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“Out of the clear blue sky she tells me she loves me”: Connection experiences between caregivers and people with dementia

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Abstract

Background: Dementia can impede the relationship and connection between the person with dementia (PWD) and their caregiver. Yet, caregiving in dementia also offers opportunities for connection, which has implications for caregiver and PWD well-being. In this qualitative study, we describe and characterize ways caregivers felt connected to the person with dementia they care for.

Methods: We conducted a telephone-based survey with caregivers of people with dementia. For this paper, we analyzed responses to an open-ended question focused on when caregivers feel most connected to the person they are caring for. Responses were analyzed and coded and themes

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AUTHOR CONTRIBUTIONS

Study concept and design: all listed authors; Acquisition of data: all listed authors; Analysis and interpretation of data: Alissa Bernstein Sideman, Jennifer Merrilees, Sarah Dulaney, Rachel Kiekhofer, Katherine L. Possin; Drafting of the manuscript: Alissa Bernstein Sideman, Jennifer Merrilees, Rachel Kiekhofer, Katherine L. Possin; Revision and approval of the manuscript: all listed authors.

were identified through an iterative process involving a multidisciplinary team of researchers and clinicians.

Results: 437 caregivers participated in this study. We identified two domains of connection: activity-based and emotion-based connections. Within activity-based connections, the following themes emerged: everyday activities; reminiscing; activities of caregiving; novel experiences; and time with family and friends. Within emotional connections, the following themes emerged: expressions of love, appreciation, and gratitude; physical affection; sharing an emotion or emotional experience; and times when the PWD seems like “themselves” again.

Conclusions: Findings provide insights into ways caregivers experience a sense of connection with the person they care for. There is a call to shift away from focusing on reducing stress and toward optimizing positive experiences as a way to better support caregivers’ health and well-being. Interventions that leverage these insights to foster caregiver – PWD connection could lead to better health and well-being for both members of the dyad. The amplification of a positive experience may be particularly important for caregivers who are struggling with limited support or respite. Clinicians may be interested in using a question about connection as a way to more fully understand a caregiver’s current experience.

Keywords

caregiving; connection; dementia; qualitative research

INTRODUCTION

Millions of people in the United States live with dementia and rely on caregivers, most often a family member, to provide emotional, medical, financial, and practical support.¹ There are many aspects of dementia that impact the relationship and connection between the person with dementia (PWD) and their caregiver. Diminished cognitive abilities, challenging behaviors, mood disorders, and emotional dysregulation can alter relationships in profound ways.^{2,3} Spouse caregivers often experience an ambiguous loss of their partner and the marriage even while the PWD is still living.⁴ Caregivers’ social networks often shrink as friendships unravel.⁵ Despite these challenges, caregiving offers opportunities for connection and strengthened bonds between the person with dementia and their caregiver even in the advanced stages of illness. For example, compared with healthy controls, caregivers of people with Alzheimer’s disease (AD) report a stronger sense of shared values and emotional closeness along with greater rapport-building behaviors, such as smiling and laughing.⁶ Engaging in caregiving tasks has been shown to increase closeness and affection.^{7,8} In other work, when caregivers created opportunities for the person with dementia to engage in meaningful activities they both experienced a sense of happiness together.⁹ Retaining interpersonal connections has been identified as a critical component of living well with dementia.

The ability to find meaning in and experience positive aspects of caregiving is associated with better health and well-being for both the caregiver and care recipient.^{10–12} Caregivers who experience positive aspects of caregiving have lower depression and anxiety^{10,13,14} and are less likely to place the PWD in long-term care.¹⁵ One study described the

positive aspects of caregiving as either resulting from caring itself (e.g., personal growth, competence, and satisfaction) or from the relationship between the dyad (e.g., fulfilling a sense of duty, satisfaction in reciprocity).¹⁰ Increasingly, research shows that the relationship between the PWD and their caregiver is crucial to their health and well-being. For example, greater relationship satisfaction is associated with the experience of positive aspects of caregiving and better outcomes for caregivers and PWD.^{10,16} Stronger “connectedness” demonstrated through more genuine smiles and more use of “we” pronouns was associated with better caregiver health.¹⁷ Among a group of caregivers caring for people with Alzheimer’s disease, greater closeness predicted lower overall informal costs of care.^{18–20}

There are calls to shift away from focusing on the negative aspects of caregiving and “reducing stress” toward understanding positive emotions associated with caregiving, such as gratitude and compassion, and “optimizing positive experiences” as a way to better support caregivers’ health and well-being.²¹ More work is needed to understand the sources of positive caregiving experiences and to leverage this knowledge to design caregiver and PWD-focused interventions. This work may also be used to modify negative narratives around caregiving in dementia, to illustrate the full spectrum of the caregiver experience including positive aspects, and thus work toward reducing stigma around dementia that may be experienced by both PWD and caregivers. The purpose of this study was to examine the ways that caregivers of PWD find or experience meaningful connection with the people they are caring for. Toward this aim, we analyzed responses to a qualitative open-ended question posed to caregivers of PWD asking them to describe ways they felt connected to the person they cared for. This work builds on existing literature on dyadic relationships in dementia by characterizing experiences of connection between caregivers and care recipients.

METHODS

Participants and setting

Participants were unpaid caregivers ($n = 437$) of people with dementia who were enrolled in a randomized control clinical trial studying the effects of a dementia care navigation program called the Care Ecosystem, which has been described in several publications.^{22–26} This program, based in California, Nebraska, and Iowa, enrolled PWD and their caregivers (typically family members or friends) as dyads. Recruitment procedures have been described previously.²³

Survey

The Care Ecosystem team implemented a telephone survey at 6-month intervals throughout the study period.²³ Survey responses from the 6-month survey are analyzed and reported in this study. The surveys included standard demographic questions as well as questions to measure caregiver well-being (burden, Zarit-12²⁷; depression, PHQ-9²⁸; self-efficacy,²² and dementia severity or stage, Quick Dementia Rating Scale, QDRS²⁹). As part of the study design, we asked an open-ended question at the end of each survey, a practice instituted to end the survey on a relatively positive note. These open-ended survey questions were developed by a multidisciplinary team (medical anthropology, neuropsychology, nursing) based on high-yield questions asked during qualitative interviews with caregivers enrolled

in the Care Ecosystem about their experiences caregiving. During the survey administered 6 months after enrollment, caregivers were asked: *“Tell me about a time you felt most connected to (patient name) in the last few months.”* Responses were recorded in writing by a research coordinator. Each participant described one example of connection. The University of California, San Francisco Institutional Review Board and the University of Nebraska Medical Center Institutional Review Board approved this study.

Analysis

Caregiver responses were analyzed in the qualitative data analysis software Dedoose.³⁰ The team first familiarized themselves with the data by reviewing a subset of responses. Responses were then inductively coded by the first author (ABS) and a clinical research coordinator, meaning codes were derived from the data and not determined a priori or from prior theory. The codes were reviewed and revised at multiple points during the coding process by the first and second authors (Alissa Bernstein Sideman and Jennifer Merrilees). Discrepancies in coding were discussed until agreement was reached and a codebook was created. ABS then validated the coding by re-coding all responses using the codebook. We then identified the nine themes presented in this paper based on our codes. We created memos that defined each of the nine themes along with examples. We reviewed these themes and the examples with our multidisciplinary team, and adjusted our themes and definitions based on group discussion until we reached consensus. We then organized these themes into two overarching domains (activity-based connection and emotion-based connection). We created tables for each domain and its sub-themes with exemplary quotations that were reviewed by the multidisciplinary team.

RESULTS

Patient demographics are presented in Table 1 and caregiver demographics are presented in Table 2. The majority of caregivers were spouses (35% wives, 18% husbands), followed by daughters (32%), sons (7%), other family members (3%), and non-family members (3%). On the measure of caregiver burden, 46% scored greater than or equal to 17 (indicating high burden) at the time the open-ended question was asked. 34% of caregivers had PHQ-9 scores greater than or equal to 5, indicating mild or worse depression, and the average score for caregiver self-efficacy indicated moderate perception of self-efficacy. The most common dementia stage was mild (49%), followed by moderate (28%) and advanced (23%). Most carried a diagnosis of Alzheimer’s disease.

Themes related to connection fell into two broad domains: (1) activity-based connections and (2) emotion-based connections (Tables 3 and 4 respectively). Although we characterized these domains as activity-based or emotion-based connection, some activities raised emotional reactions while some emotions emerged due to engagement in activities. Themes within each domain are presented alongside exemplary quotations.

ACTIVITY-BASED CONNECTIONS (TABLE 3)

Activity-based connections were those experiences that occurred while engaged in an activity. We identified the following themes within this domain: everyday activities,

reminiscing, activities of caregiving, novel experiences, and spending time with family or friends.

Theme 1: Everyday activities

Many caregivers reported feeling connected when engaging in everyday activities, including playing or making music together, outings, exercising, cooking or mealtimes, and going for a drive together. In these responses, there was an emphasis on spending quality time together during these activities.

“I enjoy spending time with my aunt by taking her to drink coffee, eating ice cream together. Just the small things in life.”

“P. will break out laughing or she’ll start humming and singing and we’ll just sit together and hum and sing together. We sing to connect when that happens.”

Theme 2: Activity-based reminiscing

Caregivers reported that reminiscing together was an important way they connected and described engaging in activities that enabled remembering the past or sharing memories of the past. Caregivers reported feeling connected when looking through old pictures, hearing stories about the past, going to places from the past, or sharing memories of the past.

“Some mornings, mom would forget where she is (in [city]) and would believe that she’s in Ireland, where she grew up as a child. We would spend the morning talking about where she grew up. I enjoy listening to her stories.”

“We always feel connected. She likes to talk a lot about my family, and my mother, and how life was back in my country. I love to listen to all her stories and how life was simple then.”

Theme 3: Activities of caregiving

Other caregivers felt connected when engaged in activities of caregiving, including washing, bathing, feeding, or attending to the person with dementia’s physical and emotional needs.

“I feel very connected in her caretaking-knowing medications, recognizing when she needs attention.”

“Every day when I give her the medicine in the morning, breakfast, when I give her lunch and we’re eating together, when we do things together and chores around the house, I feel good and feel connected.”

Theme 4: Novel experiences

Caregivers mentioned activities that involved novel experiences or getting out of the everyday routine such as travel, going on a date, dance classes, or significant life events such as anniversaries or other celebrations.

“This past time we visited Dr. P., we got to spend time together and outside of where she lives. It actually kind of ignited her-getting out pepped her up. She was more attentive and in tune and seemed to be more aware. I felt very good with her

then. I don't want to say that it impacted the next several days, but she was more alert and attentive for the next several days. The staff at [assisted living/nursing home] even noticed. I can't use my car any longer for my mother, I have to borrow a car. It is a huge effort to get her out, but it made me think that I need to get my mother out. It made my mother feel rejuvenated and made me feel useful."

"Going to [dance] classes. I feel quite happy and connected around him when we go to the classes because he can really do everything anyone else can do and I won't have to worry about him talking to other people and watch him because that's what's stressful because I don't have to protect him from being rejected from people. When we are dancing around to oldies it's just fun."

Theme 5: Spending time with family or friends

Finally, caregivers identified connection occurring during activities that involved spending time with friends and family.

"I think I feel a little more connected when we are all together as a family, when we are with the grandchildren and my daughter or when my son is here. It feels normal."

EMOTION-BASED CONNECTIONS (TABLE 4)

Other caregivers reported moments of connection that were not necessarily attached to an external activity, but rather focused on an emotional experience, interpersonal dynamic, or physical affection, as well as experiencing moments when the PWD seemed more "themselves," or were reminiscent of who they were prior to the disease. We identified the following themes within emotion-based connections: expressions of love, appreciation, or gratitude; physical affection; sharing emotions or emotional experiences; and times when the person with dementia seems more like who they were prior to the disease.

Theme 1: Expressions of love, appreciation, and gratitude

Many caregivers felt connected to the person they care for when the PWD articulated appreciation or gratitude for the caregiver, or when the PWD expressed love for the caregiver.

"Whenever she's sitting there and out of the clear blue sky she tells me that she loves me. And then everything she's done up to that point just melts away in my mind."

"Just when he says to me 'thank you so much for spending time with me.'"

"Last night we were sitting in the bed (we sleep in the same room because she's scared to sleep by herself); she said "come and sit over here; I want to thank you for taking very good care of me. I love you" and I said "I'm very happy to be able to be here to take care of you, and I do it not because I have to, but because I love you." and then we hugged, and it was a precious moment."

Theme 2: Physical affection

Other caregivers reported finding connection through physical affection such as hugging, kissing, and cuddling.

“Every night we curl up together and are closest together when we sleep under the stars together.”

“We were spooning in bed, locked in an embrace, I recently told him: let’s snuggle like spoons, like we used to. The sense of physical touch is still so strong with him. We spend a lot of time holding hands and just embracing each other.”

Theme 3: Sharing emotions

Caregivers reported sharing emotions and emotional experiences such as honesty, humor, happiness, joy, fear, and opening up emotionally. Notably, the connection occurred during both positive and negative emotional experiences.

“One time, we had a cathartic crying event, I realized that inside this person, it’s the person I love and I wish I could do more.”

“Just seeing her happy makes me feel really connected to her. The caregivers from [care center] really know how to engage and keep things fun. I saw how excited my mom was from baking cookies and peeling carrots. I just feel really good knowing that she’s happy.”

“We went to church there is a man that sits behind us and he is fidgety. Mom looks at me and says, “why do they let the kids run around here” she does this every week. We start laughing together...we have this shared laughter in the moment.”

Theme 4: Experiences of the person with dementia “being themselves” and moments of clarity

Some caregivers noted that they experienced moments where the patient seemed more lucid or more like who they were prior to the disease.

“One day we were talking, and I had J. back again and we had a conversation and then he disappeared again.”

“I feel more connected to her when she goes back to the mom role. I love it when she asks me about my day. I love it when it feels I’m daughter and not a caregiver.”

ABSENCE OF CONNECTION

There was a subset of caregivers ($n = 46$) who expressed no connection with the PWD.

“I do not feel connected to R., and I have reached a level of feeling detached. When I catch myself acting as I did before he had dementia, I forget he has it and then I feel I have wasted my energy because he doesn’t connect in the same way anymore. I have a sense of loneliness and isolation.”

“I haven’t felt connected. Things have changed. Now I do what I would do for anyone else.”

“I haven’t felt connected with her in the last few months because given her condition we talk and I try to engage her but she really cannot respond back intelligibly anymore, which is obviously really hard.”

We explored how these 46 caregivers may be different from the rest of the sample ($n = 393$) based on the quantitative survey measures. These 46 caregivers did not differ in PHQ-9, Zarit-12, self-efficacy scores (all $ps > 0.50$). They exhibited a trend towards caring for patients with more advanced dementia (t-test p -value = 0.09).

DISCUSSION

Our work shows that connection between a PWD and their caregiver can be characterized as occurring during activity-based and emotion-based experiences. Our findings mirror prior work demonstrating that activities such as mealtimes, reminiscing, and storytelling are important avenues for connection.^{31,32} However, our study expands knowledge in this field by broadening our understanding of the ways that caregivers find connection. Rather than focusing on a specific activity, such as mealtime, the use of an open-ended question created the opportunity for caregivers to describe their individual experiences of connection. Shared activities, novel experiences, and provision of care provided important moments of connection for the caregiver. In addition, experiences characterized by emotional valence, for example, expressions of affection and gratitude fostered the caregiver’s experience of connection. We identify several key contributions and future directions in understanding the role of connection between PWD and their caregivers.

Influencing the narrative around dementia and caregiving

Much of what is written and known about dementia and caregiving focuses on negative experiences involved with disease progression, functional decline, caregiver burden and the negative impact dementia has on the PWD/caregiver relationship. Although this focus is important in representing the experience of caregivers, it can contribute to a negative narrative about dementia, and thus has the potential to increase the sense of stigma experienced by PWD and caregivers. However, there is evidence that positive aspects of caregiving and pleasant events, such as those fostered through connection, exist and may carry a protective influence over negative outcomes for both PWD and caregivers.^{10–12,33} Although these positive aspects of caregiving have been less of a focus in the academic literature, caregiver-focused programs and literature frequently provide practical guidance about the importance of engaging in activities that build connection or enable experiences of joy and happiness as a way to alleviate the burden experienced and find positive meaning in caregiving.

Our work emphasizes the role of connection in this population and raises awareness about different aspects of being a caregiver of a PWD. It may be possible to reframe the narrative about what it means to be a caregiver in dementia by enabling caregivers to express and emphasize the positive aspects of caregiving and by recommending that dementia care providers, such as geriatricians, primary care clinicians, and neurologists, elicit these experiences as part of clinical practice. An emphasis on the positive has the potential to lead to a more positive view of caregiving rather than one that is comprised primarily

of burden. These findings can help reframe expectations about what might be gained or strengthened through caring for a PWD. In our work, caregivers demonstrated that it is possible to experience meaningful and poignant ways of connecting. Sharing experiences of connection could be a powerful practice for the PWD's support network (family members, friends, professional caregivers). It could help build a sense of community, contribute to better care, and increase resilience among caregivers. Shifting the narrative around dementia care to emphasize connection may help reduce stigma and better represent the full spectrum of the caregiver experience.

Sharing and supporting actionable ways of connecting in research, clinical practice, and caregiver support settings

The motivating reason for including this question at the end of a survey, which included potentially distressing questions about burden, depression, and dementia severity, was to end the survey on a more positive note. The open-ended question on connection allowed for the caregiver to focus on what was gained or maintained rather than only on what was lost. By answering this question, they were given the opportunity to acknowledge and reinforce their contributions in creating space and time for these connections. Answering the question provided the opportunity to “re-experience” the connection and the positive emotions, pride, and satisfaction associated with it. This amplification of a positive experience may be particularly important for caregivers who are struggling with limited support or respite. In all aspects of healthcare, patients and family members may be grappling with issues of disability, aging, uncertainty, and stigma about disease and illness. Thus, posing an open-ended question designed to elicit a positive experience could be a fruitful strategy for all clinicians.

Furthermore, the caregiver responses we documented provide concrete insights and examples about how to build connection when caregiving for a PWD. Our work can serve as a contribution to caregivers who are searching for ideas, as well as to caregiver-focused support programs, and providers such as geriatricians, primary care clinicians, neurologists, or mental health professionals who are seeking to share caregiver knowledge about how to connect and activities or experiences that facilitate positive emotional connection. The dissemination of these insights may help caregivers who are struggling by providing supportive ideas from others in their position about how connection can happen. This documenting and sharing of positive caregiving experiences can also shift the narrative of caregiving from one that is “tragic” to one that includes stories and narratives about ways of maintaining connection, both for caregivers and for other important relationships in the PWD's life.³⁴

Despite the many positive experiences elucidated, 46 caregivers in our study were unable to identify a recent experience of connection. For these caregivers, the question may have elicited negative emotions such as sadness and guilt. Some of the terms used by these caregivers included “loneliness,” “isolation,” “detached,” and “wasted energy.” One reported the barriers to connecting with the PWD who “cannot respond intelligibly.” There was a trend for these caregivers to be caring for PWD with more advanced dementia. More work needs to focus on outcomes for caregivers who are unable to experience connection: it could

be due to variables related to the caregiver's physical and emotion well-being, aspects about the PWD's disease severity or symptom presentation, unrealistic expectations regarding the impact of dementia on the relationship, or aspects related to their relationship prior to disease onset.

Exploring the benefits and challenges of connection for both the caregiver and the person with dementia

Although our results, along with prior research on connection and positive aspects of caregiving, provide compelling evidence of the benefits of connection, there is a need to more fully explore whether connection helps the caregiver and the PWD and in what ways. Many of the experiences of connection described in our study were entirely due to the effort of the caregiver, for example, while they were providing care, when they were setting up a shared activity, or when they were capitalizing on an expression or response by the PWD. The time and effort building connection experiences may be burdensome to caregivers. In addition, there is evidence that greater emotional empathy on the part of caregivers is linked to greater severity of depression and anxiety symptoms³⁵ These factors need to be considered in future work examining connection and the potential physical and emotional costs to caregivers. More work is also needed to explore the experience of connection from the perspective of the PWD and the ways it may impact their health, well-being, and disease trajectory. There is some evidence that connection is critical: in one study of residents in a long-term care setting, PWDs who felt unable to have a connection with family members experienced a loss of hope.³⁶

Finally, the majority of caregivers in our study were identified as the PWD's family member (97%). It is possible that family caregiver's sense of connection is influenced specifically by being related to the PWD as spouse, sibling, adult child or other relative. Differences in attitudes, individual responsibility, and conflict around caregiving may occur according to the relationship the caregiver holds.³⁷ These differences may influence the experience of connection the caregiver has with the PWD. Additionally, not all unpaid caregivers are family members and not all PWD have family.³⁸⁻⁴⁰ Thus, more work is needed to examine experiences of connection among PWD who are cared for by non-family caregivers and to expand the definition of family in work on caregiving.

LIMITATIONS

This study had several limitations. Our sample was predominantly white and female, thus impacting the generalizability of our findings. We did not analyze experiences based on whether caregivers were in the Care Ecosystem intervention or control group, although in a prior publication we found no difference between the groups in terms of connection based on pronoun usage and no caregivers mentioned the Care Ecosystem in their responses.⁴¹ We also did not ask PWD to identify their experiences of connection; future work could look at these experiences.

CONCLUSION

Our findings provide insights into ways caregivers maintain a feeling of connection with the person they care for and can help to promote a more comprehensive narrative around dementia and caregiving. In future studies it will be important to explore the impact of variables such as caregiver burden and depression, stage of dementia, and factors such as access to community resources on the experience of connection. An exploration of possible benefits and challenges involved in activity versus emotion-based connection would also be fruitful in increasing our understanding of the types of connections that promote caregiver and PWD health and well-being. Finally, in future studies it will be important to examine this question about connection from the perspective of both PWD and caregivers recruited as dyads to bring in the voice of the PWD and to compare and contrast their experiences dyadically.

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CONFLICT OF INTEREST

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Key points

- We identified and characterized ways that caregivers of people with dementia find or experience meaningful connection with the people they are caring for.
- Our study of positive caregiver experiences in dementia illustrates the full spectrum of the caregiver experience including positive aspects, and thus may work toward reducing stigma.
- This amplification of a positive experience may be particularly important for caregivers who are struggling with limited support or respite. Clinicians may be interested in using this question as a way to more fully understand a caregiver's current experience.

Why does this paper matter?

There are calls to shift away from focusing on the negative aspects of caregiving and “reducing stress” toward understanding positive emotions associated with caregiving and “optimizing positive experiences” as a way to better support caregivers’ health and well-being. More work is needed to understand the sources of positive caregiving experiences and to leverage this knowledge to design caregiver and person with dementia-focused interventions.

TABLE 1

Patient demographics.

Measure	Person with Dementia (437)
Gender	
Female	239 (54.7%)
Male	198 (45.3%)
Age (mean, SD)	73.8, 19.2
Race/Ethnicity	
White	350 (80.1%)
Asian	26 (5.9%)
Black or African American	16 (3.7%)
Native Hawaiian or other Pacific Islander	1 (0.2%)
Two or More Race/Ethnicity Designations	1 (0.2%)
Unknown	43 (9.8%)
Ethnicity	
Hispanic or Latino	71 (16.2%)
Not Hispanic or Latino	364 (83.3%)
Unknown	2 (0.5%)
Dementia Stage (6 months)	
Mild (0–12)	214 (49%)
Moderate (12–20)	98 (22.4%)
Advanced (20–30)	121 (27.7%)
Unknown	4 (0.9%)
Dementia type	
Alzheimer's	209 (47.8%)
LBD	30 (6.9%)
Frontotemporal	25 (5.7%)
Huntington's	1 (0.2%)
Parkinson's	24 (5.5%)
Primary progressive aphasia	5 (1.1%)
Vascular	45 (10.3%)
Mixed	13 (3.0%)
Other	26 (5.9%)
Unknown	59 (13.5%)
State	
California	233 (53.3%)
Nebraska	176 (40.0%)
Iowa	28 (6.4%)
Education	
Less than high school	54 (12.4%)
High school graduate or equivalent	97 (22.2%)
Some college but no degree	91 (20.8%)

Measure	Person with Dementia (437)
College degree or higher	195 (44.6%)

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TABLE 2

Caregiver demographics.

Measure	Caregiver (437)
Gender	
Female	321 (73.5%)
Male	116 (26.5%)
Age (mean, SD)	63.8, 12.3
Race	
White	351 (80.3%)
Asian	26 (5.9%)
Black or African American	15 (3.4%)
Native Hawaiian or other Pacific Islander	2 (0.5%)
Two or More Race/Ethnicity Designations	3 (0.7%)
Unknown	40 (9.2%)
Ethnicity	
Hispanic/Latino	69 (15.8%)
Not Hispanic/Latino	365 (83.5%)
Unknown	3 (0.7%)
PHQ9	
No depressive symptoms (<5)	287 (65.7%)
Mild (5 × < 10)	114 (26.1%)
Moderate (10 × < 14)	16 (3.7%)
Moderate/Severe (14)	20 (4.6%)
Zarit-12	
Low-Burden (<17)	233 (53.3%)
High-Burden (≥ 17)	201 (46.0%)
Unknown	3 (0.7%)
Self-efficacy	
Low (<14 on a 20 pt. scale)	128 (29.3%)
Moderate (14 × < 18)	258 (59.0%)
High (≥ 18)	51 (11.7%)
Relationship	
Spouse/domestic partner	233 (53.3%)
Daughter	138 (31.6%)
Son	32 (7.3%)
Sibling	7 (1.6%)
Other family	14 (3.2%)
Non-family	13 (3.0%)
Education	
Less than high school	21 (4.8%)
High school graduate or equivalent	52 (11.9%)
Some college but no degree	106 (24.3%)

Measure	Caregiver (437)
College degree or higher	258

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TABLE 3

Activity-based connections.

Theme	Examples
Everyday activities	<ul style="list-style-type: none"> • “Last night we ate on our patio and he asked if I would turn Alexa on to play music. And as we finished our meal I was walking him back to our sitting area in the bedroom and one of the songs that came on was a romantic song. He used to be an extraordinary, award-winning dancer. So, I took his arms and held on to him and we danced for a few minutes. It was pretty special.” • “Sitting down over lunch, raking leaves together, and now we have gone to do little dancing at the senior center. That’s been a connection” • “I think that he likes to go for a drive and he always likes to drive where he grew up. This is something that we enjoy doing together.”
Reminiscing	<ul style="list-style-type: none"> • “Several times, we have spent more time going over family album pictures and talking about the past.” • “When she talks about things from the past out on the patio. She feels most connected to memories from being a younger woman.
Activities of caregiving	<ul style="list-style-type: none"> • “Taking care of her here, you are connected almost all the time. I cannot really specify one exact moment.”
Novel experiences	<ul style="list-style-type: none"> • “We had a date day. It was wonderful, we went to get our nails clipped and get our hair done, we took pictures after. It was wonderful. We have not had a date in a very long time” • “Being able to make a trip to Des Moines. That was really important to both of us. It helped us feel connected to people and we were so happy to make a trip away from home.”
Spending time with family and friends	<ul style="list-style-type: none"> • “Around enjoyment with family, lots of family events. We see family a lot and it is delightful to see him so happy with grandchildren.” • “The arena that is our biggest focus is on our children and grandchildren and their successes. When we get good news about their lives that’s a really wonderful time for us together.”

TABLE 4

Emotion-based connections.

Examples

Theme

Expressions of love, care, gratitude, and appreciation

- “Maybe even once a day at least I tell him how I love him and how he’s the best dad in the world and whenever we have that conversation, I feel like we have that connection. Sometimes out of the blue he’ll thank me or say I love you first.”
- “Sometimes he realizes that it’s not so easy for me and that he appreciates it.”
- “He prays for me every time he sees me leave the rehab facility. It brings a tear to my eye.”
- “When she thanks me and says that she is so appreciative of the things that we do for her.”
- “This has been awesome. He has been sharing how proud he is of my brother and me. We’ve listened to him sharing his thoughts about us. He feels I am an accomplished human being. He’s called me a good mom. This is a major change from the negativity he used to express months prior.”
- “Just about every day. We have special moments praying and expressing gratitude and laughing together. We share these moments at least once a day.”
- “There’s been several times when she is more lucid and she actually exudes this warmth and you can just tell that she’s happy to be there with me. It’s not any specific instance or set of circumstances, although generally it’s at home when it’s peaceful. When it happens, she wants to give me a hug and a kiss and she always says ‘thank you for accepting me’.”
- “He held me when I was crying. My cousin’s son died. I was really sad and he saw me crying. He just held me. He rubbed my back. It was really tender and sweet. He was there for me even in his illness.”

Physical affection

- “In the morning when I’m helping him get ready I lean up and give him a kiss and he always smiles after that.”
- “We kiss and hug hundreds of times a day.”
- “He holds my hand and will not let it go sometimes.”
- “We have been married 60 years. We are overly connected. He looks for me all the time. He is always affectionate. He is very cuddly. He hugs me every time he has an opportunity. I always feel connected.”

Sharing an emotional experience

- “We laugh every day and tell each other how much we love each other. It wasn’t in our vows but in our culture everybody knows it’s in sickness and in health, in rich and in poor.”
- “I made a joke and we started laughing and I felt like I had my mom back again.”
- “When he opens up about how his conditions makes him feel and will let me in.”
- “3 days ago John expressed things that he is fearful when his disease gets worse.

Moments of how it was before

- “When he focuses in on my face he brightens up. He remembers the word wife sometimes.”
- “The best part of the whole day is the end of the day when he’s in bed. We can lay there and there’s no Parkinsonism there. We can just be like how it was before.”
- “When I feel most connected to him is just when he’s able to respond to me as if he knows me, when he seems more like himself. There have been a couple of days like that in the last few months, and those are the days you relish and treasure.”
- “She’s usually in her own zone most of the time, but she sings a lot- I love when she does it. I feel that is the same person from years ago. Sometimes we even sing together!”