



Resilience in dementia: Perspectives of those living with dementia



La résilience en démence : Perspectives d'individus qui vivent avec la démence

KEY WORDS

DEMENTIA

CAREGIVERS

CARE PARTNERS

RESILIENCE

PROTECTIVE FACTORS

VULNERABILITY FACTORS

COMMUNICATION

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Abstract

This study interviewed individuals living with dementia and their care partners to examine their perspective on the concept of resilience and factors associated with it. Resilience is a process through which individuals demonstrate positive adaptation despite exposure to adverse life events, such as a diagnosis of dementia. In the present study, persons with dementia and their care partners described what it meant to them to be resilient in the face of dementia and the factors they identified as contributing to or interfering with resilience through the use of semi-structured interviews. The study identified eight factors associated with resilience organized under three major themes: 'active and purposeful living', 'perspective', and 'resources'. Speech language pathologists can play a critical role in identifying team goals to bolster resilience in individuals with dementia and in their care partners. Further, because communication is an element of many of the factors associated with resilience identified in this study, it has the potential to impact resilience positively or negatively. Using resilience as a focus is argued to be clinically useful to speech language pathologists and other members of the rehabilitation medicine team to identify areas of strength and weakness for individuals living with dementia, guide intervention efforts, and support more resilient outcomes.

Abrégé

Dans cette étude, nous avons interviewé des individus vivant avec la démence et leurs partenaires de soins afin d'examiner leurs perspectives sur le concept de résilience et les facteurs qui y sont associés. La résilience est un processus qui permet aux individus de démontrer une adaptation positive malgré l'exposition à des situations négatives dans leur vie, tel un diagnostic de démence. Dans la présente étude, les individus vivant avec la démence et leurs partenaires de soins ont décrit qu'est-ce que signifiait pour eux être résilient face à la démence et ont identifié les facteurs qui contribuent et interfèrent avec la résilience, par l'entremise d'une entrevue semi-structurée. L'étude a identifié huit facteurs associés à la résilience, organisés selon trois thèmes majeurs : « une vie active et qui a du sens », « la perspective » et « les ressources ». Les orthophonistes peuvent jouer un rôle crucial dans l'identification des buts d'équipe pour augmenter la résilience des individus vivant avec la démence et celle de leurs partenaires de soins. De plus, puisque la communication est un élément important identifié dans plusieurs facteurs associés à la résilience dans cette étude, elle peut potentiellement avoir un impact positif ou négatif sur la résilience. Nous discutons de l'utilisation de la résilience comme objectif qui peut être cliniquement utile aux orthophonistes et aux autres membres de l'équipe de réadaptation pour identifier les forces et les faiblesses des individus vivant avec la démence, pour guider les efforts d'intervention et pour appuyer des résultats plus résilients.

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Introduction

Resilience is a process through which individuals demonstrate positive adaptation despite experiencing adverse life events. It is commonly described in the literature simply as individuals 'doing okay' when exposed to events or situations that have potentially negative outcomes. It is an area of substantial relevance in the rehabilitation sciences as it defines 'doing okay' as behaviours that result in adaptive functioning in the face of adversity, including disease or impairment. Importantly, the discussion of resilience has moved beyond it being viewed as a personality characteristic to an adaptive process involving interaction at multiple levels or systems- individual, family, and community or societal- as a dynamic process that can vary between and within individuals (Garmezy, 1974; Masten & Powell, 2003; Schoon, 2006; Ungar, Ghazinour & Richter, 2013). Protective factors, those that promote resilience, and vulnerability factors, those that deter resilience, can function within or across these levels and are potential targets for intervention (Luthar & Cicchetti, 2000; Masten, 2001).

To date there has been limited research examining resilience in dementia, in order to understand what it means to be adapting positively following a diagnosis of dementia. The current study examines the concept of resilience for individuals who live with dementia- the persons with dementia and their care partners- what constitutes resilience for them, and what factors they identify as promoting or impeding their resilience. The term *care partner* is used to refer to any individual associated with and involved in caring for the person with dementia, including family, friends, and professionals. A *care partner*, as opposed to the term *care-giver* was suggested by Bryden (2005) to represent equalized care relationships and ensures that "the person with dementia is at the centre of the relationship, not alone as an object to be looked at, as merely a care-recipient" (p. 150).

Speech language pathologists (S-LPs) have a significant role to play in understanding and promoting resilience in those living with dementia. Disordered communication is a prominent part of the presentation of most forms of dementia (Mahendra & Hopper, 2011), which is a barrier to understanding what constitutes resilience and what facilitates or impedes resilience for individuals living with dementia. Holland (2007) argues that "appropriate to our goals [is coaching clients about] learning to live with a disorder or a disability- developing resilience" (p. 21). Communication may also be a component affecting the ability to be resilient in the face of dementia, therefore S-LP

treatment of communication disorders have the potential to positively influence the response to dementia.

Resilience in Aging Populations

The demonstration of resilience depends on two fundamental judgments: (i) that there is a significant threat or adversity and (ii) that the outcome is "good or OK" (Masten, 2001, p. 228). Relatively few studies have examined the concept of resilience in aging populations (e.g. Harris, 2008; Hildon, Montgomery, Blane, Wiggins & Netuveli, 2010; Hildon, Smith, Netuveli, & Blane, 2008; Wiles, Wild, Kerse, & Allen, 2012). These studies examined resilience in older adults with a variety of adverse life events including illness, relationship loss, or change in socioeconomic status, which are not uncommon in aging populations, and determined that older adults can demonstrate resilience, 'be okay', in response to acute or chronic threat or adversity. While the manner in which resilience is demonstrated may differ from individual to individual, Wiles and colleagues also reported that older people understood that it was possible to face constraints in one area but exhibit resilience in another, emphasizing the complexity of the notion of resilience as a "multidimensional, contextual and ongoing process" (Wiles et al., 2012, p. 423), which is consistent with the developmental literature on resilience.

Although there are components of the resilience process that are internal to an individual, such as positive coping styles or attitude (Hildon et al., 2008; Wiles et al., 2012), focusing on the components of resilience that may be easier to modify and that are within the scope of practice of more rehabilitation professionals, lends itself to practical application from the perspective of rehabilitation. Understanding resilience, and identifying protective and vulnerability factors that affect resilience in specific populations, has the potential to contribute to individualized focused rehabilitation efforts as well as community initiatives to foster resilience in adults facing adverse situations or events.

Resilience and Dementia

Dementia is an umbrella term for a number of etiologies that result in memory loss, changes in mood, behaviour, and communication abilities that are severe enough to interfere with activities of daily life, occupation, and social interaction (Mahendra & Hopper, 2011). It is the most significant cause of disability for adults over the age of 65. There are currently approximately 500,000 Canadians living with dementia and that number is expected to increase 2.3 times by 2038 (Alzheimer Society of Canada, 2010). Because of the cognitive underpinnings of dementia, individuals may

be less able to adapt to changes in their environments or everyday demands (Mahendra & Hopper, 2011), leading to a decrease in competence and a corresponding loss of independence. Communication deficits are common in dementia, increasing in severity as the disease progresses (Yorkston, Bourgeois, & Baylor, 2010). Cognitive and communication deficits are inter-related and can negatively affect daily functioning.

Because of the progressive nature of dementia, many intervention efforts are of a pharmacologic or palliative nature, however, a number of intervention studies indicate that therapy directed at maintaining function and improving quality of life have efficacy in this population (e.g. Hopper et al., 2013; Mahendra, Scullion, & Hamerschlag, 2011). The functioning of individuals with Alzheimer's disease can be improved by utilizing intervention techniques that focus on spared memory skills as well as principles of learning that have been shown to be effective for some individuals with dementia (Woodward, 2013). A focus on resilience could contribute to maintaining functioning and improving quality of life by reinforcing or bolstering protective factors and reducing the impact of vulnerability factors.

Studies of dementia and resilience. Cotrell and Schulz (1993) suggest that in much of the research on dementia "the afflicted person is viewed as a disease entity to be studied rather than someone who can directly contribute to our understanding of the illness and its course" (p. 205). However, Harris (2008) examined resilience in two individuals with dementia, and was among the first to demonstrate that individuals with early stage dementia can exhibit resilience. Resilience was examined from multiple perspectives: the individual with dementia, the *care partner* of the individual with dementia, the referral source, and the researcher. Including the perspective of the person with dementia in the discussion of resilience demonstrated that individuals with dementia can contribute to our understanding of resilience, which is important given the criticism that the literature on resilience in older adults often excludes the individual with dementia as a direct participant (Wild, Wiles & Allen, 2013).

Applying the concept of resilience to dementia is a strengths-based approach to understanding living with dementia (Bailey et al., 2013). Further, it acknowledges that older individuals may "thrive in spite of and even at times *because* of their experience with these difficulties" (Wild et al., 2013, p. 142). Hildon et al. (2010), "resilience overrides the idea that once health begins to deteriorate and disability sets in, aging successfully is no longer possible" (p. 37).

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

Purpose and Goals of the Study

The goals of this study were (i) to describe resilience in dementia, and (ii) to identify protective and vulnerability factors that may influence resilience in dementia, from the perspectives of individuals with dementia and their family members or care partners.

Methodology

Because there is limited research on the concept of resilience in dementia, it is important to develop a clear description of resilience and how it is understood within the population, prior to measuring or quantifying the processes that underlie resilience in this population. To that end, interpretive description was used as the methodological approach as it allows for an examination of the commonalities within a specific phenomenon and is very practical in nature, focused on generating a rich description of the concept in order to inform clinical understanding (Thorne, Reimer-Kirkham, & O'Flynn Magee, 2004). This study provides an understanding of resilience from the perspective of individuals with dementia and those close to them, and begins to explore the factors they view as positively or negatively affecting their resilience.

Participants

Consistent with qualitative research design (Sandelowski, 2010), purposeful sampling was used to recruit participants. Seven individuals with dementia and five care partners participated in this study. Following ethics approval by the Health Research Ethics Board-Health Panel of the University of Alberta, participants were recruited through the Alzheimer Society of Alberta and the Northwest Territories by means of an intermediary contact who identified potential participants and distributed a recruitment letter outlining the criteria and description of the study. Individuals interested in participating in the study contacted the authors and eligibility to participate was confirmed prior to scheduling a meeting for data collection. Individuals were invited to participate if they had

dementia associated with probable Alzheimer’s disease or were the family member and/or care partner of a person with dementia associated with probable Alzheimer’s disease, and believed they were ‘doing okay’ in the context of that diagnosis. Participants had to agree to be audio- and videotaped during data collection and to not have family members or other care partners present during the data collection. In addition, participants with a diagnosis of dementia were required to complete standardized measures of cognition, depression, and quality of life.

Standardized Measures. Participants with dementia also completed the Montreal Cognitive Assessment (MoCA; Nasreddine et al., 2005), the World Health Organization Quality of Life– BREF (WHOQOL- BREF, 2004) scale, and the Geriatric Depression Scale (GDS; Sheikh & Yesavage, 1986). These well-established screening tools provided context for study participants’ descriptions of their understanding of their own resilience and were

administered and scored as outlined by each measure’s instructions. The semi-structured interviews were intentionally conducted first; the participants with dementia have had experience with memory and cognition tests as part of their dementia diagnosis and it was anticipated that beginning the session with these measures might have negatively impacted rapport and their willingness to fully participate in the interviews.

Seven participants with dementia met the inclusion criteria and participated in the study: four women and three men. The average age of participants was 72, with a range from 65-82. In addition, five care partners participated- two were wives of individuals with dementia, two were husbands, and one was the daughter of a person with dementia. Demographic information and scores for each of the screening tools for participants with dementia are reported in Table 1.

Table 1. Results of Standardized Measures Administered

| Participant Gender | Number of Years Post-Dementia Diagnosis | Montreal Cognitive Assessment (MoCA) | Geriatric Depression Scale (GDS) | World Health Organization Quality of Life BREF (WHOQOL) | | | |
|--------------------|---|--------------------------------------|----------------------------------|---|----------|----------|----------|
| | | | | Domain 1 | Domain 2 | Domain 3 | Domain 4 |
| female | 9 | 14 | 6 | 38 | 44 | 69 | 56 |
| male | 5 | 18 | 0 | 56 | 69 | 75 | 88 |
| female | <1 | 15 | 1 | 69 | 69 | 100 | 88 |
| female | <1 | 18 | 7 | 56 | 56 | 56 | 63 |
| female | 1.5 | 12 | 2 | 24 | 20 | 12 | 35 |
| male | 3 | 19 | 2 | 69 | 81 | 44 | 88 |
| male | 4 | 17 | 3 | 56 | 76 | 75 | 88 |

Note: Maximum score for the MoCA is 30, a score of 26 or above is considered normal. Maximum score for the GDS is 15; a score above 5 suggests depression. WHOQOL domains: 1- physical health, 2- psychological, 3- Relationships, 4- Environment. Maximum score for each WHO-QOL scale domain is 100 with higher scores indicating higher quality of life.

Data Collection

Semi-structured interviews were conducted with all of the participants. The semi-structured interview questions (Appendix A) were developed from a previous project examining resilience in adults with neurologic disorders (in preparation) as well as thorough discussion with a panel of experienced researchers. Two factors, physical activity and spirituality, were specifically probed as possible influences on resilience, having not emerged in the previous project (in preparation) but represented in some of the literature related to resilience. Physical activity has been identified as playing a positive role in mental health and cognitive functioning in aging (Daffner, 2010; Voelcker-Rehage, Godde, & Staudinger, 2010), which may relate to resilience. The case study by Harris (2008) identified religious beliefs as a protective factor for individuals with dementia. Specific questions regarding religion were developed based on Koenig and Bussing (2010) and the use of the term 'religion' over 'spirituality' in the interviews was purposeful, as Koenig (2011) proposes that religion is a clearer and more distinct concept than spirituality. All questions in the interview were based on levels previously identified as impacting resilience in the literature: individual, family, and community (Luthar & Cicchetti, 2000; Luthar, Cicchetti, & Becker, 2000).

Data Analysis

Transcript verification. Each interview was transcribed verbatim and spot-checked by a second listener with a sampling ratio of 2 or more minutes per 10 minutes of recording (Easton, McComish, & Greenberg, 2000; Maclean, Meyer, & Estable, 2004). Transcripts were verified with 95% agreement between the two listeners. Qualitative data analysis software (NVivo) was used to assist in organizing themes in the data related to the research questions.

Method. Thematic analysis, a process commonly used in qualitative research to identify patterns or themes in a data set, was employed as the framework to assess the data (Guest, MacQueen, & Namey, 2012). Two reviewers independently developed coding schemes based on themes and sub-themes or 'factors' within the interviews, then compared notes and arrived at a consensus. Creating operational definitions of themes and factors ensured reliability of the coding system. Reliability and validity in this study were established following Patton's (1999) recommendations. Data triangulation occurred across the participants with dementia and the care partners (Guion, Diehl, & McDonald, 2011). Analyst triangulation was accomplished by having two coders involved in analysis.

Results

Analysis of the data from the study participants revealed three major themes associated with resilience for individuals with dementia: 'active and purposeful living', 'perspective', and 'resources'. Each of these major themes are comprised of several factors that operate at one or more of the following levels: individual, family, and community. There is overlap and interaction between the factors; they are not mutually exclusive. While it is acknowledged that the data could be classified differently, there was agreement by the coders of the current data set that the divisions highlight the concepts most salient to the study participants and are an authentic representation, in the spirit in which they were discussed. The relationship between themes and factors is undoubtedly more complex than represented here, and worthy of further exploration.

Table 2 summarizes themes and factors that were identified by participants. Each factor exists on a

Table 2. Summary of Themes and Factors.

| Theme | Factors |
|------------------------------|--|
| Active and Purposeful Living | Participation Physical Activity Social Interaction |
| Perspective | Attitude/acceptance Openness |
| Resources | Education Support Strategies |

continuum, operating as a protective factor at one end of the continuum and as a vulnerability factor at the other end. Participants in this study identified the majority of factors to be operating primarily as protective. Participant quotes are utilized to illustrate each factor; for ease of reading, interjections, repetitions, and pauses were removed and participant quotes are italicized.

Active and Purposeful Living

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

Participation. The factor of 'participation' refers to participants becoming or staying busy in their everyday lives. All 12 of the participants referenced it as a protective factor. Participation overlaps with the other two factors under 'active and purposeful living', however it was conceptualized as broader than 'physical activity' and 'social interaction' as it includes activities that are not social or physical in nature and was therefore justified as a separate factor. It included activities that the individual had engaged in prior to the diagnosis of dementia as well as new activities based on interest and opportunity, including attending community groups, and hobbies. For most participants, continuing to engage in activities that were central in their daily lives prior to the diagnosis of dementia was beneficial, in that there was a sense of continuity between life before and after the diagnosis. When asked what helped her do better with dementia, one participant stated: *"Do your life, do the same thing that you've been doing before. Don't stop, activity is important."* Another participant acknowledged that how she participated in her activities has shifted since the onset of her dementia, however the maintenance of these activities despite these changes was important. She stated:

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

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

For care partners, participation was seen as important for the person with dementia and for themselves- maintaining their own interests and activities was considered important in their ability to cope with their family member's dementia. Care partners also believed that having the person with dementia engaged in activities offered some respite for them as well as slowing the decline associated with the disease. *"It's important for her [person with dementia] to be involved, to stay busy, for her own sake, but also- if she wouldn't go do things it would be harder on me."* *"Sometimes it is the only time I get a break, where I don't have to worry about him, what he's doing."* *"We both need intellectual outlets. She's in there somewhere and maybe she doesn't always get it, but I think it's important for her."*

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

Physical Activity. 'Physical activity' was defined as engagement in physical exercise of any kind. Physical activity was identified as a protective factor for all seven participants with dementia and by four of the five care partners. The types and frequency of physical activity varied across participants and included activities such as walking, going to the gym, cleaning a local community centre, and swimming.

For all study participants, physical activity was something they had done prior to the diagnosis of dementia and continued to do following diagnosis, and was considered an important component of their adaptive functioning. One participant with dementia discussed the importance of square dancing and stated:

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

For another participant with dementia, physical activity was an especially important means of social interaction, as a means of engaging with other individuals at the local gym. The significance of physical activity for mood regulation was identified by a study participant who stated *"I really don't have too many bad moods, but usually if I get myself turned around a little bit, all I do is put my clothes on and go for a walk."* Another participant with dementia solely attributed his resilience to physical activity, and that going for walks became even more integral to his daily life following

his diagnosis of dementia. When asked whether physical activity helped him 'do okay', he claimed: *"It's the best thing I can think of."* Physical activity was identified to serve a variety of purposes, however, regardless of the reason study participants engaged in exercise, the physical activity itself was central to their daily lives.

For care partners, physical activity served a number of functions. It served as stress control for themselves and for their family members. *"We've walked every day for the last ten years, maybe longer. If we don't get out, we won't be happy. Sometimes I tell him 'You need to take a walk', and I mean it!", and "It's not a lot [of exercise] but I need it, so I'm glad I still get to do it." "It wasn't to cope with this, but because we both had other activities going on they're part of probably what's helping us get through this right now."* It was also an activity they could engage in with their family member or as discussed under 'participation', as a means of occupying the person with dementia, *"She goes to [the gym] where they know her and I don't have to worry, and I get to do something for myself."*

The factor of 'physical activity' operates at all three levels, as it can include physical activities done alone (e.g. going for walks independently), with family (e.g. weekly family swims), or in the community (e.g. going to a public gym).

Social Interaction. 'Social interaction' was defined as any meaningful interaction between individuals. These types of interactions could be formal, organized situations such as Alzheimer's support groups, or casual interactions such as brief conversations at the local gym. For five of the seven participants with dementia and for all of the care partners, this was a protective factor they believed contributed to their resilience.

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

people."

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

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

Four of the five care partners of persons with dementia identified 'social interaction' as a factor contributing to resilience for the individual with dementia. *"Several of [her friends] phone her once or twice a week and they'll get engaged in an hour long conversation going nowhere but the person on the other end knows that they're just doing their part to support her."* The fifth care partner noted that her family member with dementia *"was never very social, so there's very little change. If anything, I think she does more now because of the [Alzheimer] Society."* The only reference care partners made to themselves regarding this factor was in the context of their participation in activities through the Alzheimer Society. The Alzheimer Society was seen as extremely important to all of the care partners, but will be discussed in the context of the theme 'resources.'

'Social interaction' operates at two levels: the family level (e.g. interactions with family and friends) and the community level (e.g. interactions with community or support groups).

Perspective

'Perspective' is the second major theme that refers to the view individuals with dementia and their care partners took in regard to their diagnosis. The factors included under 'perspective' were 'attitude/acceptance', and 'openness'.

Attitude/acceptance. This refers to being positive and coming to terms with the diagnosis of dementia. Six out of seven participants with dementia and all of the care partners identified having a generally positive attitude or disposition or specifically a positive attitude about their diagnosis of dementia, as contributing to their resilience. 'Attitude/acceptance' includes being positive, having a sense of humour, positive self-esteem, and accepting the diagnosis. It was discussed as a protective factor by the

participants with dementia. *"I feel I've had a very good life. I don't want you to feel that I've got this thing [dementia] hanging over me all the time."* When asked what advice she would give to someone recently diagnosed with dementia, one participant stated: *"You just have to keep smiling, because that's one of the biggest things. Don't give up."* *"Acceptance would be a big part of this. Having to accept my limitations and be okay with it."* Self-image and self-esteem for the person with dementia played into this:

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

Other participants noted that positively reframing changes in ability following the onset of dementia was important. *"I went through 'poor me' and feeling sorry and depressed. Then I changed my thoughts - 'I'm retired, 'What would I do if I was retired?'"* By changing her attitude about new limitations imposed by dementia, this participant felt she was able to look at dementia in a different, more empowering way. *"I've never said 'why me?' I've just said to myself 'This is me now, I've got to make the best of this I can.'"*

Three participants with dementia explicitly referenced having a sense of humour, being able to joke, make light, and laugh about their diagnosis, as something that helped them 'do better' following their diagnosis of dementia. One participant noted that rather than being upset at her memory loss, she would tell others *"Oh I forgot, I've got dementia, I've got Alzheimer's, that's why I forgot! And I'll make a joke about it."* *"I was angry at God. I really was. And sometimes I'd say, 'Why me God?' and then I'd say 'why not?' You have to look at it from that angle too; there are hundreds of people who have Alzheimer's."*

And

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

Care partners of persons with dementia discussed attitude in the context of separating the person from the disease and the importance of humour. *"I focus on the successes more than the struggles. But I'm realistic. And I keep a sense of humour. You have to, you have to."* Another care partner acknowledged:

There's frustrating moments, but you have to sit

back and realize that you can't see the white cane, so there are reasons this is happening. It's not my wife that's causing the problem it's this disease that is. And I think you have to keep reminding yourself of that when you get frustrated.

And

You have to keep it sort of jovial even though you are in fact nagging but her mind doesn't realize that I told her 5 minutes ago the same thing I just told her now. At least I think that's what goes on.

Two study participants with dementia and two of the care partners also noted that frustration or negative emotions related to the diagnosis of dementia made it more difficult to for them to 'be okay'. The participants with dementia worried about letting others down, had concern over negative stereotypes of people with dementia, and anxiety about making mistakes in public. This factor operates at the individual and family levels and relates to personal approaches towards living with dementia.

Openness. 'Openness' refers to sharing the diagnoses of dementia with other individuals in one's life and is strongly related to 'attitude/acceptance'. 'Openness' was identified as something that positively contributed to well-being and operated as a protective factor by five out of seven participants with dementia and by all of the care partners.

Study participants saw openness as a way of decreasing embarrassment and increasing understanding of dementia, particularly in public situations. Participants had varying degrees of openness, which appeared to be related to decisions about who to share the diagnosis with. One participant with dementia noted that she shared her diagnosis at the grocery store and stated: *"I tell people ahead of time so if I make a mistake, I don't feel silly."* While another participant noted that it was important to tell "trusted" friends, however this individual was not comfortable sharing with more casual acquaintances.

Several participants with dementia noted that by sharing the news of their diagnosis with others, there was a wider range of support that was available should they need it, and openness also increased general awareness about their condition. In one case, a participant explained the influence his care partner had on sharing his diagnosis. By sharing his diagnosis with others, he stated that his care partner was able to advocate for him more readily and increase support for both of them. Because of this openness, he felt more comfortable with his current level of functioning and found that people were more understanding once they were aware of his diagnosis of dementia.

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

Further, people discussed dementia as a ‘hidden illness’ in that it is not discernable as a visible disability, which increased the need to be open and honest with others. One participant stated: *“What’s really hard about people with early dementia is I look well. People aren’t there saying ‘Can I help you?’ so you have to advocate or your family has to advocate for you.” “It’s a hard disease, because one minute you’re good and one minute you’re bad. Or one day, you’re perfect and nobody would have a clue there’s something wrong with you.”*

For care partners of individuals with dementia, openness was unanimously agreed to be important in coping with the diagnosis for the person with dementia and for them as care partners. *“Everyone should find groups that they can be open with, and that’s where the support comes from.”*

“So the biggest thing for resilience is when [person with dementia] finally started getting relaxed, getting open with her friends.... and various people that she visits with. Everyone knows she has it. And that’s helpful to me too because there’s a support network out there now. If you keep it secret, it’s hard.”

And

“[Being open about the diagnosis] was valuable to both of us. She realizes it was beneficial. At first she was sorta letting a few people know [and making them] swear they won’t divulge it to anyone else... but eventually she just allowed it. That’s when it got a lot easier for everybody.”

‘Openness’ operates at the individual and family levels, as the decision to share the news of a dementia diagnosis is personal (individual), however, family members or care partners also were identified to play a role in the decision-making process (family) and to benefit from sharing the diagnosis.

Resources

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

Education. ‘Education’ refers to the process of becoming informed about dementia by actively searching out information regarding the disease itself, how everyday life may change, and what the future outlook of the disease is. Four out of seven participants with dementia and all of the care partners commented that learning about dementia was beneficial to them, as a means of helping them cope following the diagnosis; therefore, this factor was identified primarily as protective. Education took a variety of forms that included support groups at the Alzheimer Society, reading books about dementia, as well as using the Internet as a means of education. Several participants with dementia noted that receiving the diagnosis made it easier, however, they also acknowledged the importance of not letting their diagnosis overtake their life. One participant stated: *“I read as much as I can about Alzheimer’s, but I don’t want to get clogged with it because looking through a book is not going to give me any cure.”* Another participant noted that education decreased the fear associated with the future, and when asked ‘what helps her be okay’ she stated: *“I think knowledge – I sought out help with the Alzheimer Society. I’m not afraid of dementia.”*

Educating others and increasing awareness of the symptoms of dementia was identified as having a positive impact that would assist individuals living with dementia. Study participants commented on a lack of awareness about dementia with the general public, the medical community, and in their own lives as impeding their resilience and that increased awareness did, or would have, helped them ‘do better’ after their diagnosis. When asked what would have been beneficial following her diagnosis a participant stated:

Other people knowing about dementia: family and friends. People don’t know. People know what Alzheimer’s is, and of course, they think the worst. Some people don’t understand the beginning stages of dementia or Alzheimer’s. People are afraid of it. So I think knowledge.

Five of the participants with dementia and four of the care partners stated that the Alzheimer Society support groups played an integral role in their functioning following their diagnosis of dementia. The support groups were identified as having a variety of roles for individuals with dementia; attending meetings at the Alzheimer Society were a way of learning about the disease, its progression and everyday strategies, as well as being a place to socialize with others. As one care partner stated, *“Connecting with the Alzheimer Society was probably the biggest success part of this whole process for the two of us.”* And another, *“I can’t*

say enough about them- Best. Thing. Ever." 'Education' operates at all three levels and involves education for the individual with dementia (individual), for family members and care partners (family), as well as broader public and community awareness (community).

Support. The factor of 'support' refers to the different supports that loved ones or care partners provide to individuals with dementia and that are provided to care partners. All seven study participants with dementia commented on the integral role their family members, loved ones, or care partners, played in contributing to their resilience, identified as a protective factor when present but also observed as a vulnerability when referring to individuals who did not respond well to the diagnosis. Similarly, for care partners, 'support' was discussed as a protective and/or a vulnerability factor in terms of the value of healthy support systems and the toll that a lack of support took on the person with dementia and the care partner.

A variety of different support types were identified, depending on the participant and their relationships with their loved ones and their community. These included providing emotional regulation, compensating for memory loss (e.g. the name of an acquaintance in a public setting), transportation, assistance in public domains (e.g. at the grocery store), taking on additional household responsibilities, and keeping the individual with dementia company. Included in the description of 'support' was the notion of independence and freedom, balancing safety with independence, autonomy, respect, and graded support.

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

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

Having family and care partner support significantly contributed to resilience for study participants. Several participants commented on how much they appreciated having their loved ones take on the care partner role and how effective they felt their care partners were in that capacity. One participant noted that she could rely on her family, which helped her function in her every day life. She noted that: *"Anything I need, they talk to me. They either come right away if they can, or they come as soon as they can. They always, always answer my calls."* Another participant stated, in regard to her care partner: *"I really*

rely on him." Conversely, having to rely on others was a challenge for some, *"My biggest thing with my family is that I always, always wish I could do it myself because I hate being a burden."*

Care partners also discussed concerns about family members and friends who were not supportive following the diagnosis.

[Family member] just doesn't get it, or doesn't want to get it. Doesn't understand that [person with dementia] needs help now, not tomorrow, not on the weekend. And when [family member] doesn't help it just makes it harder on all of us. And I think it makes [person with dementia] feel bad too.

Interestingly, a common thread was the challenge and burden of transportation. *"Not being able to drive, not being able to just open the door and go. Freedom... freedom is gone to a certain extent and that's what really bothered me."* Difficulties taking public transportation or lack of access to reliable and affordable transportation compounded the loss of independence felt by study participants. Several participants with dementia and care partners relayed traumatic stories about transportation that resulted in a lack of trust of public services, increasing pressure on family and financial resources (e.g. to hire private transportation), and concerns about increasing isolation and dependence for the person with dementia.

'Support' operates at the family level, as care partners and loved ones are the individuals who provide support and care to study participants (family) and at the level of community, resources that are available in the community publically or privately.

Strategies. 'Strategies' is the final factor of 'resources' and refers to ways of adjusting, compensating, or adapting to changing needs and abilities following a diagnosis of dementia, a protective factor for individuals with dementia and for their care partners. This factor is intimately associated with the factor of 'support' and may well be subsumed as part of the factor but in an effort to accurately represent the importance placed on strategies by the participants, it is listed as a separate factor.

Environmental modifications were identified as important strategies to support resilience for individuals with dementia. Five participants with dementia and three of the care partners specifically discussed sensitivity to noise, crowds, or visual distractions as barriers to 'doing okay', and that they mitigated these by changing their environment to improve functioning. These kinds of environmental changes

included moving into a smaller home, changing how tasks were carried out, and reducing noise and clutter in the immediate environment. For example, devices or reminders to compensate for memory loss were identified as strategies to help with everyday functioning. These devices included iPads, other calendar, or reminder systems (e.g. alarms reminding participants to make lunch), as well as written notes or lists.

Several participants commented on a role-shift with care partners that occurred following the diagnosis of dementia. Changes in household responsibilities such as paying bills, buying groceries, or cooking meals often occurred, and acceptance of those changes by the person with dementia was important. One participant with dementia explained it as *"You adapt, you buy groceries a little differently. Things have changed, my husband does the groceries, he has to do the cooking and being okay with that has helped me."* Conversely, a care partner observed that he believed it was important to his spouse to continue to buy groceries *"but now I make a list for her, and I watch from a distance so I can give her some help if I see that she needs it... so we don't end up with 3 dozen bananas!"* As a vulnerability factor, two participants noted that having support with meals and daily chores would be beneficial, but that costs of such services were an impediment to accessing them.

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

Discussion

Describing Resilience

For study participants, resilience appeared to be a process of maintenance, in that they felt that their resilience was related to a degree of continuity between life before and after the diagnosis of dementia. Even though their lives had changed following diagnosis, most participants noted that a sense of normalcy and similarity to their life prior to the diagnosis of dementia was central to a view of resilience and to their positive adaptation. The actions and activities of the participants served as evidence to them of their resilience but were also recognized as contributors to their resilience. What changed for most participants was *how* they did these activities, rather than *what* they did. Consistent with this finding, Bailey and colleagues (2005) suggest that resilience for individuals with dementia "can encompass the ability to continue with established roles

and activities that (re)affirm a sense of self and build on a lifelong accumulation of social, knowledge, psychological, and material assets" (p. 394), an emphasis on the importance of continuity between life before and after dementia as identified in the current study.

Resilience Factors

Eight factors identified as contributing to resilience for persons with dementia and their care partners were grouped into three themes: 'active and purposeful living', 'perspective', and 'resources'. The factors represent a continuum from positive (protective factors) to negative (vulnerability factors).

Many factors identified in this study support previous findings in the literature. 'Participation' relates to the protective factor of *productivity* identified by Harris (2008) in a case study of two individuals living with dementia. Glymour, Weuve, Fay, Glass, and Berkman (2008) identified *social integration* as a protective factor for stroke patient's cognitive recovery, which parallels 'social interaction' in the current study. 'Attitude/acceptance' corresponds with several factors identified by Harris (2008) including: *positive attitude, a fighting spirit, and positive self-concept*. Harris (2008) also suggested that *acceptance of changing self* was a protective factor, which is similar to 'attitude/acceptance' in the current study. All three factors of the major theme 'resources' in the current study were consistent with Harris (2008): 'education' (*community resources*), 'support' (*social support networks, long-term supportive marriage*), and 'strategies' (*coping strategies, problem solving skills*).

Factors not previously identified in the literature but highlighted by participants in this study as being important in bolstering resilience were 'physical activity', and two components of support, 'openness', and 'independence'. That 'physical activity' was identified as a protective factor reinforces the importance of establishing healthy habits prior to the identification of illness, given that participants referenced continuing the physical activities they had established prior to the dementia diagnosis. The identification of 'openness' as a factor may be influenced by participants' experience with the Alzheimer Society through which participants were recruited, since the Alzheimer Society encourages people to tell others about the diagnosis. Participants with dementia and their care partners validated this recommendation, with the majority believing it played a key role in their resilience.

'Independence' was identified as a sub-factor under 'support' in the current study. While not previously

explicitly linked to resilience, Anderson, Wittrup-Jensen, Lolk, Andersen, and Kragh-Sorensen (2004) have suggested that dependency for activities of daily living was a significant factor in measures of quality of life for individuals living with dementia. Several of the participants with dementia in this study noted that their biggest impediment to resilience was their loss of independence as a result of their dementia diagnosis. Similarly, it was a focus for care partners, explicitly attempting to provide support and structure to allow for a level of independence on the part of the person with dementia; this also affected their own independence and freedom.

Limitations and Challenges of the Study

This study employed a qualitative methodological approach yielding rich information on resilience; however, there were limitations to this study related to procedure and to the population studied. Procedurally, diagnosis and medical history were not confirmed, because it was anticipated to discourage participant recruitment and significantly delay collection. It is therefore likely that study participants had varying types and severities of dementia and possible that the factors associated with resilience in dementia may not be consistent across dementia types and levels of severity. Second, while participants were invited to participate in the study if they felt they had demonstrated resilience in the face of the diagnosis, several participants noted that their primary reason for participating in the study was to help others, not necessarily because they felt they were demonstrating resilience. However, because recruitment for the study occurred through the Alzheimer Society, study participants were individuals actively taking part in support groups and accessing community resources, which arguably illustrates a degree of resilience. Further, responses during the semi-structured interviews suggested that at least in some situations or at specific points in time all of the participants identified and described themselves as being resilient. Finally, varying degrees of cognitive impairments across participants with dementia and the changing nature of dementia may have influenced the accuracy of the data obtained and was the main factor in there not being a verification step in this study.

Implications for Clinical Practice and Future Research

The concept of resilience may prove to be a useful lens through which to view approaches to clinical management in dementia. By considering resilience and the factors that support or undermine it, goals may be set to bolster resilience. Bailey and colleagues (2013) suggest asking,

“What resources does the person living with dementia have and how might they inform notions of risk?” (p. 395).

This work lends itself to a collaborative approach, given the many levels at which resilience can be considered, with speech-language pathologists playing an integral role. Given the significant communication deficits that are part of the presentation of dementia and which potentially make direct discussions more challenging, S-LPs can facilitate discussions of resilience with individuals with dementia, to inform health care teams and provide guidance regarding team goals for management and treatment. More specifically, because communication is a component of many of the factors associated with resilience identified in this study, including social interaction, participation, and openness, it has the potential to serve as both a vulnerability and a protective factor. To illustrate, for one participant with dementia, being able to express herself was difficult, but communication operated as an important strategy to get her wants and needs recognized and met. When asked what helps her be resilient she responded:

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

Using resilience as a framework, management and treatment goals and activities can be structured to focus on communication as a protective factor, to encourage resilience in our clients.

The defining characteristic of resilience for individuals living with dementia, as suggested in the current study, is that of maintenance or continuity between life before and after dementia. Assuming this bears out with further research, this finding provides insight and direction regarding the kinds of interventions and supports that would be beneficial for individuals diagnosed with dementia. These interventions and supports could include, for example, increasing accessibility and affordability of transportation for individuals with dementia, and increasing support and care to care partners as a means of benefitting both the individual with dementia and the people who care for them. Supports specific to communication enable individuals with dementia to maintain a degree of independence and autonomy, encourage social participation, and maintain safety, all of which potentially impact the resilience of care partners as well. The use of augmentative and alternative communication is an important component given the degenerative nature of dementia. S-LPs can also provide

education regarding strategies to maximize communication in various contexts as the dementia progresses.

Originally, this study sought to examine the concept of resilience in individuals with mild dementia and their care partners; however, participants with dementia had much lower scores on the MoCA than initially expected, suggestive of a more significant cognitive impairment. Despite this, themes were identified across participants with dementia and all of the interviews provided useful and meaningful data. This suggests that impairments in communication ability may not preclude participation in examinations of the experience of living with dementia if the researchers are trained to work with individuals with communication disorders. This finding challenges the assumption that data collected from individuals with cognitive impairment are inaccessible and unreliable (Cotrell & Schulz, 1993; Hess-Wiktor & Opocynska, 2012). It is also interesting to note that even with cognitive impairment, study participants still felt they were resilient.

The potential presence of depression, identified on scores on the GDS greater than 5, suggests that even individuals who may be depressed can still consider themselves to be resilient. From the perspective of persons with dementia in our study, resilience may be exclusive of depression, as individuals may be depressed and still be resilient. Similarly, the WHOQOL-BREF measure revealed a vast range of scores across participants, from within normal range to significantly below average compared to individuals with no cognitive impairments or chronic illnesses (Hawthorne, Herrman, & Murphy, 2006). Even with what would be considered 'low' quality of life scores, study participants still considered themselves to be resilient. This is especially interesting because in previous studies on resilience in older adults, the measure of resilience was 'better-than-expected' quality of life scores. The finding that participants in the current study described themselves as resilient, even with low quality of life scores suggests that resilience is not directly associated with quality of life, and although these factors may be related, resilience and quality of life do not presuppose each other. These observations regarding the apparent lack of relationship between resilience, depression, and quality of life are important for clinical management and worthy of further research.

Despite being specifically queried, religion was not identified as contributing to resilience in this study, with the exception of 2 participants who were related to each other and therefore had a similar background. Because of the limited size of this study, and the identification of religion as a factor in resilience in some of the literature

on resilience (Harris, 2008), this cannot be ruled out as a contributor to resilience and should be considered for further investigation.

The results from the semi-structured interviews provide evidence that resilience is both an inclusive and optimistic position from which to approach dementia. Even individuals who appear to be significantly cognitively impaired, depressed, and have low quality of life scores, can still be resilient.

Summary

Using data gathered from semi-structured qualitative interviews and qualitative thematic analysis, this study described resilience as well as identified protective and vulnerability factors associated with resilience from the perspective of individuals living with dementia and their care partners. The factors found in this study build on those previously identified in the literature, and suggest additional factors that may impact resilience in this population, namely physical activity, openness in sharing news of their diagnosis, and maintaining some level of independence.

The concept of resilience, as described in the current study, corresponds to maintenance or a degree of continuity between life before and after a diagnosis of dementia. Clinical implications of resilience for this population include supporting continuity between life before and after dementia as well as bolstering the multiple, modifiable factors identified as promoting positive adaptation for those living with dementia, both the persons diagnosed and their care partners. This study emphasized the importance of first-hand perspectives of individuals living with dementia as well as the inclusivity and optimism inherent in the notion of resilience and provides a basis for future investigations into the concept of resilience as applied to individuals living with dementia.

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Appendix A Interview Questions

1. **What made you sign up for this study?**
 - a. Are you doing okay?
 - b. If so, why are you doing okay
 - i. At home?
 - ii. At work?
 - iii. With family?
 - iv. With friends?
 - v. Out in the community?
 - c. What does it mean to you to be resilient/be doing okay?
2. **What helps you do okay?**
 - a. [Individual] – How are things with you personally?
 - b. [Family] – How are things with your family?
 - c. [Community] – How are things in the wider community?
3. **What makes it hard for you to do okay?**
 - a. [Individual] – personally?
 - b. [Family] – in your family?
 - c. [Community] – in the wider community?
4. **What would have helped you do better after your diagnosis of dementia?**
 - a. What would help you now?
5. **What advice would you give to someone that may be able to assist them with overcoming hurdles, such as a dementia diagnosis?**
6. **Are you religious or spiritual? Tell me about that.**
 - a. Do you think religion played a role in doing okay?
 - i. How often do you attend church or other religious meetings?
 - ii. How often do you spend time in private religious activities, such as prayer, meditation, or Bible study?
 - iii. Do you feel like you experience the presence of the divine in your life?
 - iv. Do your religious beliefs lie behind your approach to life?
 - v. Do you try to carry your religion over into all other dealings in life?
7. **Are you physically active? Tell me about that.**
 - a. Do you think physical activity was important to you once you learned you had dementia?
 - b. Do you think it plays a role in helping you be okay?
8. **Is there anything else you would like to tell me about doing okay with dementia?**