

# Declining with purpose: Resilience despite Cognitive Decline

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## Abstract

*This study represents a secondary qualitative data analysis of a sub-set of participants (n = 3) from the Alzheimer's and Emotions study who exhibited resilience. Interpretive Phenomenological Analysis was used to delve deeper into the characteristics and common themes surrounding these participants. Strategies for adapting and meaning making each one comprised in three subordinate themes. Adaptation included decisions that participants and their care providers made which aided in their adapting to their evolving condition. These included appraising one's current abilities, reappraising abilities and putting things into perspective, and adjustment to one's current needs and level of functioning. Participants found meaning by reminiscing about the things that made their life meaningful in the past, embracing their current*

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*identity as someone with MCI/AD, and maintaining familial and non-familial social support relationships. These non-pharmacological strategies might be helpful in developing resilience among a population of persons with MCI/AD.*

**Keywords:** Awareness; Dementia and Cognitive Disorders; Emotion/Worry; Self-efficacy/Coping; Mild Cognitive Impairment.

## 1. Introduction

Behavioral and emotional disturbances are common (up to 90%) in people living with mild cognitive impairment or Alzheimer's disease (MCI/AD) (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012) and are among the most frustrating conditions for informal care partners (Aalten, Van Valen, Clare, Kenny, & Verhey, 2005). Many of these disturbances can be related to anosognosia, a lack of self-awareness of cognitive impairment, a condition occurring in up to 80% of persons living with MCI/AD experience (Mograbi, Ferri, Sosa, Stewart, Laks, Brown *et al.*, 2012; Turró-Garriga, Garre-Olmo, Calvó-Perxas, Reñé-Ramírez, Gascón-Bayarri, & Conde-Sala, 2016; Simm, Jamieson, Ong, Garner, & Kinsella, 2017; Verhulsdonk, Lange-Asschenfeldt, Höft, Schwender, Supprian, Hellen *et al.*, 2017). These individuals often experience behavioral disturbances such as psychosis, agitation, and aggression. Yet a smaller subset of persons with MCI/AD remain self-aware and capable of self-reflection (Clare, Marková, Roth, & Morris, 2011). Clare and colleagues, described awareness as “a reasonable or realistic perception or appraisal of a given aspect of one's situation, functioning or performance, or of the resulting implications, which may be expressed explicitly or implicitly” (Clare, Rowlands, Bruce, Surr, & Downs, 2008). Self-aware individuals with dementia frequently experience emotional disturbances, such as depression (Aalten *et al.*, 2005; Seiffer, Clare, & Harvey, 2005; Morris, Mograbi, Brown, & Salas, 2012).

Emotional disturbances among persons living with dementia may be a rational response to undesirable social situations such as repeated cognitive testing (Sabat & Harré, 1994). Cognitive examinations might be a source of embarrassment as patients are aware they will continue to score poorly on these tests as their cognition declines overtime. Relatedly, a person experiencing an unsupportive social environment may become depressed or apathetic, a rational response in this situation (Sabat & Harré, 1994). A variety of psychological and social resources such as the ability to apply adaptive coping strategies and identifying meaning have an impact on the degree to which a person may experience emotional disturbances (Clare, 2002). Central to adaptive coping a person must appraise and accept their diagnosis in order to willingly modify their lifestyle to match their changing abilities, retrospectively assess their abilities in order to provide a realistic picture of what has changed, and finally apply appropriate adjustments (Robinson, Clare, & Evans, 2005). Additionally, the ability to find meaning in day to day life, termed meaning making, has been highlighted as a critical

component for maintaining continuity following declining health (Frankl, 1985; Menne, Kinney, & Morhardt, 2002). There exists multiple potential resources for increasing meaning following declining health including a review of positive experiences through one's life, termed reminiscing (Beike & Niedenthal, 1998; Singer, 2004), embracing a new identity (Malhotra & Rowe, 2014), and socially supportive environments (Clare, Nelis, Martyr, Roberts, Whitaker, Markova *et al.*, 2012; Woods, Nelis, Martyr, Roberts, Whitaker, Markova *et al.*, 2014; Clare, Quinn, Jones, & Woods, 2016; Halpin, Dillard, & Puentes, 2016). Although psychological and social resources, including those that help people adapt to their changing health and find meaning affect about 80% of health outcomes, healthcare spending is largely directed toward clinical care, not improving the social environment (Teutsch & Fielding, 2011).

Although there have been frequent calls for non-pharmacological interventions as a first treatment for emotional disturbances (Gitlin, Kales, & Lyketsos, 2012; Kales, Gitlin, & Lyketsos, 2015), over 40% of persons with MCI/AD are prescribed medication for mental health reasons (Puranen, Taipale, Koponen, Tanskanen, Tolppanen, Tiihonen *et al.*, 2017). This is despite the immediate risks related to polypharmacy, such as adverse reactions and inappropriate prescribing, that can lead to a cascade of other health problems, such as falls (Berry, Placide, Mostofsky, Zhang, Lipsitz, Mittleman, *et al.*, 2015). Informal care partners are often tasked with making decisions regarding what treatments to pursue – an assignment that is exacerbated by the challenge that the majority of care partners have no formal training for this new role. Consequently, many care partners mistakenly believe that medications are safe and effective, and therefore non-pharmacological treatment options are not pursued (Kerns, Winter, Winter, Kerns, & Etz, 2017).

Self-awareness for a person living with MCI/AD can be devastating for both the patient and the informal care partner, often leading to emotional turmoil that is treated pharmacologically. Yet a small contingent of patients with MCI/AD exhibit high levels of resilience despite their self-awareness (Clare, 2002). The current study explored the lived-experience of three patient/care partner dyads who navigated their diagnosis of MCI/AD through a combination of adaptive strategies and meaning making. The goal of the current study was to gain a thorough understanding of the factors that allow persons with cognitive impairment to adapt to their evolving MCI/AD status.

## 2. Methods

### 2.1. Participants

This study represents a secondary data analysis on a sub-set of participants from the Alzheimer's and Emotions study (Halpin *et al.*, 2016), which investigated the emotional reactions to the progression of MCI/AD. Additional details of the analysis and recruitment were previously described by Halpin and colleagues (Halpin *et al.*, 2016). In the original study, fourteen patient/informal care partner dyads participated in one hour, semi-structured interviews. Three patient participants understood the limits of their evolving condition, and with support from their formal and informal care partners, they were able to adjust their activities to meet their current abilities and needs and accept their condition. Interviews with these fully adaptive participants are the focus of the current study. Additional data from the Alzheimer's and Emotions study available for this analysis included the patient's Functional Assessment Staging (FAST) of Alzheimer's Disease scale score, which was abstracted from the electronic health records (Reisberg, 1988), a short demographic questionnaire, and the Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975), both of which were administered by the interviewer. This study was reviewed and approved by the Emory University Institutional Review board. All participants and their care partners gave informed consent.

#### 2.1.1. Description of the Sample

Participants were two females and one male along with their informal care partners. All participants were white and living in the metropolitan area of a large city in the Southeastern United States (Tab. 1).

Table 1 - *Demographics*

Characteristics	Mrs. Cezanne	Mr. Page	Mrs. Alvarado
Age	71	66	78
Sex	Female	Male	Female
Race	White	White	White
Education	Bachelor's degree	Graduate degree	High school graduate
Who do you live with?	Spouse	Spouse	Spouse
Diagnosis	Alzheimer's disease	Alzheimer's disease	Mild Cognitive Impairment
FAST score	5	3	2
MMSE score	24	21	29

*Note:* FAST = Functional Assessment Staging; MMSE = Mini-Mental State Examination.

## 2.2. *Materials and Procedures*

Data were analyzed using an Interpretative Phenomenological Analysis (IPA) approach by a researcher who did not perform the interviews. As Smith and Osborn (2004) explain, “Research questions in IPA projects are usually framed broadly and openly. There is no attempt to test a predetermined hypothesis of the researcher; rather, the aim is to explore, flexibly and in detail, an area of concern” (p. 55). IPA is established within two branches of philosophical thought: phenomenology and hermeneutics (Smith & Osborn, 2004). Phenomenology is concerned with the way people gain knowledge in the world, as influenced by language, thought, feelings, and physical experience. The hermeneutic approach embraces that meaning can be attained through reflection. The basis for this approach is understanding the lived-experience from another person’s point of view, and to appreciate the social and cultural context that may influence that outlook.

Analysis proceeded in a process that included initial exploration of the data, a review of the emergent themes, and a final synthesis of the themes across cases. The detailed, interpretative, case-by-case analysis of individual transcripts involved in IPA is best suited for small samples (Smith, 2004; Smith, Flowers, & Larkin, 2009). The idiographic nature of IPA requires each transcript is read closely and multiple times to become familiar with the content. In addition, the researcher listened to each of the interview tapes to check for transcription errors and to add additional dimensions of data analysis, noting voice inflection and timing. During this phase, unfocused initial notes were made in the left-hand margin of the transcript to summarize the content. Next, the researcher reviewed the entire transcript, seeking patterns or inconsistencies within the interview. This step included identifying repeated language and evaluating the meaning of the repeated language and how the participant had made sense of the phenomena or how they presented themselves in relation to it. Emergent conceptual themes that captured the essence of the participant’s account were noted in the right-hand margin on each of the three individual transcripts. Finally, a list of superordinate themes was constructed through clustering of themes and the links between them. These clusters were repeatedly matched with the text, and linked with the language participants used to illustrate their interpretations, ensuring that emergent themes were grounded in the participants’ accounts (Elliott, Fischer, & Rennie, 1999). Analysis proceeded in this way through repeatedly examining the transcripts and updating or revising the superordinate themes accordingly.

As the purpose of IPA is to understand the participants' lived-experience, it is also necessary to reflect on the researcher's own worldview and how this might influence the researcher's interpretation of the data (Elliott *et al.*, 1999; Biggerstaff & Thompson, 2008). In this regard, the researcher maintained a reflective diary, including personal thoughts and reflections, throughout the research process.

### 3. Results

Below is a brief description of each participant, followed by highlighted representative quotes and examples of each superordinate theme identified. To ensure anonymity, pseudonyms are used for each dyad.

#### 3.1. Participants

Mr. Page is a 66-year-old married, white male. He attended a school focused on computer technology before joining the Army where he reached the rank of Captain. While serving during the Vietnam War he worked in data processing and munitions. Upon returning home, he worked for an electrical engineering and manufacturing company. Mr. Page also attended night classes at a local university where he earned his master's degree in Marketing with a focus on Data Processing in the early 1970s. An early adopter of computer technology, Mr. Page stated, "[school name] was fun because they had uh, computers that you couldn't get anywhere else. The uh, IBM 3270's and the uh, Spetra 70". Eventually he joined a large technology company and was responsible for establishing data centers. Mr. Page was diagnosed with nasal/paranasal cancer along with an autoimmune disease for which he was prescribed 60mg of Prednisone for an extended period. At a standard medical check-up about four years prior, it was discovered that Mr. Page had a detached retina, likely resulting from his high dose of prednisone, and had experienced vision loss. Given he had not reported the vision issue, his optometrist recommended an additional neurological screening which led to his diagnosis of probable AD. Currently Mr. Page needs help with multiple Activities of Daily Living (ADL's) and Instrumental Activities of Daily Living (I-ADL's) including dressing himself – especially picking out clothes and dressing correctly, bathing, meal preparation, and driving.

Mrs. Alvarado is a 78-year-old married Hispanic female. She is originally from Puerto Rico and Spanish is her first language. At eighteen years old,

she moved to New York City for medical treatment. There she met her husband and had her first daughter. When she became pregnant with her second child, the couple moved back to Puerto Rico, where she had a third child. One-by-one her children moved to Georgia to attend college and each child stayed. As her daughters married, Mrs. Alvarado pined to join them and be near when her grandchildren were born and her children urged her to move closer. She recalled her daughter stating “mommy it has to be Georgia. I cannot, I cannot uh, I cannot think of having any children without you here and she really meant it the year after her first child was born the year after we got there”. Mrs. Alvarado’s voice shone with excitement when she talked about her grandchildren, stating “Oh they are my life \*laughs\* we love them so much”. About three years ago, Mrs. Alvarado’s daughter noticed that she was having difficulties completing normal tasks; subsequently she received a diagnosis of MCI. She mostly stopped cooking, as she “gets confused”. She is still responsible for the family accounting but now relies heavily on her daughter to help her with this task.

Mrs. Cezanne is a 70-year-old married white female. As a young woman, Mrs. Cezanne attended architecture school in the northeastern United States because “there weren’t any schools to take her in the southeast”. Always motivated, she spoke fondly about her previous position, which resulted in her flying “all over the country lecturing”. Several members of her family had experienced Lyme disease so when she began to have similar symptoms she attributed them to that condition. Ultimately, her doctors diagnosed her with probable AD five years before the interview. Along with her cognitive decline, including difficulties in finding words and general “fuzziness”, she experienced problems with motor control that created an increasing fall risk. The independent Mrs. Cezanne now holds her husband’s hand while navigating stairs and the couple decided to move from their large home to an independent living facility in a suburban neighborhood. Immediately following her diagnosis, Mrs. Cezanne was proactive about taking regular driving tests – though she was not happy when she received an unfavorable score and was told she should stop driving. “I flunked \*laughs\* and the, and I threw my pen across the room at the interrogator. And she left very quickly”. Despite this initial anger, Mrs. Cezanne quickly accepted her new situation and gave her car to her son. In addition to no longer driving, Mrs. Cezanne needs help dressing herself, particularly in the mornings when she is “most fuzzy”.



### 3.2. *Adaptation*

As highlighted above, each of the three participants experienced varied levels of independence in their life prior to their cognitive impairment diagnosis. Following their diagnosis, all participants made key decisions that allowed them to adapt to their changing abilities and care needs. The theme of adaptation comprises three sub-themes of appraisal and acceptance, retrospection, and adjustment to the current situation.

#### 3.2.1. *Appraisal and Acceptance*

For all three participants, their capacity to appraise their current physical and cognitive function was essential for their ability to adapt to their changing cognitive status. The act of appraisal was often facilitated and supported by the informal care partner taking on an additional responsibility. This was true for Mrs. Cezanne, who had given up driving. Initially this angered Mrs. Cezanne but shortly thereafter, she became content with the new arrangement. Mr. Cezanne commented, “I have driven her everywhere <since> and we have a close relationship because we spend time in the car and if I need to I just take a book or a magazine or a computer and I just do my thing while she is doing whatever she is doing, so it worked out remarkably well”.

At times, this appraisal process was not instantaneous and instead required time for the changes to be implemented. This is the case for Mr. Page, who as described above, experienced vision loss that was identified by his formal caregiver. Despite his continued difficulty with depth perception, he continued to drive following this realization. Only after experiencing several minor car accidents did he appraise himself as unfit to drive.

- Investigator: You, did you have to give up driving because your
- Mr. Page: Oh, immediately, yeah it was the, uh, the fifth or the sixth accident in a week that I figured out that I was not going to be doing this for much anymore. And I gave her my license and said you are driving now \*laughs\*.
- Mrs. Page: Lucky for me \*Stated in a joking, but positive, tone\*

Due to her diagnosis, Mrs. A is less able to contribute to daily tasks at home, such as cleaning. However, no task has replaced this as her contribution to the household. Consequently, Mrs. A now feels guilty for taking time to read, a lifelong passion, instead of contributing to household

chores. “I love to read but I have many other things to do that I feel like guilty, like bad, sitting down to read and I wish that I would take this away from me, she said”. Some of this guilt may influence her appraisal that she is less able to contribute to daily tasks at home, such as cleaning. She elaborated that “I feel like uh, I shouldn’t be doing this because I have to do that other thing...like cleaning or paperwork”. Despite this guilt, she reads about an hour a day, “From ten until I go to bed that’s when I read a little bit”.

### 3.2.2. *Retrospection*

In addition to appraisal of current abilities, participants and their care partners reflected on the patients’ premorbid levels of functioning to give a realistic appraisal of what had changed since their diagnosis.

Rather than experience distress that her difficulty with wayfinding was a sign of her cognitive decline, Mrs. Alvarado identified that this had indeed always been a challenge for her.

- Mrs. Alvarado: I have always, um, since young, um, since my children were small I remember I used to get lost very often uh, like um, especially turning on my turns when I was supposed to go right I would go left and visa-versa and my children when they were with me in the car they would tell me, no-no mom it’s the other way but I think that’s something that has been in my life forever
- Mr. Alvarado: Yes, when we were driving and she was telling me direction when she used to tell me to turn right I used to turn left
- Mrs. Alvarado: \*laughs\*
- Mr. Alvarado: And she would say “I told you right” but I knew that I was right, you know then, ohhh this is the way

This reappraisal of pre-morbid abilities was also evident for Mrs. Cezanne given her being “fuzzy” in the mornings. Her husband described that she requires help getting dressed in the morning, “She needs some help with that. She is most fuzzy in the morning. We understand a lot of Alzheimer’s patients have sun-downing affect but she is ready to go in the evening. But in the morning she can be a very fuzzy person”. Yet, the couple reflected that this was not a surprise because, “She has always been an evening person. I was reverse. We matched each-taking care of kids was good because I was in the morning taking care of her and she was up late taking care of her [them]”.

### 3.2.3. Adjustment

Adjustment involved adapting not by relinquishing a responsibility such as driving, but by modifying a situation or avocation in order to achieve a desirable result. This was evident for participants and supported by their informal care partner. Mrs. Cezanne, a lifelong painter who described her art style, prior to her diagnosis, as pictorial. Following her diagnosis, her painting style adjusted over time. Her husband described the change, “Her work is changing. She is still quite creative but it changed, it has changed distinctly. That is the kind of thing she is doing now. Which I like a lot”. Mr. Cezanne continued with his supportive language used to describe the changing painting style, “It’s just, not pictorial like she used to do. And uh, she has gotten much more abstract and has been very successful at it in my opinion”. Adjusting to changing circumstances was tied to the informal care partner’s ability to amend their own expectations and provide a supportive environment. This was also evident in the ample art supplies Mr. Cezanne ensured were available and the art retreat that Mrs. Cezanne had attended in North Carolina. Furthermore, her church helped support her art by hanging some of her paintings in their gallery.

For all participants, informal care partners were critical for providing a supportive environment for maintaining daily tasks. Rather than forbidding participants to complete tasks that had become part of their identity, these tasks were modified to fit the participant’s current and changing abilities. This was true for Mrs. Alvarado, who had always been the family accountant. Although difficulties with managing money is often one of the first challenges a person with cognitive impairment experiences, Mrs. Alvarado began receiving help from one of her daughters.

- Mrs. Alvarado: “I admit I am having some problems with it because so we get billed for things that I don’t think we should have been billed for and I used to be very good at that, coming back you know and why this and no-no-no. I go to my daughter because I find [...] I am not capable now of doing that because I get confused so I, I can, I can admit that [...] my daughter helps me and so many that she has called and they say no that you don’t have to pay it because blah-blah-blah and that’s what I used to do in the past I used to be able to handle that I um, I get nervous and I kind of do not understand the other side when I do it so I have given that to my daughter she is very good at that”.

### 3.3. *Meaning Making*

Meaning making or an overall sense of purpose was important for maintaining daily motivation. Participants each found meaning through their self-identity and some combination of the subthemes of meaning making: reminiscence, their current identity, and important social relationships.

#### 3.3.1. *Reminiscence*

Participants found meaning through reminiscence, or thoughtfully recalling meaningful events from their own past. These positive events were authentically recalled and reflected on rather than ruminated over as situations that cannot be obtained again. This thoughtful recounting of the past helped participants to attach meaning to their lives. Mr. Page in particular reminisced about his past employment in data processing, “I really felt like I was doing important work”.

#### 3.3.2. *Embracing AD Identity*

Participants were not only self-aware of the prospects related to their diagnosis, but also they embraced this new identity. Mrs. Cezanne adopted her new self-identity as someone living with AD. “I think that people who keep things inside too much, um. It is not good...I set out to be the poster child”, she remarked. Indeed, Mrs. Cezanne took an advocacy position – speaking to future formal care providers, “Well, I think one of the things that I have done is, I, the, the um, going to the auditorium and talking to medical student-school people about Alzheimer’s”. This opportunity was supported by her formal care providers as Mr. Cezanne recounts, “Oh, yeah her doctors have given her little hot spot opportunities. He got her to speak to a couple hundred young doctors at <the local hospital> in a very big forum where she was telling them about. Just to help them know what a person that’s got Alzheimer’s is like”.

In addition to advocating to the medical community, she arranged a support group, first for people with AD and then adding persons with Parkinson disease. “I started an Alzheimer’s group at our church. And it has just morphed into Parkinson and all the other dementia’s and we get together twice a month and talk”. The couple also each attended other outside support groups for AD, as Mr. Cezanne reported, “she has done extremely well, I think, in rationally thinking through her disease and how she wanted to approach it, keeping her spirits up and having, like she has explained already I think, being very open to the world about everything and helping other

people learn that it's ok to be open and she set up her own Alzheimer's group and we go to, actually I go to four more and she goes to three more".

Support groups also gave an opportunity to build a community of like-minded individuals as reported by Mr. Page who attended monthly support group luncheons over the past four years. "We started with what, four, four years ago now, um are still coming together and we see them and they are almost like family because we, we, we know their story...I find that to be a very uh, exhilarating, uh, experience because the, the uh, the zest, the enthusiasm, the um, sometimes funny uh things that uh people share it's, it's really heartening and well worth our time as far as I am concerned".

### *3.3.3. Social Relationships*

Social relationships provided a basis for meaning making among each of the participants. Mrs. Alvarado exemplified this construct given her lifelong closeness with her immediate family. As mentioned above, she relocated from Puerto Rico in order to be with her children and grandchildren. She spoke fondly about babysitting her granddaughter, "My son's daughter she's seven so tonight we are going to stay over because they live right near around the area so, wonderful". Likewise, Mr. Page looked forward to planning a family vacation with his children and grandchildren, "There are going to be eight of us from the family all going together on a cruise and...I am really pumped about that so (laughs)".

Non-familial relationships also played an important role in making meaning for participants. For Mrs. Cezanne, these non-familial relationships were especially important when it came to dancing. The independent living facility where she and her husband lived held at least one dance a week and Mrs. Cezanne was often the one to gather others and begin dancing. Her husband talked about how she had just recently gathered a group of five other women to dance. "When she goes to the third floor here we are certain what she will do as soon as the music comes on she'll get up and dance. Even if she gets back to the chair afterwards and just you know goes into an Alzheimer's state of non-recognition of anything".

## 4. Discussion

This study represents an initial effort to describe the lived-experience of three patient/informal care partner dyads who not only navigated their illness without emotional pathology but also, with the support from their care partner, sought opportunities to thrive. While previous studies have

identified that resilience is possible among this population (Clare, 2002), few have explored the mechanisms that might lead to resilience. In the current study, persons with MCI/AD utilized various strategies to remain resilient including adapting to and find meaning in their life despite their declining cognitive and physical functioning. These strategies included adaptation through appropriately supportive environments and identifying and sustaining meaning in life.

Persons with higher levels of self-awareness require more supportive environments in order to avoid negative emotions (Clare *et al.*, 2016). This supportive environment is likely beneficial to both the patient and the informal care partner (Frazer, Oyebode, & Cleary, 2012). Previous studies have shown anosognosia to decrease quality of life in both persons with MCI/AD and care partners (Nelis, Clare, Martyr, Markova, Roth, Woods *et al.*, 2011). Likewise, care partners' quality of life is predictive of a person with mild-AD's level of awareness (Sousa, Santos, Nogueira, Belfort, Rosa, Torres *et al.*, 2015). In the current study, informal care partners were able to adjust their expectations of their partner while concurrently allowing resilient patients to maintain their autonomy.

Identifying and sustaining meaning in life is challenging for this population, particularly as it relates to experiencing ageism. Ageism has been considered a defensive reaction to others becoming dependent and/or mentally unstable (Flicker, 1999). Unaffected persons often avoid persons with MCI/AD, by emotionally and physically distancing themselves from the afflicted person (Halpin, 2015; Swift, Abrams, Lamont, & Drury, 2017). Likewise, persons diagnosed with MCI/AD may isolate themselves in order to avoid the depersonalization often felt with declining cognition and physical functioning. As a result of this isolation, persons with MCI/AD may have less social resources at their disposal – leading to more negative emotions (Clare *et al.*, 2012; Woods *et al.*, 2014; Clare *et al.*, 2016; Halpin, Dillard, Idler, Clevenger, Rothschild, Blanton, *et al.*, 2017). Indeed the threat of ageism may decrease results of cognitive tests enough to suggest pathological cognitive impairment (Mazerolle, Régner, Barber, Paccalin, Miazola, Huguet *et al.*, 2016). Yet, previous studies have shown that social involvement can decrease this threat (Sabat, 2014). Despite experiencing persistent levels of ageism over time, one group of older adults who volunteered for a program they found meaningful reported lower levels of anxiety toward that ageism following their volunteer commitment (Halpin *et al.*, 2017). In the current study, resilient participants not only took pride in the things they accomplished before their MCI/AD diagnosis, but they also

took on a new mission of advocating for and connecting with others with similar conditions. These roles may have a protective effect against ageism.

This study represents an in-depth exploration of the lived-experience for three patient/informal care partner dyads. IPA is well suited for small-samples as the method allows for the detailed accounting of individual experiences (Smith *et al.*, 2009). Nevertheless, small samples do not allow for generalizability to a wider context, particularly considering that our sample was racially homogeneous. Although our sample was diverse educationally, future studies should seek to confirm these results using larger and more diverse samples. Additionally this study involved an hour-long interview with each dyad. It is likely that coping strategies alter over time with changing circumstances. As the current study is a secondary data analysis, additional data collection was not feasible. Additional interviews over time could help to determine the stability of the coping techniques described above.

This study revealed common themes across patients identified as resilient despite their MCI/AD diagnosis. Taking into account individual characteristics is important for creating a supportive environment – such as reflecting on a person’s pre-morbid abilities to contextualize their changing cognition. There were also supportive situations that spanned each of our participants such as having opportunities to make their life feel meaningful. Understanding the coping resources used by persons living with MCI/AD who have positively navigated their illness could help develop, target, and advocate for non-pharmacological strategies for MCI/AD patients even prior to distress due to emotional disturbances. Effective non-pharmacological approaches could not only significantly improve MCI/AD patients’ quality of life, but also save in health care expenditures among persons living with MCI/AD.

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