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Understanding Experiences of Caregivers of Spouses With Dementia During Caregiver Health Care Emergencies

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Abstract

Background and Objectives: Caregivers of persons with dementia are frequently spouses. Caregiver hospitalization causes disruption to caregiving. The goal of this research was to understand the preparedness and stress trajectory of peri-caregiver hospitalization.

Research Design and Methods: Mixed methods were used. Caregivers of spouses with dementia ($n = 1,000$) were surveyed to determine their perceived preparedness for their own hospitalization. Journey mapping interviews ($n = 18$) were used to map caregivers' experiences during 5 phases: (a) their spouse with dementia (SWD)'s dementia diagnosis; (b) their SWD's dementia progression; (c) their own health event; (d) their own hospitalization; and (e) their own return home from the hospital.

Results: Among the 452 (45%) eligible caregiver survey respondents, 75 (17%) had experienced hospitalization in the previous 12 months and 51 (68%) hospitalizations were unexpected. Twenty-three (31%) of hospitalized caregivers indicated they did not have prior plans in place for the care of the SWD. When asked about an unexpected hospitalization in the future, 233 (52%) felt somewhat prepared and 133 (29%) felt not at all prepared. Journey mapping revealed 3 groups of caregivers: Group 1 ($n = 7$) rated their stress lower during their hospitalization, Group 2 ($n = 7$) rated their stress highest during their hospitalization, and Group 3 ($n = 4$) were at a sustained high-stress level.

Discussion and Implications: Many caregivers are not prepared for their own hospitalization. The stress trajectory through important phases of dementia caregiving and a caregiver's own hospitalization is not universal. Meeting the needs of caregivers' peri-hospitalization should be tailored to the individual caregiver.

Keywords: Hospitalization, Journey mapping, Mixed methods

Background and Objectives

Caregivers for persons with dementia are frequently spouses or partners who are instrumental to a person with dementia's overall health and quality of life (Brodaty & Donkin, 2009; Ornstein et al., 2019; Rykkje & Tranvåg, 2019). In 2019, more than 16 million family members and other unpaid caregivers provided an estimated 18 billion hours of care to persons with dementia (Alzheimer's Association Report, 2020). These caregivers assist with daily activities, cope with behavioral symptoms, schedule and attend medical visits, manage complex medication regimens, and make routine and high-stakes medical decisions (Kasper et al., 2015). Caregiving for a person with dementia may be rewarding for some (AARP, 2020; Pristavec, 2019; Tarlow et al., 2004), but caregiver burden is well-documented and has the potential to lead to poor health outcomes among caregivers (AARP, 2020; Adelman et al., 2014; Oliveira et al., 2019; Perkins et al., 2013; Waligora et al., 2018).

Health systems rarely engage family at the point of care or collect data on outcomes that reflect the lived experiences of family and unpaid caregivers, except for the recent

requirements under The Caregiver Advise, Record, Enable Act (AARP, 2016; Coleman, 2016), which primarily affects hospital-based practices. Although there has been much attention to preparing for the eventual decline and adverse outcomes of a person with dementia, there is a gap in structured support and planning for a caregiver before a crisis. Moreover, caregiver hospitalization causes a major disruption to the essential relationship and caregivers may not have planned for such unexpected events.

The purpose of this research was to use survey and journey mapping to better understand spousal caregiver preparedness for their own unexpected hospitalization and the trajectory of caregiver stress before, during, and after their own unexpected health event. Thus, this research aims to illuminate the caregiver experience around their own health event and identify opportunities for interventions to ease caregiver stress during their own health care crisis. We hypothesized that most caregivers for spouses with dementia (SWD) would not be prepared for their own health care events and caregivers would identify hospitalization as the most stressful phase for them.

Research Design and Methods

Study Design

Using mixed methods, we first conducted a survey of caregivers of SWD identified in the electronic health record (EHR) and second employed journey mapping interviews to further describe the lived experience of caregivers who recently experienced a hospitalization.

This research was approved by the KPCO Institutional Review Board (IRB; 1768361-1). A HIPAA Waiver of Authorization was obtained to identify dyads using the EHR. The IRB granted a waiver of signed consent for the survey wherein completion of the survey demonstrated consent. All participants who participated in journey mapping were verbally consented and received a \$20 gift card for their participation.

Quantitative Survey Methods

Setting

Caregivers of a SWD were the primary contact for this research and were all active members of Kaiser Permanente Colorado (KPCO). KPCO is an integrated health system providing health care to KPCO members in Colorado.

The quantitative survey was initially mailed or emailed starting in December 2021 based on caregiver EHR contact preferences. Caregivers that preferred email ($n = 859$) were outreached via email with a unique link to a REDCap survey up to three times and then sent one paper copy of the survey as a final and fourth attempt (Harris et al., 2009, 2019). Caregivers who preferred standard mail ($n = 141$) received two paper copies of the survey. Survey distribution and data collection continued through May 2022. Survey responses were not identifiable.

Participants

We surveyed KPCO members who were caregivers of a SWD. Caregivers were identified in the EHR by matching a person with dementia with a spouse living at the same address using previously tested methods (Boxer et al., 2022).

Using the Virtual Data Warehouse (Ross et al., 2014), we purposefully oversampled for caregivers who self-identified as part of a historically marginalized population including racial/ethnic minorities (i.e., non-White or Hispanic; National Collaborating Centre for Determinants of Health, 2022), individuals residing in areas of lower socioeconomic status (SES; defined as neighborhood poverty level $\geq 20\%$ and $\geq 25\%$ of neighborhood population is without a high school diploma), or individuals whose EHR indicates they are LGBTQ+.

Variables and data sources

To confirm eligibility, two questions were included at the beginning of the survey, "Are you a caregiver of a person living with dementia?" and "What is your relationship to the person living with dementia?" Survey responses indicating the respondent was not a caregiver to a person with dementia ($n = 46$) or not a spouse or partner to a person with dementia ($n = 11$) were not included in the final survey results.

The remaining 22 questions were divided into three sections. The first section of questions was about the SWD, including how long they had the diagnosis of dementia, how long the caregiver had been caring for their SWD, the activities they helped their SWD with, the amount of time they spent in the caregiving role, and if others assist them

in caregiving. The second section asked about the caregiver's health and preparedness for the care of their SWD in case of an unexpected caregiver health care emergency. Caregivers were asked if they had an expected or unexpected hospitalization in the last 12 months and if they had a care plan in place prior to their hospitalization for the SWD. Caregivers were asked how prepared they were to find care for their SWD if they (the caregiver) were unexpectedly hospitalized in the future. Additionally, caregivers were asked how confident they were that their SWD would receive adequate care if they (the caregiver) were unexpectedly hospitalized. The third section of questions requested self-reported participant demographics.

Reducing bias

To reduce sampling bias, we confirmed eligibility by specifically asking survey respondents if they were spousal caregivers of a SWD. Additional strategies to reduce bias included keeping the survey responses confidential, making clear that their participation was voluntary, and that questions related to demographics would not be put in the EHR.

Study size

We identified a convenience sample of 1,000 caregivers of a SWD.

Quantitative variables and statistical methods

Descriptive statistics were used for information gathered from the EHR and the quantitative survey questions. Missing data were kept as missing and reported in the final results.

Qualitative Journey Mapping Interview Methods

Journey mapping originates in customer and user experience research and is designed to elicit the user's perspective. This technique is often used to identify problem points or gaps in a user experience (Howard, 2014). Journey mapping is becoming more common in health care research to visualize health care experiences and patient perspectives (Bartlett & Boyle, 2022; Benson et al., 2022; Davies et al., 2023; Joseph et al., 2020, 2022; McCormick et al., 2022; Saragosa et al., 2022; van Schalkwijk et al., 2022).

Participant selection

Caregivers of SWD were identified as eligible to participate in journey mapping interviews and purposefully selected if they had experienced a hospitalization within the past 12 months. Eligible caregivers were sent a recruitment email or letter and called by study staff up to three times to participate in a virtual journey mapping interview. Eighteen caregivers refused participation in a journey mapping interview primarily because they were not interested (56%), they did not have enough time (22%), or they opted out prior to being called for recruitment by study staff (22%).

Setting

One women PhD-trained, senior research specialist (K.G.) and a women masters' level project manager (T.M.) recruited and conducted journey mapping interviews from March to June 2022. Both study staff members have extensive experience conducting qualitative interviews. Semistructured journey mapping interviews were conducted by phone between the interviewer and the interviewee. Caregivers who participated

in journey mapping interviews were 61% White and 78% women (Table 1).

Data collection

Prior to conducting the journey mapping interview, interviewers clarified to participants the purpose of the study and confirmed that the individual contacted was a caregiver of a SWD. Interviewers used standardized language to

begin the interviews to define the purpose of the study and fully disclose the funding source: "Researchers from KPCO are studying ways to improve caregiver planning for their own health care emergencies. We are especially interested in improving planning for caregivers of SWD. Dementia is a brain disorder that slowly leads to loss in memory and changes in behavior and personality. We want to learn about how caregivers take care of themselves and the decisions they make when they have to seek care for themselves.

Table 1. Demographics from Survey Respondents and Journey Mapping Participants

	Survey respondents (<i>n</i> = 452)	Journey mapping participants (<i>n</i> = 18)
Age mean (<i>SD</i>)	77 (7.6)	76 (6.9)
Women	287 (64%)	14 (78%)
Race/ethnicity <i>N</i> (%)		
White/Caucasian	348 (77%)	11 (61%)
Black/African American	14 (3%)	0
Asian/Asian American	11 (2%)	1 (6%)
Hispanic	49 (11%)	3 (17%)
Other	0	1 (6%)
Multiple races	2 (1%)	1 (6%)
Not reported	28 (6%)	1 (6%)
Sexuality <i>N</i> (%)		
Straight or heterosexual	414 (92%)	17 (94%)
Lesbian, gay, or homosexual	3 (1%)	0
Not reported	35 (7%)	1 (6%)
Education <i>N</i> (%)		
Less than a high school diploma	17 (4%)	1 (6%)
High school diploma or equivalent/some college credit	177 (39%)	6 (33%)
Associates/bachelor's degree	147 (33%)	7 (39%)
Master's/professional/doctorate	95 (21%)	3 (17%)
Not reported	16 (3%)	1 (6%)
Gross annual household income <i>N</i> (%)		
Less than \$25,000	29 (6%)	1 (6%)
\$25,000 to less than \$50,000	120 (27%)	2 (11%)
\$50,000 to less than \$100,000	140 (31%)	10 (56%)
\$100,000 or more	61 (13%)	1 (6%)
Not reported	102 (23%)	4 (22%)
Do you have an impairment or condition that affects your caregiving activities? <i>N</i> (%)		
Yes*	112 (25%)	6 (33%)
No	325 (72%)	11 (61%)
Not reported	15 (3%)	1 (6%)
Do you take any medication(s) that can affect your caregiving activities? <i>N</i> (%)		
Yes	26 (6%)	2 (10%)
No	413 (91%)	9 (50%)
Not reported	13 (3%)	7 (39%)
How confident are you in filling out medical forms by yourself? <i>N</i> (%)		
Extremely	218 (48%)	9 (50%)
Quite a bit	151 (33%)	4 (22%)
Somewhat	56 (12%)	3 (17%)
A little bit	13 (3%)	1 (6%)
Not at all	7 (2%)	0
Not reported	7 (2%)	1 (6%)

Notes: *SD* = standard deviation.

*Kidney problems, diabetes, need hip and knee replacement, chronic pain, cancer, on oxygen, scoliosis, bad knees, bad back, back injuries, and back pain.

This research is funded by the Alzheimer's Association." Interviewers used semistructured interview guides to conduct each journey mapping interview with probes. The initial interview guide was pilot-tested between authors T.G. and K.G. and modified accordingly. Caregivers were asked to provide details about their role as a caregiver of a SWD and the context surrounding their hospitalization such as if the hospitalization was planned or unexpected and how the hospitalization unfolded. Additionally, they were asked if they had thought about how their hospitalization might affect care for their SWD before the event, how the hospitalization affected their SWD, and if they had plans in place prior to their hospitalization about who could help take over their caregiving roles.

Journey mapping interviews helped to understand the extent of the stress caregivers were experiencing, during five journey phases: (a) their SWD's diagnosis of dementia, (b) their SWD's progression of dementia symptoms, (c) their own health event or change in condition, (d) their hospitalization, and (e) their return home from hospital. A journey mapping worksheet was developed to help guide caregivers to self-rate their stress in each phase of their journey and to track responses (Ly et al., 2021). The journey map worksheet was sent to caregivers ahead of the interview to visually assist the caregiver during the phone conversation (see [Supplementary Material](#)). The caregivers were asked the same core questions to rate and explain their stress level from zero (no stress) to five (high stress) during each of the five phases mentioned above. The worksheet was adapted from values-elicitation worksheets for qualitative interviews (Tuzzio et al., 2021). The five journey phases were chosen as easily identifiable time periods, which commonly cause stress for caregivers and that the caregiver could easily remember (i.e., when the SWD was first diagnosed with dementia and when the SWD experienced progression in their dementia symptoms). The remaining three journey phases were specifically targeted for pre-hospitalization, hospitalization, and posthospitalization. Journey mapping interviews concluded by asking participants to voluntarily self-report their demographic information and were made aware that their responses would be kept private and secure and not placed in the EHR.

Journey mapping interviews were conducted in English and audio-recorded using Microsoft Teams by study staff. Study staff took notes during the journey mapping interviews to document caregivers' stress ratings. Journey mapping interviews lasted on average 33 min (range: 22–52). Audio recordings were then transcribed and deidentified by an outside professional transcription service. Transcripts were not returned to participants for comment or correction. However, following the caregiver rating of each of the five phases, interviewers confirmed the scoring with the caregiver to corroborate.

Data analysis

Transcripts of the journey mapping interviews were inductively coded by K.G. and T.M. using Grounded Theory (Glaser, 1999) in Microsoft Word or ATLAS.ti (Version 8.4.26.0). Coded quotations were examined for emergent themes, grounded in the experience of the caregivers. Thematic analysis of the coding results determined that saturation of common themes was reached after 18 interviews.

Caregivers' stress ratings from the journey mapping interviews were recorded in Microsoft Excel and agreed upon by both K.G. and T.M. For participants who mentioned more

than one score for a phase, we averaged the scores, and any scores described as earlier five were recorded as a five, as the maximum stress level. The stress ratings for individual interviews were plotted as line graphs of stress level rating versus journey phase. All plots were imported into an interactive whiteboard to compare plots and identify patterns. Based on the caregiver narratives and map shapes, three final journey groups emerged. The average journey map scores were plotted for each group and compared to the individual plots and thematic summaries for each group. Representative quotes for the groups and phases were added to the average plots to build a representative journey map for each of the three groups. Caregiver quotations are labeled according to their journey maps—Caregivers 1–7 in Group 1, Caregivers 8–14 in Group 2, and Caregivers 15–18 in Group 3.

Results

Quantitative Survey Results

Participants

Surveys were completed by 509 (51%) of the 1,000 invited. Comparing those caregivers who responded to the survey ($n = 509$) versus those who did not ($n = 491$), both groups were mean age 78 years old, women (62% vs 55%), White/Caucasian (81% vs 66%), non-Hispanic (86% vs 78%), and resided in areas of high SES (92% vs 88%). Of the 509 completed surveys, 46 (9%) individuals indicated they were not a caregiver to a person with dementia, and 11 (2%) indicated they were not a spouse or partner to a person with dementia and therefore excluded. This left our total survey sample at 452 (89%) participants who self-identified as both caregivers and spouses of a person with dementia making them eligible for the study.

Descriptive data

Most respondents were women (64%), White (77%), and a mean age of 77 (± 7.6 ; [Table 1](#)). Most (44%) survey respondents indicated their SWD had a diagnosis of dementia for 1–3 years and that they had been caring for their SWD for the same amount of time ([Table 2](#)). The amount of time spent caring for their SWD varied with 31% spending 41+ hr per week. More than half of the study participants (59%) did not receive additional assistance in caring for their SWD and if they did have support, it mostly came from their children (28%). The top three caregiving activities reported were attending medical appointments (88%), managing finances (83%), and managing medications (78%).

Outcome data

A total of 17% ($n = 75$) of caregivers reported that they experienced a hospitalization within the last 12 months, of which, 68% were unexpected ([Table 2](#)). Of those, 31% did not have a care plan in place for their SWD prior to their hospitalization. Among the 452 survey respondents, 18% indicated they were very prepared, 52% reported they were somewhat prepared, and 29% indicated they were not at all prepared to find care for their SWD if they, the caregiver, were unexpectedly hospitalized in the future. Last, 36% reported they were very confident, 48% reported they were somewhat confident, and 14% indicated they were not at all confident that their SWD would receive the care they need if they were unexpectedly hospitalized in the future.

Table 2. Survey Responses (*n* = 452)

Survey question	N (%)
Approximately how long has your spouse/partner had the diagnosis of dementia?	
Less than 1 year	64 (14%)
1–3 years	200 (44%)
4–6 years	112 (25%)
More than 6 years	71 (16%)
Unknown, not reported	5 (1%)
How long have you been caring for your spouse/partner?	
Less than 1 year	57 (13%)
1–3 years	180 (40%)
4–6 years	102 (23%)
More than 6 years	108 (24%)
Unknown, not reported	5 (1%)
Please select the activities you currently help your spouse with (check all that apply)	
Walking/ambulating	127 (28%)
Bathing/grooming	153 (34%)
Dressing	147 (33%)
Feeding	79 (17%)
Transferring (e.g., moving from bed to a chair or into the car)	83 (18%)
Toileting (i.e., going to the bathroom)	83 (18%)
Shopping	311 (69%)
Cooking/preparing food	344 (76%)
Managing medications	354 (78%)
Attending medical appointments	399 (88%)
Using the phone/technology	289 (64%)
Doing housework	304 (67%)
Doing laundry	294 (65%)
Driving or using public transportation	321 (71%)
Managing finances	376 (83%)
Other (please describe)*	31 (7%)
Unknown, not reported	4 (1%)
Approximately, how many hours do you spend caring for your spouse/partner per week?	
Less than 1 hr	31 (7%)
1–8 hr	113 (25%)
9–20 hr	89 (20%)
21–40 hr	68 (15%)
41+ hr	142 (31%)
Unknown, not reported	9 (2%)
Do others assist in the role of caring for your spouse/partner?	
Yes	181 (40%)
Unknown, not reported	4 (1%)
If yes, what is their relationship to your spouse/partner?	
Sibling	10 (2%)
Child	126 (28%)
Other family (please describe)**	20 (4%)
Friend	10 (2%)
Paid in-home caregiver	49 (11%)
Other (please describe)***	6 (2%)
Unknown, not reported	1
Have you been hospitalized in the last 12 months?	
Yes	75 (17%)
Unknown, not reported	4 (1%)
If yes, was the hospitalization...	
Unexpected (for example, you were hospitalized for an illness that came on suddenly and that you couldn't plan for)	51 (68%)

Table 2. Continued

Survey question	N (%)
Planned (for example, a surgery that was scheduled ahead of time and required staying in the hospital)	24 (32%)
If yes, did you have plans in place prior to your hospitalization for the care of your spouse/partner with dementia?	
Yes	52 (69%)
How prepared are you to find care for your spouse/partner with dementia if you were unexpectedly hospitalized in the future?	
Very prepared	82 (18%)
Somewhat prepared	233 (52%)
Not at all prepared	133 (29%)
Unknown, not reported	4 (1%)
How confident are you that your spouse/partner with dementia would receive the care they need if you were unexpectedly hospitalized?	
Very confident they would receive the care they need	164 (36%)
Somewhat confident they would receive the care they need	217 (48%)
Not at all confident they would receive the care they need	65 (14%)
Unknown, not reported	6 (1%)

Notes: Due to rounding, percentages may not add up to 100%.

*Not indicated, safety precautions, work or legal matters, mental support (e.g., time management, directions, and remembering things), and social support (e.g., company, communication, and leisure activities).

**Grandchildren, parents, and nieces/nephews.

***Neighbors, special classes, or day care.

A total of 20% (88/452) of caregivers left comments on the survey, which were coded into four common themes. Of 32% (28/88) reported physical and/or mental exhaustion, 42% (37/88) reported the need for more caregiver support, resources, and/or financial assistance, and 17% (15/88) reported help making in-home or out-of-home arrangements. Last, 27% (24/88) reported they felt good about their current situations.

Qualitative Journey Mapping Interviews

A comparison of the demographics of caregivers who participated in journey mapping versus survey respondents is shown in Table 1. Their caregiving roles varied widely depending on their SWD's stage of dementia. Caregivers with a SWD in the early stages of the disease provided help with appointments, household chores, and medication management and had responsibility for financial decisions. For example, Caregiver 17 described:

Well, ... there's no issues with eating or, you know bathroom, stuff like that. ... she's just very confused on dates, especially appointments. Every time we go somewhere I tell her what time we have to leave or what time the appointment is and she just gets confused.

Similarly, Caregiver 2 described how as the disease has progressed, they take on more responsibilities:

And [as] we've seen this disease progress, I have taken over most of the household chores: cooking, cleaning. My wife used to handle all of our finances. I am now handling all the finances. Just things that take some type of organization, I have assumed.

Caregiver 2 went on to state:

My wife is on several medications, especially since the diagnosis of the Alzheimer's. So we have written down every

medication that she takes, when she takes it, how much she takes, when the medication needs to be renewed. So we have a complete list, which I would advise anybody to have, because again, as this progresses I am the one that is responsible for her taking her medication because she will not remember to do so.

Spouses with dementias (SWDs) with advanced disease require extensive assistance with daily activities and caregivers have to manage their SWD's behaviors such as wandering. Often round the clock monitoring is needed and help with basic functions like bathing and toileting. For example, Caregiver 10 reported they had only been sleeping an hour or two a night for about 2 years. Caregiver 4 described their situation as:

I pretty well do everything for him, including thinking for him. Sometimes he doesn't understand what's going on and I tell him.

Many caregivers had experiences around their hospitalization that were notable, especially when the hospitalization was unexpected. Most interviewees ($n = 10$) indicated that they did not have a plan in place for support, either for an emergency or for support in general. Caregiver 16 described what happened when they unexpectedly went to the hospital,

When I went to the hospital, it was by ambulance. So I had to leave him [SWD] here by himself. And I was gone for two months. I was in rehab for two months.

Caregiver 4 who had an unexpected hospitalization and had to rely on their neighbors as backup caregivers while hospitalized:

Well, I started feeling really bad. And of course, he wasn't in any shape to help me out, he can't make [a] phone call

or do anything like that. So I knew I was in trouble. So I called my neighbor next door and asked her to come over. She came over, made the phone call to [the doctor] for me. And then they decided that I should go in. So at that time, her husband [neighbor] watched my husband, took care of him.

Similarly, Caregiver 15 who did not have a plan in place prior to their hospitalization described the stressful situation when they left their SWD alone with some support from their friend:

So I was in the hospital Wednesday, Thursday and Friday... [SWD] was at the house alone...and my friend that lived down the street coming in, sitting with him. But when I talked to him [from the hospital], I asked him to please not leave the house, you know?

Caregiver 18 reported that they didn't have a plan in place prior to their hospitalization. This quote describes their reluctance to be admitted to the hospital for fear of who would care for their SWD:

And every time I would go into the ER, they would say, "We want to keep you overnight." I would say, "I can't stay overnight. I have my husband at home. I'm his only caregiver." So they would let me go home. And then I would arrive back there in a matter of weeks. And so finally, they just said, "You're not going home this time. You have to have surgery."

Caregivers may depend on family members to come forward when there is a need. However, if there was no existing support, caregivers expressed that they did not know what to do or what would happen to their SWD in the event of their own health problems. This quote from Caregiver 9, with family support at a distance, describes how her neighbors stepped in until their son arrived:

I thought it was probably a stroke or something like that, so I called 911. The people in the building realized, I guess, they probably saw the emergency personnel here. And they pretty much took care of my husband, watched out for him overnight until my son was able to get him. I did call my son as well. And so he flew in, was here the next day from LA.

In contrast, Caregiver 1 described the urgency of their situation and that they did not know what to do because they didn't have support:

I took a terrible fall. I could not reach anyone to help me to the emergency room or take care of my husband. So I ended up leaving him at home and taking myself to the emergency room. And by time I could reach anybody, I was ready to come home. So I said, "What's the use of you coming now? I'm going to come home."

During the journey mapping interviews, each individual caregiver rated their stress levels during each of the five journey phases. Each caregiver's scores were plotted on their own individual journey maps. Each individual journey map was then visually reviewed to identify patterns. Finally, stress levels

were grouped into three overall patterns, and the average scores during each of the five journey phases were reported (Figure 1A–C).

Group 1 Journey Map: Stress Lowest During Hospitalization ($n = 7$)

Seven caregivers (Caregivers 1–7) rated their stress lower during their own hospitalization. The mean scores and representative quotations of these caregivers are shown in Figure 1A. Some explained their lower stress level was due to not having to worry about caregiving because someone had taken over their caregiver duties. Caregiver 1 who had a planned hospitalization and therefore had a backup caregiving plan in place stated:

When I was in the hospital for my hip replacement, my stress level as a caregiver actually went down ... I had the bases covered. My son-in-law was with my husband [SWD] ... so I wasn't really worried. And we made sure that he had his pills and all of that. Everything was mapped out. So that helped my stress level for the surgery a lot ... I still had a little bit of anxiety. But right then and there, I was more concerned about me.

Caregiver 6 who was unexpectedly hospitalized for three days stated:

I remember telling my nurse the day after surgery ... I said, this is awful to say, but ... it's so nice to just be able to relax. In that situation, it was my brother and sister-in-law had come to town. They were with [SWD] ... and they knew her food schedule and all of that.

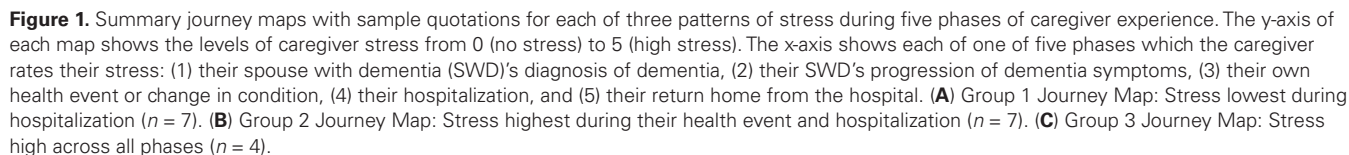
Group 2 Journey Map: Stress Highest During Hospitalization ($n = 7$)

Seven caregivers (Caregivers 8–14) expressed their stress was highest during their health event and hospitalization due to concern about their own health and who would serve as backup caregivers. The average stress levels for this group are shown in Figure 1B. Caregiver 14 who experienced an unexpected hospitalization and did not have family or friends to support their caregiving role explained how it felt during hospitalization:

[I] didn't know what I was going to do with him. If my daughters lived here, I would feel a lot better. But bless their hearts, they don't. I didn't know what's going to happen with him.

Some caregivers indicated that their stress and pain were so high during their health event and hospitalization that they did not have time to worry about anything else. Caregiver 8 who had experienced an unexpected hospitalization and had help with caregiving expressed:

I was trying to figure out what was wrong with me ... The pain was so intense. I didn't think too much about anything except the pain. But I didn't need to worry about him [SWD] because I knew. Because even though this happened, when we were on the way to the hospital, [son] had



knows what they're doing." And for me, it was a relief. But of course, the very next moment, I'm thinking, "But what about [SWD]? How's that going to work?" ... until our son got here, there was that sense that, "Oh my gosh, things are just spinning out of control."

Discussion and Implications

In this mixed-methods study, the objective was to better understand spousal caregiver's preparedness for their own hospitalization and the trajectory of stress during expected stressful phases of dementia caregiving including their own unexpected health event. We hypothesized that most caregivers for SWD would not be prepared for their own health care event. We also hypothesized that caregivers would identify the hospitalization period as the most stressful time period for them. There are two major results of this study that are important for improving the caregiver experience and that helped us better understand spousal caregiver preparedness for their own unexpected health event.

The first result is that caregivers reported being unprepared for the care of the SWD, which confirmed our first hypothesis. The results of the survey indicated a general lack of preparedness and confidence among caregivers for their own health events with 81% indicating they were somewhat/not prepared and 62% that were somewhat/not confident for the care of their SWD. The journey mapping interviews alluded to similar findings and revealed that there is a general lack of preparedness among caregivers for the care of their SWD in the event of their own unexpected health event (e.g., reluctance to go to the hospital knowing they would leave their SWD alone or having no one to step in as the backup caregiver). The survey also revealed that many caregivers of SWD are not confident that their SWD will receive the care they need if they themselves (the caregiver) have a health event. This may be one of the drivers of stress for the journey mapping participants in Group 2 who had increased stress during hospitalization. To avoid the stress of being hospitalized, caregivers may delay seeking timely care for themselves in a hospital setting, which can increase the acuity at the time they seek care. This is a well-known phenomenon for caregivers of those with dementia (Acton, 2002; Oliveira et al., 2019; Wang et al., 2019). However, caregivers also reported that just being sick and having pain was a contributor to their stress independent of

I was on a cane and then I went to crutches and one night I was sitting in my chair and I was trying to get up with my crutches and [SWD] was trying to help me and we both fell. I couldn't get up. He had to call the ambulance and they took me to [hospital] for a few days ... it was just such a hard time. And now I keep putting off my knee replacement because I'm not sure what to do with [SWD]. I'm sure he's going to be all right. But we have the dog that he has to take care of. And a cat. So he has to take care of them and I'm just, I just don't know what to do.

I was the one that took myself into the ER that night. [SWD] couldn't ... I was having significant abdominal pain. Honestly, once I was in the ER, it was a relief that I was being cared for by competent people. And even when they told me I needed surgery, I felt like, "Well, somebody

their worries about their SWD. Based on years of research, it is well understood that caregiving affects the caregiver's health (AARP, 2020; Adelman et al., 2014; Oliveira et al., 2019; Perkins et al., 2013; Waligora et al., 2018). Caregivers of a SWD do not always come into their role healthy or may decline in health during their time in caregiving. Our survey showed that 25% of spousal caregivers' reported that their caregiving role was affected by their own disability or condition. Thus, spousal caregivers should be encouraged and supported to prepare for the possibility of their own health emergency.

A second major finding was that stress levels around a caregiver hospitalization were not universal. We hypothesized that caregivers would identify the hospitalization as the most stressful time period for them. However, this was not the case. The two larger groups of journey-mapping interview participants experienced opposite levels of stress during hospitalization. Group 1 had lower stress levels during hospitalization and experienced hospitalization as a "break" or "relief" from caregiving responsibilities, while Group 2 had higher stress levels during hospitalization because they were worried about their SWD's care. Both the lower and higher level of stress during hospitalization demonstrates the burden of caregiving from opposite perspectives, caregivers who need a break and caregivers who fear the repercussions of taking a break. There are many potential issues that could influence the different stress levels that these two groups experienced including stress levels prior to the hospitalization, extent of caregiver illness, caregiver burden, and whether the caregiver has support. All these potential influences on stress warrant further study; especially in light of designing caregiver interventions.

Regardless of how a caregiver perceived their stress, the time of hospitalization for most caregivers was generally chaotic, often due to the need to rapidly engage or the lack of an immediate backup caregiver. Those with a backup caregiver available and in close proximity, like a child or a neighbor, voiced gratitude regarding their immediate availability. For some, this was a temporary solution until a backup caregiver from out of town could arrive. In the heat of the moment of being ill, nearby and temporary assistance can bridge the gap in care until the official backup caregiver plan can be employed.

Specific to the role of caregivers, previous research used journey mapping as a method to describe the role and experiences of young caregivers in the care of a relative with an acute or chronic illness (Saragosa et al., 2022). Their meta-ethnographic synthesis revealed that young caregivers serve an essential, but often overlooked role in the care of family members including those with a diagnosis of dementia. To the best of our knowledge, little research exists using journey mapping interviews to describe the lived experiences of caregivers of SWD. Using this emerging method for visually representing the caregiver experience allowed us to gain a better understanding of the caregiver experience compared to a typical semistructured interview. The goal of employing this method was to not only understand when caregivers may experience stress but also to inform the optimal timing to introduce an intervention. Additionally, to the best of our knowledge, this is one of the first studies to examine the preparedness and confidence of caregivers for their own unexpected health events.

Limitations

There are a few limitations to report. First, in the survey, reports of hospitalizations in the past 12 months were self-reported and therefore at risk for underreporting (Daddato et al., 2019). Second, the journey mapping interviews represent a small sample of individuals. Although we looked for factors that could affect caregiver stress such as support from family, friends, and the community, whether caregiver hospitalization was unexpected versus planned and the dementia severity, we did not identify any specific pattern, likely due to a small number of individuals. Third, while we purposefully oversampled for marginalized groups in our survey and journey mapping interviews, the majority of our participants were female, White, and heterosexual. This limitation is often encountered in other dementia-related research and highlights the need to employ strategies to reduce potential barriers to recruitment in the future (e.g., language barriers, trust, and burden; Indorewalla et al., 2021). Last, given that our cohort of caregivers was from an integrated health system, the results may not be as generalizable to other caregivers of SWD in other health care systems. However, we believe that the overall experience of caregiving for an SWD may be similar regardless of an individual's payer source or health care network.

Implications

Potential adverse effects of caregiving on the caregiver span multiple domains including: psychological, physiological, and behavioral (Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, 2016). Approaches to disrupt the cascade of caregiver psychological and physiological stress and burden leading to decline in health and wellbeing are important to both members of the dyad. Our previous research indicates that caregiver hospitalizations also place the SWD at an increased risk of being hospitalized themselves within six months of their spousal caregiver being hospitalized (Boxer et al., 2022). This work attempts to gain a greater understanding of the lived experience of the caregiver around their own health event and hospitalization. Hence, tailored interventions may improve outcomes for both the caregiver and SWD.

Conclusion

Meeting the needs of caregivers peri-hospitalization should be tailored to the individual caregiver. There is necessarily no one common caregiver story surrounding their hospitalization. Insight into the needs and timing of planning caregiver support in case of caregiver hospitalization warrants further study.

Supplementary Material

Supplementary data are available at *The Gerontologist* online.

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Conflict of Interest

None.

Data Availability

Data, analytic methods, or materials are not available to other researchers for replication purposes. The data used in the study were not publicly available to other researchers due to privacy and ethical concerns and the protection of personal data as required by the IRB. However, the researchers have provided the journey mapping worksheet used in the study as an Supplementary Material. This research study was not preregistered.

Author Contributions

Study concept and design: Rebecca S. Boxer; Acquisition of data: Blythe A. Dollar, Kathy S. Gleason, Tobie E. Taylor-McPhail; Analysis and interpretation of data: Rebecca S. Boxer, Andrea E. Daddato, Blythe A. Dollar, Kathy S. Gleason, Courtney R. Kraus, Tobie E. Taylor-McPhail; Preparation of manuscript: Rebecca S. Boxer, Andrea E. Daddato, Blythe A. Dollar, Kathy S. Gleason, Courtney R. Kraus, Tobie E. Taylor-McPhail.

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