'I wish they would remember that I forget:' The effects of memory loss on the lives of individuals with mild-to-moderate...
'I wish they would remember that I forget:' The effects of memory loss on the lives of individuals with mild-to-moderate dementia

Sara M Powers, Nicole T Dawson, Maura L Krestar, Sarah J Yarry and Katherine S Judge

Dementia published online 7 October 2014
DOI: 10.1177/1471301214553236

The online version of this article can be found at:
http://dem.sagepub.com/content/early/2014/10/07/1471301214553236

Published by:
SAGE
http://www.sagepublications.com

Additional services and information for Dementia can be found at:

Email Alerts: http://dem.sagepub.com/cgi/alerts
Subscriptions: http://dem.sagepub.com/subscriptions
Reprints: http://www.sagepub.com/journalsReprints.nav
Permissions: http://www.sagepub.com/journalsPermissions.nav
Citations: http://dem.sagepub.com/content/early/2014/10/07/1471301214553236.refs.html

>> OnlineFirst Version of Record - Oct 7, 2014
What is This?
‘I wish they would remember that I forget:’ The effects of memory loss on the lives of individuals with mild-to-moderate dementia

Sara M Powers
Department of Psychology, The College of Saint Rose, Albany, NY, USA; Department of Psychology, The University of Akron, Akron, OH, USA

Nicole T Dawson
Department of Psychology, Cleveland State University, Cleveland, OH, USA

Maura L Krestar
Department of Clinical Health Sciences, Texas A&M University Kingsville, Kingsville, TX, USA; Department of Psychology, Cleveland State University, Cleveland, OH, USA

Sarah J Yarry
VA New York Harbor Health Care System, Brooklyn Campus, New York, NY, USA

Katherine S Judge
Department of Psychology, Cleveland State University, Cleveland, OH, USA; Margaret Blenkner Research Institute, Benjamin Rose Institute on Aging, Cleveland, OH, USA

Abstract

Purpose of study: Due to changing cognitive and functional capabilities, individuals with dementia face challenging care-related issues such as feelings of embarrassment, relationship strain, and symptoms of depression and anxiety. Limited research exists examining individuals with dementia’s perceptions and concerns about these issues and how their perspectives can impact the quality and process of their illness experience.

Design and methods: As part of a larger study, individuals with dementia (n = 114) answered five open-ended questions about their illness experience including: (1) daily routine, (2) concerns about memory loss, (3) relationships with others, (4) fears, and (5) what they wish others understood/knew. For each question, individuals with dementia’s responses were analyzed for common themes within and across questions.

Corresponding author:
Katherine S Judge, Department of Psychology, Cleveland State University, 2121 Euclid Avenue, CB 109, Cleveland, OH 44115, USA.
Email: k.judge46@csuohio.edu
Results: Individuals with dementia commented on a wide range of issues involving their memory loss, including negative emotional impacts, future concerns and illness progression, forgetting, loss of independence, and the negative and positive influences on interpersonal relationships. Across questions, many individuals also stated that their memory loss did not significantly impact their lives.

Implications: Discussion highlights how these findings can be used to expand our understanding of individuals with dementia’s illness experience and to develop efficacious interventions for addressing negative aspects of living with memory loss while supporting positive aspects.

Keywords
dementia, illness experience, memory loss, stress process model for individuals with dementia, subjective experience

The diagnostic rate of individuals affected by dementia-related illnesses continues to grow each year (Ory, Yee, Tennstedt, & Schulz, 2000) and is projected to affect over 13 million people by the year 2050, with Alzheimer’s disease as the most common diagnosis (Hebert, Scherr, Bienias, Bennett, & Evans, 2003). The majority of psychosocial research on such illnesses has examined the physiological, emotional, and psychological needs and burdens of caregivers of individuals with dementia (IWDs) (Leggett, Zarit, Taylor, & Galvin, 2010; Pearlin, Mullan, Semple, & Skaff, 1990; Zarit, Todd, & Zarit, 1986). Only recently have IWDs been included in the research process (de Boer et al., 2007; Pearce, Clare, & Pistrang, 2002). Part of this exclusion stems from IWDs’ cognitive and functional losses (Cotrell & Schulz, 1993) along with perceptions that IWDs are not able to reliably discuss their illness experience (Carpenter, Kissel, & Lee, 2007).

To better understand the illness experience from the perspective of the individual, a small but growing number of researchers have advocated for the inclusion of IWDs in the research process (Aminzadeh, Byszewski, Molnar, & Eisner, 2007; Clare, 2010; Clare, Roth, & Pratt, 2005; Harris, 2002; Menne, Judge, & Whitlatch, 2009; Menne, Kinney, & Morhardt, 2002). As such, studies have found that IWDs can provide accurate and meaningful information about their own personal illness experience (Arlt et al., 2008; Yarry, Judge, & Orsulic-Jeras, 2010; Clarke, Tucke, & Whitlatch, 2008; Lodgson, Gibbons, McCurry, & Teri, 2002; Krestar, Looman, Powers, Dawson & Judge, 2012; Whitlatch, Feinberg, & Tucke, 2005). Focusing on the illness experience from the perspective of the individual may elucidate significant aspects of living with dementia that cannot be garnered from proxy reports and also highlight areas needing additional research and the development of intervention protocols.

To date, studies examining the illness experience of IWDs have been based on relatively small samples and have focused on the early stages of the disease. Generally, these authors have identified various areas that IWDs have reported to be important to their illness experience, such as maintaining a sense of self as well as positive interpersonal relationships. For example, Harman and Clare (2006) used semi-structured interviews allowing participants to guide the interviewer through their own experiences with dementia and memory loss by explaining their coping strategies, understandings of the disease, and personal representations of dementia. Two
themes emerged within this study (“It will get worse” and “I want to be me”) showcasing how IWDs were making sense of their diagnosis and also wanting to maintain their personal identity. The sample consisted of only early-stage IWDs, which may not generalize to individuals with more moderate-to-severe symptoms of dementia.

Wolverson, Clarke, and Moniz-Cook (2010) explored preservation of hope in IWDs. Their analysis revealed that IWDs emphasized themes dealing with the realization of limitations and adjustment of goals, as well as the importance of maintaining current quality of life (e.g., maintaining relationships and health, positive coping). This study included 10 IWDs in the early stages of the disease and strictly focused on the relevance of hope. Although the goals of previous studies may not be to generalize the illness experience of IWDs, it is imperative that researchers explore the lived experiences of larger samples of IWDs with a range of dementia symptoms.

Other qualitative studies have evaluated the impact of a dementia diagnosis and found that IWDs respond with a range of emotional reactions (e.g., denial, grief, positive coping responses), allowing researchers to infer both personal coping strategies as well as the effects of stigmatizing labels associated with the diagnosis of dementia (Harris & Durkin, 2002). Menne, Kinney, and Morhardt (2002) focused on interview questions associated with changes in relationships, major concerns about daily activities, fears associated with the disease, and limitations in a sample of six individuals in the early stages of dementia. Results found that IWDs routinely commented on their desire to maintain continuity (e.g., ability to drive, help others, or complete daily activities) while simultaneously coping with dementia-related changes. Menne and colleagues (2002) also applied a theoretical framework (e.g., continuity theory) to illuminate the illness experience of early-stage IWDs.

Overall, the research findings to date have found IWDs can provide meaningful information about living with dementia. However, these promising results are limited by the small sample sizes used and the restricted range of dementia severity. By including individuals in the early stages of the illness, these findings may not be generalizable to, individuals with more moderate-to-severe symptoms. For example, individuals with mild symptoms of dementia may have different concerns and daily challenges such as driving, continuing to work, or accepting their diagnosis. Whereas individuals with moderate-to-severe symptoms may struggle more with completing personal activities of daily living, living in a nursing home, or feeling frustrated and embarrassed about their memory loss. Including individuals with a range of dementia severity would address this gap in the literature and would provide important information about the illness experience.

It has been noted that previous researchers utilizing a form of qualitative analysis have often ended qualitative themes too soon, disregarding the addition of more participants within the qualitative analysis (Dey, 1999). Along with this analytical issue, there are very little resources that provide strict guidelines for sample size and are typically ambiguous with specific limits (e.g., What constitutes a small or large enough sample size?). The current study addresses this gap in the literature by using a much larger sample and by including individuals with a range of dementia symptoms (i.e., mild to moderate). The inclusion of a larger sample representing a wider range of dementia symptoms would add to our current understanding of the illness experience.

Additionally, as noted by Menne et al. (2002), the application of theoretical frameworks for understanding the illness experience of IWDs has been limited. The current study also addresses this gap in the literature by using The Stress Process Model for Individuals with Dementia (SPM for IWDs) (Judge, Menne, & Whitlatch, 2010). Adapted from the stress process model for
caregivers (Pearlin et al., 1990), the SPM for IWDs addressed the lack of conceptual models in the literature and proposed a theoretical framework for studying the illness experience of IWDs by integrating the emotional, functional, and psychological viewpoints of IWDs. Similar to the original model, the SPM for IWDs highlights direct and indirect pathways among the interrelated constructs that may factor into the illness experience. The SPM for IWDs consists of primary objective and subjective stressors (e.g., cognitive and functional status, perceived distress, role captivity, perceived dependency), which have an impact on secondary role and intrapsychic strains (e.g., family, work, and social role strains, self esteem, self-efficacy), that also affect various outcomes of well-being (e.g., quality of life, depression, anxiety). Other varying factors include background and context characteristics (e.g., age, gender, socioeconomic status, education level) and potential mediators of the stress process (e.g., personality, spirituality, social support, financial resources).

Guided by the SPM for IWDs (Judge et al., 2010), the current study utilized selective components of this model (i.e., primary stressors, secondary strains, and mediators) to build upon the work of Menne et al. (2002) and further develop questions aimed at understanding specific areas and issues (e.g., perceived distress and dependency, family and role strain, self esteem, social support) associated with the illness experience.

**Methodology**

**Design**

The current study was part of a larger randomized control trial of a dyadic caregiving intervention, Project *ANSWERS* (Judge, Yarry, & Orsulic-Jeras, 2010; Judge, Yarry, Looman, & Bass, 2012). Data for the subsequent analysis were collected as part of the larger Project *ANSWERS* study during the Time 2 in-person interviews where participants were asked a series of self-report Likert-type scale measures and five open-ended questions. Only data from the five open-ended questions are analyzed and discussed in this paper.

**Participants**

Participants were recruited through 16 local service agencies in the Greater Akron and Cleveland area, including various Alzheimer’s Association Chapters. Inclusion criteria included older adults who (a) had a diagnosis of memory impairment, (b) had a family caregiver, (c) were community dwelling, and (d) a score of 7 or above on the Mini-Mental State Examination (MMSE) (Judge et al., 2010). Reasons for exclusion consisted of (a) placement in a nursing home, (b) death, and (c) not meeting the MMSE score cut off. A total of 190 caregiving dyads were identified as possible participants for the current study. Thirty-eight declined to participate and 21 dyads were not eligible to participate. Reasons for not participating in the study ranged from being too busy to the caregiver indicating that the IWD would be too impaired to participate. A total of 131 dyads agreed to participate in the study and 114 IWDs were able to provide responses to the open-ended questions.

The analysis for this paper is based on the 114 older adults who completed the five open-ended questions. Participants were experiencing mild-to-moderate symptoms of cognitive impairment, as indicated by a mean MMSE score of 22.54 (standard deviation (SD) = 5.55). Over half of the participants were female (54.4%), ranging in age from 50 to 95 ($M = 77.32; SD = 9.54$) and the majority of participants had a diagnosis of Alzheimer’s disease (50.0%). Table 1 displays the participants’ full demographic profiles.
Data collection

Approval for this project was received from the Institutional Review Boards of The Benjamin Rose Institute on Aging and Cleveland State University. As mentioned earlier, the focus of the present paper is the results from the five open-ended questions. Guided by a similar study methodology (Menne et al., 2002), the open-ended questions were administered verbally and did not have prepopulated responses or options, allowing for a wide range of responses from participants (e.g., “What do you fear most about your memory loss?”). Participant’s responses to each of the five open-ended questions were recorded verbatim by an interviewer and then transcribed into a data worksheet.

Unless IWDs preferred a different location, all interviews took place in the home of the participant, promoting a confidential and relaxed environment. All interviewers had extensive experience working with IWDs and were trained how to maintain professionalism and avoid the influence of personal biases and experiences. The five open-ended questions were asked at the end of the full interview protocol, allowing interviewers to build rapport with participants and allowing IWDs to speak freely and comfortably about their illness experience. On average, interviews lasted approximately 45–60 min.

Data analysis

Guided by a coding process developed by Strauss (1987), two primary coders (S.P. and N.D.) and two additional team members (M.K. and K.J.) utilized coding strategies that allowed for a systematic grouping of IWDs responses. First, concept indicators were identified for each of the five interview questions, which assigned various descriptive labels to multiple response units (e.g., sentences and response paragraphs) and aided in the sorting and understanding of

Table 1. Demographic information (n = 114).

<table>
<thead>
<tr>
<th>Respondent characteristic</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (range = 50–95 years)</td>
<td>77.32</td>
<td>9.54</td>
</tr>
<tr>
<td>MMSE score (range = 0–30)</td>
<td>22.54</td>
<td>5.55</td>
</tr>
<tr>
<td>Spouse of caregiver</td>
<td>59.7</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>54.4</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>86.1</td>
<td></td>
</tr>
<tr>
<td>College graduate</td>
<td>25.4</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>61.4</td>
<td></td>
</tr>
<tr>
<td>Diagnosisa</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>50.0</td>
<td></td>
</tr>
<tr>
<td>Dementia—any type</td>
<td>26.3</td>
<td></td>
</tr>
<tr>
<td>Mixed dementia</td>
<td>0.9</td>
<td></td>
</tr>
<tr>
<td>Mild cognitive impairment</td>
<td>5.3</td>
<td></td>
</tr>
<tr>
<td>Vascular dementia</td>
<td>5.3</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>14.9</td>
<td></td>
</tr>
</tbody>
</table>

Note: SD: standard deviation; MMSE: Mini-Mental State Examination.

Data analysis

Guided by a coding process developed by Strauss (1987), two primary coders (S.P. and N.D.) and two additional team members (M.K. and K.J.) utilized coding strategies that allowed for a systematic grouping of IWDs responses. First, concept indicators were identified for each of the five interview questions, which assigned various descriptive labels to multiple response units (e.g., sentences and response paragraphs) and aided in the sorting and understanding of
the data set (Miles & Huberman, 1994). After the initial scan of the data set and substantial engagement with the wording, phrases, and information provided in each of the responses, the two primary coders clustered the labels and refined the coding themes. The research team also utilized operational visualizations (e.g., tables and lists) to aid in the theoretical development of each step in the coding process. This entire process was rigorously repeated for each of the five questions, leading to thematic codes for each question.

We chose to examine emergent themes by each question, rather than across questions, as our main goal was to evaluate IWD’s responses for each of the open-ended questions. Specifically, by grouping the themes by each question, we were able to maintain a level of theoretical sensitivity and parse out what IWDs were experiencing for each question. Each response also could receive multiple codes if the researchers agreed that the response reflected multiple themes within the specific question being answered. Consensus between the two independent primary coders was established and ranged from 94.7% to 97.4% agreement.

Results

Findings

Analysis of IWDs’ responses revealed several important themes that highlight the importance of examining the illness experience from the perspective of the individual. Across the five open-ended questions, themes varied along a continuum, ranging from no or minimal impact to both negative and positive aspects of living with dementia. Themes for each individual question are discussed in more detail below along with response excerpts for illustrative purposes.

Across each of the questions, a portion of data were not coded into themes as the responses were either “don’t know” or not interpretable. The percentages of uncoded data were 16.7%, 14.8%, 9.5%, 13.8%, and 18.4% for questions 1–5, respectively. Although these uncoded data do not provide direct information about IWD’s illness experience, the data are informative for understanding what types of questions individuals with mild-to-moderate symptoms of dementia may be most likely to answer.

How does memory loss affect your daily routine? When asked how memory loss affects their daily routine, half of the participants (51.8%) indicated their memory problems had minimal (20.2%) to no effect (31.6%) on their daily routines. Responses varied from simply “it doesn’t” or “not too much” to more explicit and illustrative statements such as “not terribly because [I am] able to do things enough for myself.”

Twenty-two percent of responses reflected a negative impact on IWD’s daily routine. Areas identified included experiencing negative emotional feelings such as disgust, embarrassment, and frustration and difficulties associated with managing the cognitive and functional symptoms, such as forgetting, losing one’s independence, and not being able to complete usual tasks and activities throughout the day. The following data excerpts reflect these struggles:

I think I am very depressed about having this problem, hence I stay to myself;
I get disgusted. I leave stuff around and can’t find it right away;
Makes it difficult. I don’t have the freedom I used to have;
It restricts me on everything I’m exposed to. Your life is never the same after you experience this, for example, I can’t use my power tools when I am here by myself; and
It affects me terribly because I can’t remember people’s names at church. It embarrasses me when I have to ask.

Nearly 10% of IWD’s responses reflected using positive coping strategies for managing their memory loss. Strategies identified included using external memory aids (e.g., use of notes and calendars); simplifying routines, managing their emotional reactions and expectations (e.g., acceptance and reframing); and staying actively engaged in their lives. For example, one individual talked about staying active within the community responding, I haven’t allowed it to. I keep active at the cultural center and that helps a lot. I’m with a lot of people and that helps.

What concerns you most about your memory loss? One-third of participants (34.8%) identified the cognitive and functional symptoms of memory loss as their most salient concern. Concerns ranged from forgetting names and appointments, losing one’s independence, to not being able to accomplish daily tasks and activities on their own. The following data excerpts highlight these concerns:

That I can’t remember certain important things. I don’t like to feel that way. People take advantage of you. I left my keys in my car with it running and I didn’t even know I did it—that bothers me;
Not being able to remember names and how to get to places when I drive;
The fact that I may not remember . . . ex. turning off the stove. Doing something that will jeopardize my health; and
That I will miss out on activities that brought me much joy and fulfillment.

Twenty percent of responses were future oriented and concerned about the progression of the illness and the subsequent implications of living with dementia. One individual commented that living in a nursing home was a major concern, stating: “When I see people in nursing homes with second-stage AD. Being in that situation with a stranger—with just a bed, dresser, & one TV to share with a stranger. I’m concerned that I won’t get the family pictures/documents together in time for my children.” Another individual stated: “That one day I will be unable to care for myself and my animals and that I will run out of money. That I will have no concept of personal dignity.” Other examples of future concerns expressed included the associated genetic risk for their children and grandchildren and lack of effective medications for more severe memory loss symptoms. The following excerpt illustrates this concern: “If I were my daughter, I would be concerned because my mother had Alzheimer’s. I have this problem. I worry.”

Participants (14.8%) also expressed concerns about the interpersonal impact of their illness. Examples included feelings of frustration and depression, loss of one’s identity and dignity, and relationship stress with family and friends. One individual stated: “That I am losing my identity. That it doesn’t matter what I think cause someone else will do what they want. It bothers me that my memory is not as keen as it once was. To have someone tell you ‘I told you.’ It makes me wonder if I did or didn’t hear that. I have accepted this condition. I just don’t want to be a burden to anyone.” Another individual stated: “I don’t want to get into a relationship because they will notice and leave me.”

Several participants (3.5%) indicated using positive coping methods, such as acceptance and reframing. For example one IWD stated, “ . . . I accept it. It is what
comes with old age,” while another IWD simply stated, “I do the best I can.” A small percentage of IWDs (12.2%) reported minimal to no concerns about their memory loss.

**How has your memory loss affected relationships with others?**

When asked how memory loss affected their relationships with others, 62% of participants indicated minimal to no impact. For example, one individual stated: “There has not been an adverse effect in any way. Nobody has shied away because of this,” while another individual commented: “I can’t say that it has. I am not an outgoing person. I have a few friends. I am satisfied.” Similar to themes identified in prior questions, participants (22.4%) also indicated their relationships were negatively impacted by their memory loss. Areas discussed included changes in the dynamics of their relationship, such as decreased patience, increased stress and frustration; decreased interaction and involvement with friends and family; and social withdrawal, isolation, and avoidance. The following experts illustrate how IWD’s relationships were negatively affected:

- It’s frustrating—my friend came to play a game with me but I couldn’t play it—we were both upset;
- We don’t really get involved in much activities with other groups. It is very narrow now; I’ve withdrawn a lot. I use to be very active. I now feel I have nothing to offer;
- Some people avoid contact or limit contact. Sometimes I feel that I am treated differently—as though I am much less intelligent than I am. Or unable to make decisions for myself; and
- Memory loss is tied closely to human relationships, as I lose close relationships with others, I feel it is a great void.

A small percentage of participants (6%) felt their memory loss was a catalyst for a closer and stronger social support network. For example, one individual said, “I get along better with my youngest brother than I used to. It’s made it better.”

**What do you fear most about your memory loss?**

Nearly 30% of participants indicated they did not have any fears related to their memory loss. For example, one individual stated: “I really don’t have a fear. I accept what I have. I am satisfied.” Thirty percent of responses indicated cognitive and functional losses were feared the most. Examples ranged from forgetting names, not recognizing people, to not driving and losing one’s independence. The following data excerpts illustrate these IWD’s fears of losing their independence and their sense of self:

- Not being able to recognize my friends and relatives. I am not looking forward to the day when that comes;
- Being in a situation where I can’t remember names and not being able to drive myself;
- Becoming infantile. To be fed, not enjoying world around me . . . ;
- Just not being able to care for myself. Others may have to bathe me.

Participants (16.5%) also identified fears regarding their future and progression of the illness. For example, one individual stated, “Getting to stage 2 & 3—living conditions and situation. The financial impact it could have.” Other individuals commented on the loneliness that potentially threatened their overall well-being, saying things such as, “…I will be alone in my own world.” A small percentage of participants (6.1%) identified safety risks as their fear. Examples shared included wandering, forgetting how to get back home, and more specifically, “that I will get lost and not know where I am. I don’t even remember...
the number to the house." Another small percentage of IWDs (6.1%) indicated changing interpersonal dynamics and relationships were their fears.

What about your memory loss do you wish others understood or knew?. Responses for the final question took on a variety of views, incorporating overall knowledge as well as the emotional, physical, and psychological toll memory loss takes on the individual and their relationships. Almost 45% of the sample indicated there was not anything they wished others understood or knew about their memory loss. Responses ranged from simply stating “no” or “no problem” to “…are all in the same boat,” and that “…everyone understands the best that they can.” One individual stated, “I think everyone has their own problems like memory loss that they have to face and become adapted to,” pointing out that accommodation and compensation are a part of aging.

Participants (28.1%) wished others understood the impact of memory loss from the perspective of the IWD. Areas discussed include understanding the needs, feelings, and struggles from through the perspective of IWDs thereby enabling persons without dementia to appreciate and recognize both the gains and losses that accompany memory loss. For example, one individual simply stated, “…the huge amount of daily efforts and frustration that it takes to cope [with memory loss],” while another participant explained, “the loneliness during the day. It limits me in all aspects of my life.” Other individuals discussed specific struggles such as whether to disclose information about their illness. For example, individuals who felt that others did not need to know about their medical and illness experience stated things such as, “I don’t try to explain it because I don’t think they understand—I just don’t talk.”

Participants also (20.2%) indicated they wished others understood the etiology, symptoms, and progression associated with memory loss. IWDs commented they wished others understood how memory loss impacted their cognitive and functional abilities and that IWDs were not being careless or inattentive. Participants stated things such as “…if I make a mistake it is due to memory loss—not that I don’t care,” and “…I truly have memory loss and I am not trying to put anything over them.” One individual felt very passionate about the question, and when asked, responded, “That aging is normal and if we have this condition accept it. It can happen to anyone. Just be a little more compassionate and accept it. Support the AZ group. Support the trials. Get involved.”

Discussion

The findings from this study contribute significantly to the growing body of literature describing the illness experience from the perspective of the IWD. Across the five questions, several salient themes emerged underscoring the heterogeneity of individual’s perceptions and experiences living with dementia. The impact of living with dementia ranged from no/minimal impact to both negative and positive aspects of the illness experience. The most commonly expressed theme across questions was that memory loss had very little (e.g., no, minimal) impact on both negative and positive aspects of the illness experience. This finding is important as it indicates a large proportion of IWDs did not perceive or appraise their memory loss as significantly affecting their daily routines. Another interpretation could be that IWDs with mild-to-moderate dementia effectively cope with and compensate for their memory loss, thereby resulting in minimal changes to their perceptions, cognitive appraisals, and daily routines.
Another central theme across all questions was the negative impact of living with dementia, which included emotional, social, cognitive, and functional aspects. Examples of the emotional impact included feelings of frustration, depression, and embarrassment and loss of one’s sense of self. Cognitive and functional difficulties included completing daily tasks and activities, forgetting names, faces, and doctor’s appointment, and loss of one’s independence. Although less readily expressed, participants also discussed the beneficial or positive experiences of their illness experience. Specifically, IWDs’ commented on implementing coping strategies such as acceptance and reframing, developing a stronger support system, and realizing that others understand the illness and may be experiencing similar problems. Results from this larger sample of IWDs are informative for clinicians and researchers who work with IWDs. Specifically, these results are important for understanding how individuals live and cope with dementia and how to improve IWD’s well-being and protective factors while simultaneously addressing stressors and strains. A more detailed review of key findings and the implications are discussed below.

Participants clearly articulated how memory loss negatively affected them. Throughout the questions, participants often detailed how their memory loss made them feel embarrassed, frustrated, depressed, and even “berserk.” Gillies (2000) found that memory function was often described as “lost” or “dying,” ultimately affecting the individual’s self-esteem and emotional reactions to memory loss. While this was not found in a large percentage of the sample, it is vital for understanding how cognitive changes can impact psychological well-being and potentially lead to other psychosocial issues.

To combat these negative reactions and feelings toward memory loss, researchers should focus on developing assessment and intervention protocols that positively reframe the appraisal of a dementia diagnosis. The process of positive reappraisal has been predominantly evaluated within caregivers (e.g., Hilgeman, Allen, DeCosters, & Burgio, 2007), however it is important to extend these findings into intervention work with IWDs and potentially as a dyadic protocol that includes both care partners. Additionally, intervention protocols that provide IWDs with strategies for coping with and managing the wide range of symptoms associated with dementia. For example, Judge et al. (2010) tested the effects of a dyadic intervention for IWDs and their family caregivers. The intervention protocol provided counseling and cognitive rehabilitation-based skills for managing the cognitive, functional, emotional, and behavioral symptoms of the illness. Results found positive results for both care partners, including less distress in managing daily activities, less symptoms of anxiety, and decreased relationship strain for IWDs (Judge et al., 2010) and decreased emotional health strain, role captivity, and relationship strain; fewer symptoms of anxiety and depression and improved caregiving mastery for caregivers (Judge et al., 2012).

Interesting results were found related to what IWDs wished others understood or knew about their illness. Specifically, IWDs wanted individuals without dementia to better understand their illness experience in hopes of being able to appreciate the ups and downs of their illness experience. This may be a valuable insight when developing interventions aimed at alleviating worry in IWDs and potentially caregivers. For example, McAfee, Ruh, Bell, and Martichuscki (1989) found that including the IWD during discussions of concerns that affected the entire family provided a sense of empowerment and allowed for a more complete understanding of the worries and fears associated with the disease. Therefore, interventions focused on educating the caregiving dyad as well as potential secondary and tertiary caregivers on what to expect in the future, may provide families with a better
understanding of the illness experience and a useful set of tools for discussing difficult transitions and associated changes.

Another important finding from this study is the positive aspects reported by participants, which are seldom evaluated or acknowledged. Our results suggest that IWDs are able to find and maintain their sense of self along with utilizing positive coping strategies. Although positive aspects of a dementia diagnosis have not been directly examined, the idea of coping with dementia-related symptoms has been previously evaluated. Researchers have found that despite losses, many IWDs try to continue living their lives as best as they can (Clare, 2002, 2003; de Boer et al., 2007; Harris & Sterin, 1999; Menne et al., 2002), while remaining engaged in activities (Clare, 2002; Menne et al., 2002) and maintaining a routine (Stocker & Turner, 2004). In a broader conceptualization of these themes, older adults in general tend to manage their losses by carefully selecting what is important in their lives, optimizing those priorities, and therefore striving to compensate for any losses (Baltes & Baltes, 1990). Moreover, it is not surprising that older adults diagnosed with mild to moderate forms of dementia will attempt to optimize skills and cognitive capabilities through the use of compensatory strategies. Based on the selection, optimization, and compensation theory (Baltes & Baltes, 1990), researchers should develop intervention protocols and educational programs geared toward enhancing compensatory strategies and helping IWDs reframe their diagnosis in a positive light.

With respect to using the SPM for IWDs as a framework for understanding the illness experience of IWDs, findings of the study provide support for several of the domains, including key issues pertaining to primary stressors (e.g., forgetting, safety risks, loss of independence, and functionality), secondary stressors (e.g., loss of interpersonal relationships, negative emotional impacts), and potential buffering mediators (e.g., positive coping strategies, stronger support system). Most of the themes aligned with the model, however, several themes warrant reappraisal of the model to ensure that IWD’s illness experience is represented accurately. For example, the theme focused on preoccupation and worry about the future may be useful in expanding the domain of secondary stressors for clinicians and researchers to use in tailoring interventions for IWDs. Interventions aimed at assisting caregiving dyads discuss their care preferences and values while planning for their future care goals may decrease potential anxiety stemming from IWD’s concerns about the future and progression of their illness. The intervention, Early Diagnosis Dyadic Intervention (EDDI), is one such example of a protocol designed specifically to facilitate dyad’s understanding, discussion, and decision-making processes about their care values and preferences (Whitlatch, Judge, Zarit, & Femia, 2006).

Limitations of the current study

It is important to take into account the limitations of the current study. First, as evidenced by the mean MMSE score, the majority of participants in the study were experiencing mild-to-moderate symptoms of dementia. Individuals with more severe symptoms of dementia may have expressed different views about their illness experience or may have experienced difficulty in providing responses. Our sample of community-dwelling older adults did not include a variety of cultural backgrounds (i.e., 85.5% were Caucasian) nor did we evaluate gender differences. It would be useful for future studies to incorporate individuals from diverse backgrounds, as there may be differences in concerns and fears as well as influences on daily routines and interpersonal relationships (Dilworth-Anderson, Williams,
& Gibson, 2002). Finally, across the five questions 9.5–18.4% of the responses were not factored into the analysis as these responses were either not interpretable or not coded into themes (e.g., “don’t know”). This rather larger amount of unusable data warrants further investigation to determine when IWDs are able to provide information about their illness experience.

**Future directions for research**

For future research, it is important to evaluate changes in IWDs’ perspectives over time using longitudinal methodologies. To date, there are very few studies that have been able to track changes in the illness experience over time from the perspective of the IWD (Caddell & Clare, 2010). Clare (2004) suggests that in order to understand perceptions of the self, levels of awareness, and overall understandings of the disease, the illness experience should be documented consistently over time in order to develop and implement appropriate interventions.

Findings from the current study also have implications for future applications of the SPM for IWDs to the illness experience as well as identifying key areas in need of intervention. Foremost, we have documented that IWDs are capable of appropriately discussing their illness experience, articulating how memory loss impacts their lives and therefore effectively giving insight into their concerns and fears about the disease. For example, participants who expressed concerns about their memory loss and conveyed less effective ways of coping may be in most need of intervention. Targeting individuals who may not have strong support systems, ineffective coping mechanisms, high amounts of role strains, or low levels of self-efficacy may allow practitioners and researchers the opportunity to develop interventions tailored to the specific needs of IWDs. As suggested by Gillies (2000), professionals should build upon coping strategies and the specific challenges of IWDs to understand levels of awareness and improve the way treatment and interventions are implemented.

Finally, the findings may facilitate the development of quantitative measurements. Specific themes that emerged in this study could give way to the development of important measurements that assess specific aspects of the illness experience that have yet to be studied. To date, many quantitative measures used to evaluate the illness experience of IWDs have been adapted from previous measures used for other populations (e.g., caregivers, older adults without dementia). Instruments that have been specifically designed to appraise the illness experience of IWDs are still in their infancy, creating a need for future research to develop appropriate assessments, response scales, and implementation guidelines.

In line with prior research, using data collected directly from IWDs allowed for valuable insight into the lived experience of dementia and the impact of memory loss (Sabat, 2001). By valuing the voices of IWDs and including them in the research process, researchers, clinicians, as well as friends and family members may better understand the illness experience of IWDs and thereby improve upon the forms of care, support, and interventions used for coping with and managing the symptoms of dementia.

**Funding**

This study was supported by the Alzheimer’s Association (NIRG-05-13032) and the National Institute on Aging (R03AG026552).
References


Clare, L. (2002). We’ll fight it as long as we can: Coping with the onset of Alzheimer’s disease. *Aging and Mental Health, 6*, 139–148.


Sara M Powers, PhD, is an assistant professor of psychology at The College of Saint Rose in Albany, NY. Her research interests include the sociocultural stress and coping experience of informal caregivers, bereavement trajectories, and the experiences associated with living with chronic illness.

Nicole T Dawson, PT, MA, GCS is a doctoral candidate in adult development and aging psychology at Cleveland State University. She is also a board-certified clinical specialist in geriatric physical therapy. Her current area of research includes developing and testing nonpharmacological interventions to improve functional and psychosocial outcomes in patients with dementia, identifying predictors of falls in older adults with cognitive impairment, as well as gaining a better understanding of the illness experience of individuals with dementia.

Maura L Krestar, PhD, is an assistant professor of communication science and disorders in the Clinical Health Sciences Department at Texas A&M University Kingsville in Kingsville, TX. Her research interests include perception of emotional speech as well as self-reports and memory impairment.

Sarah J Yarry is a staff psychologist at the VA New York Harbor Health Care System, Brooklyn Campus. Her clinical interests are cognitive evaluation for dementia diagnosis and assisting individuals with dementia and their family caregivers to manage dementia-related behavioral and emotional changes. Her program of research focuses on developing interventions for individuals with dementia and their family caregivers, psychosocial factors related to dementia and caregiving, and program evaluation for dementia-related interventions.

Katherine S Judge is an associate professor and director of the Adult Development & Aging Doctoral Program in the Psychology Department at Cleveland State University and an Adjunct Senior Research Scientist at Benjamin Rose Institute on Aging. For nearly 20 years, she has been developing, implementing, and evaluating psychosocial interventions for individuals with dementia and their families, with an emphasis in cognitive rehabilitation, counseling-based, and care-coordination interventions. Her research examines the stress process and illness experience of living with dementia along with how to promote well-being and positive outcomes.