective of the patient with alzheimer's disease: A neglected dimension of dementia research. *Gerontologist, 33*(2), 205-211. Retrieved fromhttp://login.ezproxy.library.ualberta.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=fcs&AN=6358374&site=eds-live&scope=site

Donellan, W.J., Bennett, K.M., & Soulsby, L.K. (2014). What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study. *Aging Mental Health, 19* (10), 932-939.

Duggleby, W. (2011). Connecting with hope. Retrieved from: http://www.nurs.ualberta.ca/livingwithhope/video.htm

Duggleby, W., Schroeder, D., & Nekolaichuk, C. (2013). Hope and connection: The experience of family caregivers of persons with dementia living in a long term care facility. *BMC Geriatrics, 13*(112). Retrieved from http://www.biomedcentral.com/1471-2318/13/112. doi:doi:10.1186/1471-2318-13-112

Duggleby, W., Swindle, J., Peacock, S., & Ghosh, S. (2011). A mixed methods study of hope, transitions, and quality of life in family caregivers of persons with alzheimer's disease. *BMC Geriatrics, 11*(88). Retrieved from http://www.biomedcentral.com/1471-2318/11/88. doi:10.1186/1471-2318-11-88

Duggleby, W., Williams, A., Wright, K., & Bollinger, S. (2009). Renewing everyday hope: The hope experience of family caregivers of persons with dementia. *Issues in Mental Health Nursing, 30*, 514-521. doi:10.1080/01612840802641727

Easley, C., & Schaller, J. (2003). The experience of being old-old: Life after 85. *Geriatric Nursing, 24*(5), 273-277. Retrieved from http://dx.doi.org.login.ezproxy.library.ualberta.ca/10.1016/S0197-4572(03)00246-5

Easton, K. L., McComish, J. F., & Greenberg, R. (2000). Avoiding common pitfalls in qualitative data collection and transcription. *Qualitative Heath Research*, 10, 703-707.

Edmonton Foundation of Community Leagues (2008). League Directory. Retrieved from: http://www.efcl.org/LeagueDirectory/tabid/120/Default.aspx.

Felten, B. (2000). Resilience in a multicultural sample of community-dwelling women older than age 85. *Clinical Nursing Research, 9*(2), 103-123. doi:10.1177/105477380000900202

Flynn, R., & Mulcahey, H. (2013). Early-onset dementia: the impact on family caregivers. *British Journal of Community Nursing, 18* (12), 598-606.

Fratiglioni, L., De Ronchi, D., & Agüero Torres, H. (1999). Worldwide prevalence and incidence of dementia. *Drugs & Aging, 15*(5), 365-375. Retrieved from http://login.ezproxy.library.ualberta.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=2009465502&site=eds-live&scope=site

Garmezy, N. (1974). The study of competence in children at risk for severe psychopathology. In E. J.Anthony and C. Koupernik (Eds.). The child and his family. Yearbook of the international association for child psychiatry and allied professions. (Vol. 3, pp. 77–97). New York, NY: John Wiley and Sons.

Giannopoulos, P. F., Joshi, Y. B., & Praticò, D. (2014). Novel lipid signaling pathways in alzheimer's disease pathogenesis. *Biomedical Pharmacology, 88*(4), 560-564. doi:10.1016/j.bcp.2013.11.005

Gilgun, J. F. (1999). Mapping resilience as process among adults with childhood adversities. In H.I. McCubbin, E.A. Thompson, A.I. Thompson, J.A. Futrell (Eds.), *Dynamics of Resilient Families* (41-70). SAGE Publications Inc. Retrieved from http://login.ezproxy.library.ualberta.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=sih&AN=15312785&site=eds-live&scope=site

Gilmour, H., Gibson, F., & Campbell, J. (2003). Living alone with dementia: A case study approach to understanding risk. *Dementia (14713012), 2*(3), 403-420. Retrieved fromhttp://login.ezproxy.library.ualberta.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=2004062137&site=eds-live&scope=site

Haberstroh, J., Muller, T., Knebel, M., Kaspar, R., Oswald, F., & Pantel, J. (2014). Can the Mini-Mental State predict capacity to consent to treatment? *GeroPsych: The Journal of Gerontopsychology and Geriatric Psychiatry, 27* (4), 151-159.

Harris, P. (2008). Another wrinkle in the debate about successful aging: The undervalued concept of resilience and the lived experience of dementia. *International Journal of Aging and Human Development, 67*(1), 43-61. doi:10.2090/AG.67.1.c

Hermes, M., Hageman, D., Naumann, E., & Walter, C. (2011). Extraversion and its positive emotional core- further evidence from neuroscience. *Emotion, 11* (2), 367-378.

Hildon, Z., Montgomery, S., Blane, D., Wiggins, R., & Netuveli, G. (2009). Examining resilience and quality of life in the face of health-related and psychosocial adversity at older ages: What is 'right' about the way we age? *The Gerontologist, 50*(1), 36-47. doi:10.1093/geront/gnp067

Hildon, Z., Smith, G., Netuveli, G., & Blane, D. (2008). Understanding adversity and resilience at older ages. *Sociology of Health and Illness, 30*(5), 726-740. doi:10.1111/j.1467-9566.2008.01087.x

Hopper, T., Bayles, K. A., & Kim, E. (2001). Retained neuropsychological abilities of individuals with alzheimer's disease. *Seminars in Speech & Language, 22*(4), 261. Retrieved from http://login.ezproxy.library.ualberta.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=edb&AN=95170078&site=eds-live&scope=site

Kirschner, H.S. (1986). Determination of mental competency, a neurological perspective. *Current Neurology and Neuroscience Reports, 13*, 6.

Lamond, A. J., Depp, C. A., Allison, M., Langer, R., Reichstadt, J., Moore, D. J., Jeste, D. V. (2008). Measurement and predictors of resilience among community-dwelling older women. *Journal of Psychiatric Research, 43*(2), 148-154. Retrieved from http://dx.doi.org.login.ezproxy.library.ualberta.ca/10.1016/j.jpsychires.2008.03.007

Luthar, S., Ciccetti, D., & Becker, B. (2000). The construct of resilience: A critical evaluation and guidelines for future work. *Child Development, 71*(3), 543-562.

MacKinlay, E. (2012). Resistance, resilience, and change: The person and dementia. *Journal of Religion, Spirituality & Aging, 24*(1), 80-92. doi:10.1080/15528030.2012.633048

MacLean, L. M., Meyer, M. & Estable, A. (2004). Improving accuracy of transcripts in qualitative research. *Qualitative Health Research*, 14, 113- 123.

Masten, A. S. (2001). Ordinary magic: Resilience processes in development. *American Psychologist, 56*(3), 227-238. doi:10.1037//0003-066X.56.3.227

Masten, A. S., & Coatsworth, J. D. (1998). The development of competence in favorable and unfavorable environments. *American Psychologist, 53*(2), 205. Retrieved from http://login.ezproxy.library.ualberta.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=bsh&AN=271448&site=eds-live&scope=site

Masten, A. and Powell, J. (2003). A resilience framework for research, policy and practice. In Luthar (Ed.), *Resilience and vulnerability: Adaptation in the context of childhood adversities* (1-24). Cambridge: Cambridge University Press.

McCann, T. V., Bamberg, J., & McCann, F. (2015). Family carer's experience of caring for an older adult with severe and persistent mental illness. *International Journal of Mental Health Nursing, 24* (3), 203.

Moye, J., Marson, D.C., & Edelstein, B. (2013). Assessment of capacity in an aging society. *American Psychologist, 68* (3), 158-171.

Nasreddine, Z., Philips, N., Bédirian, V., Charbonneau, S., Whitehead, V., Collin, I., Cummings, J., Chertkow, H. (2005). The Montreal cognitive assessment, MoCA: A brief screening tool for mild cognitive impairment. *Journal of the American Geriatrics Association*, 53, 695-699.

Nichols, P., Horner, B., & Fyfe, K. (2015). Understanding and improving processes in an increasingly multicultural aged care workforce. *Journal of Aging Studies, 32*, 23-31.

Nygren, B., Aléx, L., Jonsén, E., Gustafson, Y., Norberg, A., & Lundman, B. (2005). Resilience, sense of coherence, purpose in life and self-transcendence in relation to perceived physical and mental health among the oldest old. *Aging & Mental Health, 9*(4), 354-362. Retrieved from http://login.ezproxy.library.ualberta.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=2009037724&site=eds-live&scope=site

O'Dwyver, S., Moyle, W., & van Wyk, S. (2013). Suicidal ideation and resilience in family carers of people with dementia. *Aging & Mental Health, 17* (6), 753-760.

Mahendra, N., & Hopper, T. (2013) in Papathanasiou, I., Potagas, C., & Coppens, P., *Aphasia and related neurogenic communication disorders* (pg. 397-430). Burlington, MA: Jones & Bartlett Learning.

Patton, M.Q. (1999). Enhancing the quality and credibility of qualitative analysis. *Health Services Research*, 34(5), 1189-1208.

Polifroni, E. C. (2010). Power, right, and truth: Foucault's triangle as a model for clinical power. *Nursing Science Quarterly, 23* (1), 8-12.

Quinn, C., Clare, L., Pearce, A., van Dijkhuizen, M. (2008). The experience of providing care in the early stages of dementia: An interpretative phenomenological analysis. *Aging & Mental Health, 12* (6), 769-778.

Richardson, G. (2002). The metatheory of resilience and resiliency. *Journal of Clinical Psychology, 58*(3), 307-321.

Rosenberg, E. (2015). How do I find out more about EMFACS? [FAQ]. Retrieved from: erikarosenberg.com/faq

Rutter, M. (1985). Resilience in the face of adversity: Protective factors and resistance to psychiatric disorder. *British Journal of Psychiatry, 147*, 598. Retrieved from http://login.ezproxy.library.ualberta.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=edb&AN=24825038&site=eds-live&scope=site

Schmidt, T., & Paslawski, T. (in press). Resilience in dementia: perspectives of those living with dementia. *Canadian Journal of Speech-Language Pathology and Audiology.*

Snyder, C. R., & Lopez, S. J. (2005). *Handbook of positive psychology.* New York: Oxford University Press, 2005. Retrieved from http://login.ezproxy.library.ualberta.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=cat00362a&AN=neos.4276180&site=eds-live&scope=site; http://www.myilibrary.com/?id=84554;http://login.ezproxy.library.ualberta.ca/login?url=http://www.myilibrary.com?id=84554

Snyder, L. (2001). The lived experience of alzheimer's -- understanding the feelings and subjective accounts of persons with the disease. *Alzheimer's Care Quarterly, 2*(2), 8-22. Retrieved from http://login.ezproxy.library.ualberta.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=2001072880&site=eds-live&scope=site

Speech-Language Pathology and Audiology Canada (2015). Who we are: Info sheet. Retrieved from: http://sac-oac.ca/sites/default/files/resources/

Staudinger, U.M., Marsiske, M., & Baltes, P.B. (1993). Resilience and reserve capacity in later adulthood: Perspectives from lifespan theory. *Development and Psychopathology*, 5, 541-566.

Thorne, S. (2008). *Interpretive description.* Walnut Creek: Left Coast Press, Inc.

Tolkien, J.R.R. (1982). *The two towers.* Boston: Houghton Mifflin Company.

Wagnild, G. (2003). Resilience and successful aging: Comparison among low and high income older adults. *Journal of Gerontological Nursing, 29*(12), 42-49. Retrieved from http://login.ezproxy.library.ualberta.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=2004045359&site=eds-live&scope=site

Wells, M. (2010). Resilience in older adults living in rural, suburban, and urban areas. *Online Journal of Rural Nursing & Health Care, 10*(2), 45-54. Retrieved from http://login.ezproxy.library.ualberta.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=2011316183&site=eds-live&scope=site

Werner, E. E., & Smith, R. S. (1982). *Vulnerable, but invincible: A longitudinal study of resilient children and youth.* New York : Adams, Bannister, Cox. Retrieved from http://login.ezproxy.library.ualberta.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=agr&AN=CAT92955642&site=eds-live&scope=site

Windle, G. (2011). What is resilience? A review and concept analysis. *Reviews in Clinical Gerontology, 21* (2), 285-292.

Wolverson (Radbourne), E. L., Clarke, C., & Moniz-Cook, E. (2010). Remaining hopeful in early-stage dementia: A qualitative study. *Aging & Mental Health, 14*(4), 450-460. doi:10.1080/13607860903483110

World Health Organization. (2001). International Classification of Functioning, Disability and Health. Geneva: World Health Organization.

Yesavage, J.A., & Sheikh, J.I. (1986). Geriatric depression scale (GDS): Recent evidence and development of a shorter version. *Clinical Gerontologist*, 5(1-2), 165-173.

Appendix A

Interview Questions for Individuals with Dementia

1. What does it mean to you to be resilient/doing okay?
2. What made you sign up for this study?
    a. Do you think you are doing okay?
    b. Tell me what helps you do okay….
        i. At home
        ii. At work
        iii. With family
        iv. With friends
        v. Out in the community
    c. Tell me what makes it harder to do okay
        i. At home
        ii. At work
        iii. With family
        iv. With friends
        v. Out in the community
3. How are things
    a. [individual] with you personally?
    b. [family] with your family?
    c. [community]- out in the community?
4. What makes it hard for you to do okay?
    a. [individual] personally?
    b. [family] in your family?
    c. [community] in the wider community?
5. What helped you after your diagnosis of dementia?
6. What would have helped you to do better after your diagnosis of dementia?
    a. What would help you now?
7. What advice would you give someone else that might help them overcome hurdles, such as a dementia diagnosis?
8. Is there anything else you would like to tell me (about doing okay with dementia)?

Appendix B

Interview Questions for Family Members and Carers of Individuals with Dementia

Relationship to person with dementia (inc. length of time knowing them):

1. What does it mean to you to be resilient/doing okay?

2. What made you sign up for this study?
    a. Do you think you and [family member with dementia (FMD)] are doing okay?
    b. Tell me what helps you do okay/ What makes your FMD do okay….
        i. At home
        ii. At work
        iii. With family
        iv. With friends
        v. Out in the community
    c. Tell me what makes it harder to do okay for you/ for your FMD
        i. At home
        ii. At work
        iii. With family
        iv. With friends
        v. Out in the community
3. In relation to your FMD, how are things
    a. [individual] with you personally?
    b. [family] with your family?
    c. [community]- out in the community?
4. What makes it hard for you to do okay?
    a. [individual] personally with your FMD?
    b. [family] in your family with your FMD?
    c. [community] in the wider community with your FMD?
5. What helped you after your FMD was diagnosed with dementia?
6. What would have helped you to do better after your FMD was diagnosed with dementia?
    a. What would help you now?

7. What advice would you give someone else that might help them overcome hurdles, such as a dementia diagnosis?
8. Is there anything else you would like to tell me (about doing okay with dementia)?

Appendix C

Supplemental Questions - Factors Related to Resilience (Paslawski & Schmidt, in preparation; Duggleby, 2011; Harris, 2008)

1. Does keeping busy help you to do okay?
    - No
    - Maybe
    - Yes
    - Don’t know
2. Does being physically active help you to do okay?
    - No
    - Maybe
    - Yes
    - Don’t know
3. Does having social connections help you to do okay?
    - No
    - Maybe
    - Yes
    - Don’t know
4. Does maintaining a positive attitude help you to do okay?
    - No
    - Maybe
    - Yes
    - Don’t know
5. Does accepting your diagnosis help you to do okay?
    - No
    - Maybe
    - Yes
    - Don’t know

6. Does being open about your diagnosis with others help you to do okay?
    - No

  - Maybe
  - Yes
  - Don’t know
7. Does being independent help you to do okay?
  - No
  - Maybe
  - Yes
  - Don’t know
8. Does having information about dementia help you to do okay?
  - No
  - Maybe
  - Yes
  - Don’t know
9. Does your family or [care partner support] (note: will substitute in name of care partner during interview) help you to do okay?
  - No
  - Maybe
  - Yes
  - Don’t know
10. Does having strategies to adjust to change help you to do okay?
  - No
  - Maybe
  - Yes
  - Don’t know
11. Does being able to communicate your desires and feelings help you to do okay?
  - No
  - Maybe
  - Yes
  - Don’t know