"Each Day We Lose a Little More": Visual Depictions of Family Caregiving for Persons with Dementia

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Abstract

More than 11 million Americans provide unpaid care for people with dementia (PWD) and need emotional, financial, and physical support. This study explored how participants in Caregiver Speaks, a social networking and image-based storytelling intervention designed to help caregivers make meaning of caregiving, described their caregiving experiences and needs. Strategies of thematic analysis were used to identify patterns in 28 different caregivers' images ($N = 59$) and text interactions on social media. Caregivers identified as white (71.4%), as women (92.9%), and as an adult child or child-in-law of the PWD (85.7%). Through images and text, caregivers explained interrelated changes in their behaviors (e.g., managing dual roles), thoughts (e.g., realizing severity of illness), and feelings (e.g., trapped) throughout the caregiving process. Findings reiterate that caregiving changes significantly over time, that visual storytelling helps to concretely capture those changes, and that interventions are needed to respond to caregivers' hardships across the caregiving time span.

Keywords

caregiving; dementia; end of life; qualitative methods

Introduction

According to a 2022 report, an estimated 6.5 million Americans aged 65 and older are living with Alzheimer's disease or other dementias. This number is projected to reach 12.7 million by 2050 (Alzheimer's Association, 2022). More than 11 million Americans are providing direct care to a person with dementia (PWD), which equates to about 16 billion hours of unpaid care, at an average of 27.1 hours per caregiver per week (Alzheimer's Association, 2022). Most financial costs associated with dementia caregiving are incurred by family members, who often suffer significant psychological and physical costs as well.

Compared to caregivers of individuals without dementia, twice as many dementia caregivers report substantial emotional, financial, and physical challenges (Alzheimer's Association, 2022), which tend to intensify as the PWD enters advanced stages of the disease (Vick et al., 2019). Moreover, the duration of the illness from diagnosis to death averages between four to eight years, with some individuals with dementia living as many as 20 years with the disease (Alzheimer's Association, 2022). The long duration of illness often indicates a high degree of burden for the PWD and the families providing care (Reuben et al., 2022).

Caregiver support is paramount to ameliorating the high degree of burden many dementia caregivers experience. Successful interventions include case management, psychoeducational approaches, counseling, psychotherapeutic approaches, respite, support groups, or a combination of these (Alzheimer's Association, 2022). Novel approaches to improving caregiver psychological well-being include interventions that incorporate narrative forms of communication known as storytelling or story-sharing (Rolbiecki et al, 2021). Storytelling includes the sharing of one's personal experiences and understanding of their world using sounds, images, or words (Haigh & Hardy, 2011). In health research, varied types of storytelling interventions have been effectively used, for example, to enhance chronic disease self-management (Gucciardi et al., 2016), promote posttraumatic growth (Rolbiecki et al, 2020), improve providers' attitudes toward patients (George et al., 2014), and encourage positive behaviors associated with diet (McGloin & Eslami, 2015) and physical activity (Perrier & Martin Ginis, 2017). In dementia care, storytelling interventions have been used to improve PWDs' quality of life (Vigliotti et al., 2019), communication, and relationships (Park et al., 2017). More recently, various forms of storytelling have been used to support family caregivers (Cooper, 2021; Rolbiecki et al, 2020).

Emerging research suggests that photovoice or photo elicitation may be useful techniques to facilitate storytelling to understand the caregiver experience and as supportive or therapeutic tools for caregivers (Rolbiecki et al, 2020). Photovoice is a participatory method in which people use images to identify and express their experiences. Photovoice has been used effectively as a research method to identify the needs of caregivers (Ilagan et al., 2020). A small but growing number of studies suggest therapeutic benefits of the method for caregivers, including increased sense making and new ways to imagine self and caring roles (e.g., Capous-Desyllas et al., 2020). The majority of photovoice work on caring, however, falls short of exploring how discussing the images and photos affects participants (Ilagan et al., 2020).

Photo elicitation is broadly defined as the use of photographs to generate discussion (Collier & Collier, 1986). When participants themselves take or select the photographs utilized in photo elicitation, the images not only have the potential to generate discussion or elicit stories, but they can also imbue personal narratives with deeper meaning than can be conveyed by words alone (Jiménez-Alonso & De Luna, 2021). Although it has been employed in dementia caregiving studies as a research method (Rayment et al., 2019), like photovoice, photo elicitation has rarely been investigated for its therapeutic utility in interventions aimed at improving caregiver mental health.

One exception is Caregiver Speaks (CS), a technologically mediated storytelling intervention that is currently being tested as a strategy to reduce distress among hospice family caregivers of PWDs (Rolbiecki et al, 2021). CS utilizes photo elicitation along with social networking via an online group to help dementia caregivers make meaning of their caregiving experiences. The intervention is informed by Park and Folkman's (1997) meaning-making model of stress and coping, which posits that effective coping with an adverse life event is achieved when individuals reconstruct and transform the event's meaning and then incorporate that meaning into a larger narrative about themselves. In response to a series of questions and prompts from a trained facilitator, CS participants share their stories with one another by posting and describing photos and other images that evoke information, feelings, and memories relative to the PWD and/or their experiences as caregivers. The present study is an exploration of how dementia family caregivers use images and text to share their daily caregiving experiences and needs.

Methods

Study Design

This is a qualitative exploration of participants' images and text excerpts describing their dementia caregiving experience as part of the CS intervention, described below. The intervention employed images to elicit participants' stories given the strengths they are shown to have in collecting data with this population, such as more participant engagement with visual cues, more patient-centered discussions, and potential benefits of meaning making, versus using interviews alone (Ilagan et al., 2020).

Sample

Data were provided by a convenience sample of 28 dementia family caregivers as part of an ongoing, multi-site clinical trial investigating the effect of CS on caregivers' anxiety and depression (Grant number, ClinicalTrails.gov identifier, and University Institutional Review Board [IRB #2016062 MU]). Inclusion criteria required that all participants were English-speaking adults providing unpaid care to an adult with advanced dementia who was receiving services from a U.S. hospice agency. Multiple family members of each PWD were allowed to enroll in the study. Participants were consented by study staff during a phone or Zoom orientation session. Staff read participants information from an IRB-approved informed consent document and, if caregivers wanted to participate in the study after hearing this information, they digitally acknowledged their consent via a check box in REDCap (Research Electronic Data Capture; Harris et al., 2009), a secure web application for building and managing online research databases. All study activities, including the full consent process, were approved by the University of Missouri IRB.

Procedures

Participants who were eligible for the study were randomized into an intervention or a control group. Intervention participants entered a private Facebook group in which they were prompted to share photos and text that captured their experience with caregiving. A facilitator shared six different prompts over the course of ten weeks to encourage participants to share their caregiving experiences to encourage meaning making. The

prompts included guiding the participant to introduce themselves and their caregiving situation, discuss the benefits and challenges of caregiving, describe their timeline of caregiving, explore losses and gains, and share their identity and identity shifts. Once their care recipients passed away, caregivers left the active caregiving group and entered a separate group for bereaved caregivers. The data analyzed in the present study include 59 unique images and corresponding text posted to the online CS group by all participants (n = 28) that were enrolled in the active caregiving group (i.e., their care recipients were still living) between October 2020 and March 2022. Each caregiver shared one to three images. The full study protocol is described here (Rolbiecki et al, 2021).

Data Analysis

Three members of the research team conducted the analysis for this study. First, the group created a matrix that charted each participant's image(s) alongside a summary of the images' meanings based on corresponding text participants posted online. The matrix was 20 pages long and presented a comprehensive view of each participant and their caregiving narrative. Then the group used strategies of applied thematic analysis, guided by steps and principles developed by Guest et al. (2011), to capture key patterns in the way participants posted about their experiences as caregivers. To begin the thematic analysis, each member of the coding team independently reviewed the images and text, noting all possible patterns in the matrix. Next, the team met and agreed upon an initial set of key themes based on common patterns all reviewers identified in the data. They defined these themes in a codebook. Then, they conducted initial coding. Coders met weekly to discuss and compare ideas, refine the codebook with additional definitions as needed, and seek agreement or understanding on coding. Next, the coders met to review their initial coding report, collapsing, and expanding themes as appropriate based on the breadth and depth of initial themes and connections between the themes, creating a second iteration of the codebook. Then they conducted a second, more focused round of coding, resulting in the final themes presented in the following results section. Trustworthiness of study findings was enhanced by peer debriefing or discussions of the analysis, particularly around areas of disagreement, and rich data and multiple text and photo examples (Corbin & Strauss, 2014).

Results

Participant demographics are described in detail in Table 1.

Participants described their experiences of caregiving through images and text by explaining often interrelated changes in their behaviors, thoughts, and feelings. Key behavior changes were summarized by three subthemes including changes related to caregiving duties, management of dual roles, and self-care.

Changes in Behaviors

Caregiving Duties.—It was common for caregivers to use pictures and text to describe what they did as caregivers. These tasks represented changes from their pre-caregiving routines and actions. For example, supplementing the image of a collage, CG1 wrote, "My days have changed considerably over the last 6 years." She went on to describe the pictures

in the collage, pointing out her daily actions such as cleaning, cooking, playing music, or putting lotion on her mother. Others also shared pictures to show that they now did specific chores they had not done in the past. CG2 shared a picture of frozen banana bread, the last thing her mom made for her, explaining that she now did the cooking and "had become the mom." CG3 shared a picture of her mother using a cane to get into the car, remarking, "I think they both [the cane and the fact that I have the car keys] represent a loss of mom's independence - decreased walking and driving abilities." CG4 shared a picture of hands holding a heart, explaining that she was now doing the shopping for her mom, which felt uneasy, given they used to do this together.

Caregivers also showed pictures representing changes to enacting more intimate forms of care. CG5 showed a box of wipes and expressed upset that "I never thought I'd be wiping my mother." Several caregivers showed pictures of walkers, beds, or medical devices to illustrate how they now provided care. Still others described new actions like enrolling a PWD into hospice or writing a PWD's obituary. Sometimes caregivers used multiple pictures to demonstrate a change over time. For example, CG6 shared two pictures of her mother to explain the difference in the way she cares for her now versus six years ago:

> The first photo is Mom holding her great grandson, my first grandbaby, six years ago. Mom's decline was apparent by then even by anyone who observed her. Mom LOVES babies. I took the second photo yesterday. When I visited Mom, I took her a baby doll. I wasn't sure how she'd react, but she loved it. It didn't matter to Mom if the baby was real or not. If I had tried to do this years ago, Mom would have been insulted and/or upset.

Dual Roles.—Another difference in caregiver behavior involved the move to act in multiple roles. CG7 shared a picture of a circular lid and wrote that it represents that "work is like love, it is endless." She elaborated that "I work a full-time job, my husband and I own a business, so I work 3 nights a week at our business after I get off from my day job. When I get home, I take over the care of my mother-in-law." Sharing a picture of a puzzle, CG1 also described the challenge of occupying multiple roles. She explained:

> I feel like I am broken into pieces, the caregiver, the mom, the wife, the sister, the friend; but the pieces don't always fit together as neatly as they used to. I often feel like I'm losing pieces of myself along the way and finding new ones.

CG8 shared a picture of a cartoon figure being stretched to describe her overwhelm in being a caregiver: "I work full time, recently had major surgery, have my family and pets to take care of, mom's house, my house, mom." CG9 also described being overwhelmed by posting a picture of many intersecting dark swirled lines along with text explaining that she was coping with her own illness on the top of caring for her mother:

> Last Thursday, I went into the doctor for a constant hoarse voice and walked out with a cancer diagnosis. Unbelievable. The picture shows the constant swirl of darkness that pierces me constantly. I can't be [with my mom] since I need to get a doctor, a surgeon, a 2nd opinion and plan for surgery and then recovery … I can't go through my own health drama and try to manage my mom at the same time. I know this process since I have done it before, and it is draining.

Self-Care.—Most caregivers noted the importance of self-care, and some shared pictures of friends or outings that helped them feel more grounded. More often, however, caregivers expressed an unmet need for self-care. This was usually a result of the ongoing nature of caregiving, isolation, lack of help, and/or scheduling interruptions. CG9 shared a downloaded image of a man sitting cross-legged below a thought bubble of many question marks and wrote:

> I am by myself. I am tired. I don't know why my brothers are not helping. I don't even ask anymore. I have learned to use the bathroom when [my mom] does (after basically tying her to the stool) … There is no way I can maintain this level of work and I think it is just a pile of problems waiting for that one last thing that breaks me. Then what? Who cares for the caretaker when the caretaker is down? I fret over that all day ... every single day. I give up, what happens to my mom?

She also shared a picture of an overflowing laundry basket (Figure 1) and wrote, "I don't take care of me." She also wrote, "I don't comb my hair; I remind me to shower and brush my teeth… I will need to take some time soon since I don't feel good and need to have my own health condition checked." Some caregivers showed pictures representing not being able to engage in activities that brought them joy or self-care in the past, such as travel. Some showed pictures of beds, chairs, or themselves with their relative with dementia in home spaces to indicate that they were now confined at home.

Changes in Thinking

As caregiving progressed, participants began to think about the PWD, the PWD's illness, and their own role in new ways. The three major changes in thinking are summarized below, including new thoughts about the severity of their PWD's illness, the passing of time, and how to best care for their relative amid functional changes.

Realizing Severity of Illness.—One of the main ways participants shared their thoughts about caregiving via text and pictures was to use these modalities to talk about the ever-changing reality of the situation with their relative with dementia. CG7 posted a picture of a heart-shaped puzzle and wrote that it represented how "each day we lose a little more of my mother-in-law … There is not much left of who she was." Sharing a picture of a dried lake, CG11 noted being drained as she talked about the realization that things were getting hard—that her husband was "seeing and smelling things that were not there" and in the "noneating stage" and "an empty shell." When CG6 shared the previously described picture of her mom with the doll (Figure 2), she noted the realization that her mother was "far beyond" distinguishing between real babies and dolls. Several participants shared pictures indicating the reality that the PWD they cared for was nearing the end of life. For example, CG12 shared a picture of a bouquet of flowers her coworkers brought her to show their support when she returned home to enroll her mother into hospice. One of the things the flowers symbolized for her was "[the] harsh reality that everything eventually comes to an end." Sharing a picture of her grandmother with her grandfather, CG13 noted that the hospice worker inquired if the family let the PWD know it was okay to die:

I'm not sure I'm really ready for that, but I know she is. And that's a hard pill to swallow. But it does make me wonder if she's just waiting for us to tell her that it's ok, we'll be fine and for her to go be with papa.

Passing of Time.—Relatedly, participants used pictures of clocks or other images that symbolized time to discuss the passing of time with their loved ones and new thinking around the meaning of time. For example, sharing a picture of her father, CG14 said that "our children understand what's happening and they make the most of the time they have together." CG15 shared a picture of dice, saying that time has changed a lot and now each day feels like a roll of the dice regarding whether her mother would be okay. Sharing a picture of a clock with wings, CG16 described her mom's changes and how quickly time passes. Posting a picture of her mother, she also explained that she went from having her mother "always be there" to thinking about her mother as there for "as long as God was going to let me cherish her."

What To Do

Like CG12, many caregivers saw their role as "figur[ing] out how I can take care of everything," which she expressed with a picture of a dark hallway with a light on. A significant change in thinking among caregivers was growing confusion about how to handle each new situation that arose regarding their relative's changing state or needed care. Using a picture of question marks, CG17 explained:

> My experience as caregiver most recently is "what do I do now?" My love's condition is changing so rapidly that I don't have an answer for how to feed her when she is sleeping so much[.] What is she thinking about? Is she in pain? Looking back, it seems like the days were easier when this all started, but it seemed hard then. Now my main concern is her comfort and her best interest.

CG13 shared a picture of a walker, saying that at first her grandmother did not need it but now they had to use it all the time as she has declined. She lamented about how difficult it is when "I can't figure out what's wrong. In those moments I try to do everything I can to get her situated, then go have a [crying session]. Then get myself together and start the process over again."

Changes in Feelings

Feelings changed as PWDs' illnesses progressed. Participants used pictures and text to express new emotions, summarized by three subthemes: sadness, fatigue, and entrapment.

Sadness.—Caregivers expressed a great deal of sadness and pain, especially regarding the way their relative with dementia changed as their illnesses progressed. For example, sharing a picture of her mom, CG15 said that "Seeing my mom's weight loss hurt so bad. Going from 160 pounds to 81 pounds in front of my eyes changed my life." Posting a walker, CG13 used the words "painfully heart wrenching" noting it was "extremely hard to watch someone who used to never stop moving become someone who can't move anymore." CG12 described "such heavy sadness" when posting a picture of flowers that were sent to her when she moved her mother into hospice. CG3 noted the difference between what she felt and

what she displayed to the world when she started learning about her mom's illness with picture of an apple with one side whole and the other side bitten: "My reflection to the world was 'whole' but, where the world couldn't see, a 'bite' had been taken out of me."

Fatigue and Overwhelm.—Another common feeling expressed was exhaustion. CG14 posted a picture of a flower explaining that as a caregiver she felt "wilted and tired." CG18 described their exhaustion with a picture of a wild-looking cat. She explained that learning about and watching her mother suffer her illness was exhausting and unpredictable. The exhaustion was linked to pure overwhelm. Sharing a picture of the puzzle reference above, CG1 posted that:

> Over the last six years I've discovered I'm more independent and stronger than I ever realized but I'm also exhausted. I feel like I've lost my fun self and wonder if she will ever come back … I'm afraid I'll go right from this to being the patient.

CG19 described the nature of being tired as a caregiver as being overwhelmed by a 2-pound weight, noting that, "Two pounds does not seem like very much weight. It's not more than I can handle, but it's enough that it can make moving through your days just a bit more difficult."

Trapped.—A final prominent feeling was that of being trapped. CG20 used a spider trapped inside by window glass (Figure 3) to demonstrate this feeling, posting, "Sometimes I feel like the spider, frustrated at not being able to be out in the sunshine and fresh air and free." CG21 shared similar feelings of stuck-ness brought on by caregiving with a picture of a maze "that they had yet to escape." Others talked about limits on where they could go and what they could do as caregivers, discussing cancelled trips and plans. For example, CG22 remarked that the PWD's illness "has really confined us to home and just made things more difficult."

Discussion

An exploration of study participants' experiences as represented by photographs, other images, and corresponding text highlighted the centrality of change to the dementia caregiving experience. By sharing snapshots in time—both literally and figuratively—caregivers communicated changes in their behaviors (taking on caregiving duties, occupying dual roles, and reflecting on self-care), thoughts (realizing illness severity, acknowledging the passing of time, and wondering what to do), and feelings (increasing sadness and overwhelm and trapped in a caregiving role). With few exceptions, they described the experience of caring for a family member with dementia as dynamic, variable, and at times transformative.

In many ways, these findings corroborate prior studies in the field. In conducting their recent mixed-methods systematic review, Bressan et al. (2020) identified change as a paradoxical constant in the dementia caregiving literature, concluding that "caregiving for individuals with dementia is an ever-changing process characterized by continuous adjustment" (p. 1942). These study findings also contribute to an ongoing discussion of adaptation as a process that is both challenging and indicative of caregivers' resilience, as well as a process

that strengthens resilience longitudinally. This view was aptly summarized by Zhou et al. (2021) who wrote, "[Resilience] represents a *developmental trajectory* [emphasis added] in which individuals enhance their capacities, learn, and grow … over time" (p. 1383). Han et al. (2019) echoed this line of thought, equating resilience with "inherent adaptation" among family caregivers of PWD.

This study also underscores the potential of visual imagery to enhance communication regarding the realities of caring for a family member with dementia. Images were found to be particularly useful in communicating information about change, allowing caregivers to share photographs of their relative with dementia at different points in the disease trajectory. Supplemented with brief explanatory text, these images contained countless points of information that may have been time consuming or otherwise difficult to identify and share via other mechanisms. For example, Figure 4 captured the tenderness with which the caregiver's mother held her baby doll, a powerful contrast to the disrespect the caregiver suggested her mother might have felt in the doll's presence years ago. Similarly, reading that someone's relative lost nearly 80 pounds over the course of their dementia is very different from seeing a photograph of the same person weighing 160 and later 81 pounds. Multiple photographs were not always required to communicate deeply about caregivers' experiences, however. For example, viewing the image of the spider caught inside by window glass alongside caregivers' choice of words like "confined" and "escape" caused analysts to nominate and eventually retain "trapped" as a subtheme describing changes in caregivers' feelings. Likewise, collectively viewing numerous images of storms sensitized analysts to caregivers' feelings of overwhelm, represented by destructive yet uncontrollable forces.

Implications for Practice

These study findings have several implications for practice with family caregivers of PWD. First, they strengthen the call for family caregiver support across the illness trajectory, recognizing that caregivers' needs change over time, consistent with conclusions of prior research (Kokorelias et al., 2022). Further, the findings specifically highlight some of the behavioral, cognitive, and affective changes caregivers experience as PWDs approach their final days, underscoring the potential value of care from clinicians and service providers with expertise in end-of-life care, such as members of hospice interdisciplinary teams. It should be noted, however, that there are decidedly few hospice interventions for PWD, and most are supported only by early-phase research (Lassell et al., 2022). Practice-informed research is sorely needed to address the significant and continually changing needs of family members caring for a PWD at the end of life.

These findings also suggest that visual images can be used to enhance communication regarding the realities of caring for a family member with dementia. Practitioners may wish to consider incorporating photographs and other images into their work with family caregivers, particularly when an in-depth understanding of caregivers' experiences is needed to provide appropriate support. Images may also enrich peer support for family caregivers, serving as a powerful vehicle for eliciting and providing support in formal or informal group settings, including online environments, where caregivers increasingly turn for informational, emotional, and instrumental support (Friedman et al., 2018). Incorporating

images into practice with caregivers may also better serve the needs of caregivers with communication differences that might otherwise interfere with service use, such as expressive language disorders, limited English proficiency, or simply a preference for visual rather than language-based communication. Images may also be an effective, yet gentle way to prepare family caregivers for the end stage of dementia caregiving and the eventual death of their family member. Many family caregivers of PWD do not conceptualize dementias as terminal illnesses, even though they eventually lead to death (Bosisio et al, 2018; National Institute on Aging, 2022). Lack of awareness of the realities of dementia at the end of life and the corresponding caregiving responsibilities can serve as a barrier to planning for needed decision making and support (Bosisio et al., 2018). Viewing images capturing life across the dementia caregiving trajectory, including its final stages, may help family members of PWD better prepare for future needs. In sum, these findings affirm the changing nature of caregiving, identify creative ways to capture that change, and provide ideas for how to use images to support caregivers in identifying areas of need and providers in seeing potential points of intervention.

Study Limitations and Directions for Future Research

Our study is subject to several limitations. First, we note that our study data included images and text captions. It is possible that some caregivers were limited in how they were able to describe their situations in text excerpts, and that alternate data collection techniques (e.g., individual interviews and focus groups) would have generated more in-depth information on topic prompts. The sample was also limited to caregivers who were willing and able to access a private Facebook group as part of a formal research study; the experiences of other caregivers were not captured, restricting the transferability and generalizability of study results. In addition, while our inclusion of family caregivers of PWD receiving hospice care addresses a noted gap in an existing evidence base that has largely ignored this growing population (Lassell et al., 2022), we acknowledge this as an additional limit on our findings' transferability to other dementia family caregivers.

Future research focused on the effect(s) of communicating about caregiving in ways that are supported by imagery would make a much-needed contribution to the evidence base on photo elicitation and related techniques as potential therapeutic or supportive interventions. In addition to measuring effects on clinically relevant outcomes (e.g., psychological distress and post-caregiving grief intensity), such studies might examine linkages between engagement with imagery-based interventions and specific caregiving behaviors, such as advance care planning, which might be facilitated by a greater awareness of future care needs, as one example. Finally, future research utilizing a broader range of data collection techniques and reaching more caregivers—including those who are unable or unwilling to engage with social media-based research or who are not receiving hospice care—would strengthen the knowledge base in this area, while ensuring that the experiences of diverse caregiver types are adequately reflected in the dementia caregiving literature.

Funding

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What this paper adds

- Use of visual images and corresponding text to enrich the field's understanding of the dementia caregiving experience.

- How caregivers perceive changes in the experience over time.

- Multifaceted nature of caring for a family member with dementia as the illness progresses toward advanced stages and what caregivers need for support as the situation changes.

Applications of study findings

- Visual images enhance communication about the experience of caring for a family member with dementia.

- Practitioners may consider incorporating images into their work with vital care providers to understand caregiver needs.

- Supportive interventions for dementia family caregivers are recommended across the full disease trajectory, as caregiving demands change over time.

Figure 1.
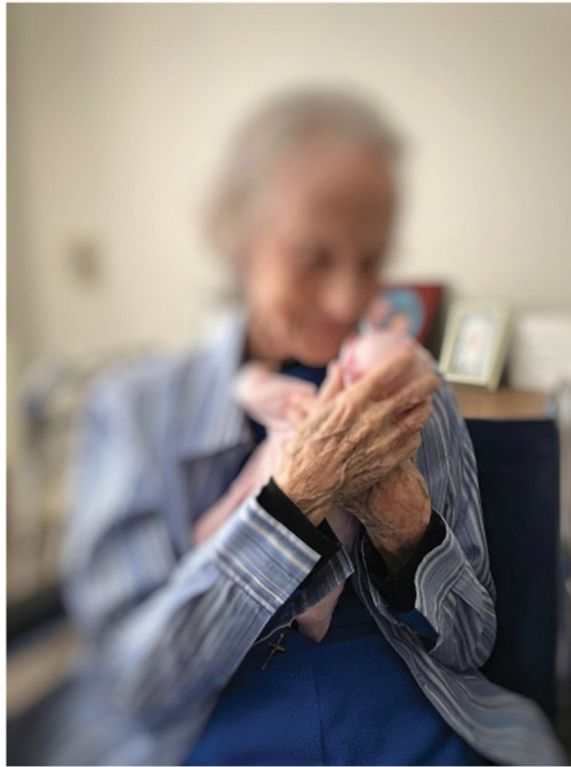Laundry.

Figure 2.
Woman with a baby.

Figure 3.
Spider.

Figure 4.
Woman with a doll.

Table 1.

Patient Characteristics (N = 26)

	n	%	M	SD	Range
Age			85.8	7.1	70–96
Gender					
Women	23	88.5			
Men	3	11.5			
Relationship to caregiver					
Parent or parent-in-law	22	84.6			
Spouse	2	7.6			
Sibling	1	3.9			
Grandparent	1	3.9			
Primary health diagnosis					
Heart failure	1	3.9			
Kidney failure/renal disease	1	3.9			
Dementia/Alzheimer's	22	84.6			
Other	2	7.6			
Severity of dementia					
Mild	3	11.6			
Moderate	9	34.6			
Severe	14	53.8			
Longevity of dementia (yrs)			5.2	3.6	0–15
Not reported	11	42.4			
1 year or less	3	11.5			
2–5 years	5	19.3			
>5 years	7	26.8			

Note. All results based on the primary caregiver report.