


“You Feel Very Isolated”: Effects of COVID-19 Pandemic on Caregiver Social Connections

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Alycia A. Bristol, PhD, RNAGCNS-BC^{1,2}, Aaron C. Mata³, Melody Mickens, PhD⁴, Kara B. Dassel, PhD², Lee Ellington, PhD¹, Debra Scammon, PhD⁵, Amber Thompson, MA⁶, Gail L. Towsley, PhD^{1,2}, Rebecca L. Utz, PhD⁶, and Alexandra L. Terrill, PhD⁷ 

Abstract

One in five individuals in the United States provides care and support to ill, disabled, and aging family members in the home, leading to feelings of burden, stress, and poor health and well-being. Social support represents an important buffer for family caregivers that allows them to feel less isolated and more positive about their caregiving role. This sequential mixed-methods study aimed to examine the effect of the COVID-19 pandemic on family caregivers' social connections. Eighty-two caregivers completed a web-based survey which comprised of fixed-choice and open-ended questions. Survey data showed that the majority of caregivers (83%) reported an increase in stress and feeling lonely (77%) during the pandemic. Qualitative interviews with a subsample of caregivers ($n=27$) further explored social connections during the pandemic. Three themes echoed the quantitative findings and centered around defining boundaries, intentionality in social interactions, and loss of social resources. Although caregivers were often strained by new or increased caregiving demands, many experienced positive changes such as feeling a deeper connection with the care-recipient. Findings from this study highlight the need for further consideration of the impact of social isolation on the well-being of caregivers.

Keywords

caregiving, social support, social isolation, COVID-19, loneliness

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Introduction

One in five individuals in the United States are family caregivers (AARP, 2020). Given the aging of the population and the trend to shift ongoing and long-term care away from hospitals and other health care facilities into home and community-based settings, the value of and need for informal caregivers will continue to rise. Numerous programs have emerged in recent years to empower caregivers to feel more prepared and confident to provide care (AARP, 2020). These include education programs, such as those focused on management of patient symptoms (Fiest et al., 2018); support groups, which provide opportunities to connect with and learn from other caregivers (Zebrak & Campione, 2020); and a variety of home and community-based services that provide formal support and services related to

¹College of Nursing, University of Utah, Salt Lake City, UT, USA

²Gerontology Interdisciplinary Program, University of Utah, Salt Lake City, UT, USA

³College of Social & Behavioral Sciences, University of Utah, Salt Lake City, UT, USA

⁴Division of Rehabilitative Medicine, School of Medicine, University of Utah, Salt Lake City, UT, USA

⁵Department of Marketing, School of Business, University of Utah, Salt Lake City, UT, USA

⁶Department of Sociology, University of Utah, Salt Lake City, UT, USA

⁷Department of Occupational & Recreational Therapy, College of Health, University of Utah, Salt Lake City, UT, USA

Corresponding Author:

Alexandra L. Terrill, PhD, University of Utah Department of Occupational & Recreational Therapies, 520 Wakara Way, Salt Lake City, UT 84108, USA.
Email: alex.terrill@hsc.utah.edu



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nutrition, health, and respite (Compton et al., 2020; Zebrak & Campione, 2020).

Social connections decrease caregiver psychological distress and represent a critical aspect to supporting the mental health of caregivers (George et al., 2020; Hossain et al., 2020). Previous work found that caregivers with close relationships and firmly established social connections report greater life satisfaction (Haley et al., 1987). Prior to the start of the COVID-19 pandemic, 21% of caregivers identified feeling alone and reported a decline in their health status since becoming a caregiver (AARP, 2020). Assuming a caregiving role places individuals at risk of experiencing high levels of burden and isolation (Lindt et al., 2020; Liu et al., 2020; Sheehan et al., 2021) and social isolation has been identified as a risk factor for increased caregiver burden (Adelman et al., 2014).

During the COVID-19 pandemic, many community-based supports, and services, such as adult day care and support groups, were temporarily suspended, reduced, and/or eliminated (Dang et al., 2020). Previous research demonstrated that past incidences of medically necessary quarantine and isolation have the potential to worsen mental health (Hossain et al., 2020). Caregivers, like all people who followed the “stay home” and “socially distance” public health directives, were not able to access the informal support they typically received from friends, family, and neighbors. Thus, caregivers experienced greater social isolation and became responsible for additional duties and increased time providing care to the care-recipient (Budnick et al., 2021; D’herde et al., 2021; Park, 2021).

Both theory and empirical research suggest that social connections are key to maintaining positive emotional and physical health (Gariépy et al., 2016; Umberson et al., 2010; Umberson & Karas Montez, 2010), while social isolation is associated with adverse mental health (Pancani et al., 2021; Rohde et al., 2016). During COVID-19, social isolation became a necessity to reduce spread of infection. Within the general population, this resulted in increased rates of loneliness and stress (Philpot et al., 2021), and placed older adults at risk for adverse health outcome such cognitive decline (Steinman et al., 2020; Donovan et al., 2017). Yet, some adults reported an increase in social support, as they deliberately sought out new forms of social connections or invested in deeper relationships with fewer people to combat feelings of stress and uncertainty associated with the ongoing pandemic (Philpot et al., 2021).

The imposed social isolation of COVID-19 has the potential to increase caregivers’ feelings of loneliness, compounding burden and leading to decreased health status among caregivers. To better support caregiver mental and physical health, it is necessary to better understand caregivers’ social connections during times of increased stress, such as during a pandemic. Therefore, this study sought to consider how increased social isolation impacted caregivers’ social connection with the care-recipient, other family

members, and external communities. Understanding the influence of increased social isolation may support future planning of how community services targeting caregivers’ well-being may be delivered in a pandemic.

Methods

Design and Procedures

We utilized an exploratory sequential mixed-method design, which supports in-depth consideration of caregivers’ experiences by including a qualitative phase to explore quantitative findings (Creswell & Clark, 2017). Participants were recruited through social media and flyers distributed by local/national organizations such as the Alzheimer’s Association and Area Agencies on Aging. Eligibility criteria included: 18 years or older and self-identifying as a caregiver. Caregivers were defined as an individual who provides unpaid care such as emotional support and/or assists with basic care tasks to another person of any age with a mental and/or physical health condition or disability (Dassel et al., 2021).

Quantitative survey data were collected from May through June 2020 through an electronically delivered survey (Qualtrics, Provo, Utah). Several survey items focused on identifying significant challenges of caregiving during COVID-19 and access to services such as transportation, support groups, and community resources such as adult day programming. Additional items focused on caregivers’ mental health, stress, loneliness, and social needs during the pandemic (see [Supplementary Material](#)). Short open-ended questions allowed caregivers to describe changes to the caregiving role as a result of COVID-19.

Subsequent qualitative data were collected via semi-structured phone interviews with survey participants who agreed to be contacted for an interview between July and September 2020. Interviews addressed topics specific to caregiving during COVID-19 (see [Supplementary Material](#)). Interviews ranged from 20-90 minutes in length, with an average interview length around 40 minutes. Interviews were conducted until no new themes emerged regarding caregivers’ experiences during COVID-19 and data saturation was reached (Guest et al., 2006). The study was approved by the University of Utah Institutional Review Board.

Analysis

In this study, we focused our analysis specifically on caregivers’ experience with social connections during COVID-19. Quantitative survey responses were analyzed using descriptive statistics. Quantitative survey item data relevant to this study are reported. Additional survey items and results are reported elsewhere (Dassel et al., 2021).

As this study sought to focus on concepts of social connections, deductive content analysis was used to analyze

Table 1. Quantitative survey.

Select survey items and responses	N (%)
Change in time spent caregiving since the COVID-19 outbreak	
Provide more hours of care	49 (65.3%)
No change	21 (28.0%)
Provide fewer hours of care	5 (6.7%)
Change in caregiving stress since the COVID-19 outbreak	
Increased stress	60 (83.3%)
No change	10 (13.9%)
Decreased stress	2 (2.8%)
Most significant challenge(s) of being a caregiver during COVID-19	
Managing isolation for self and/or care-recipient	58 (25.1%)
Worrying that they or their care-recipient would get infected with COVID-19	52 (22.5%)
Getting respite from caregiving responsibilities	40 (17.3%)
Getting groceries or essential supplies	28 (12.1%)
Coordinating assistance provided by others	18 (7.8%)
Homeschooling and/or providing childcare to young children in the home	15 (6.5%)
Other	11 (4.8%)
Financial strain caused by COVID-19	9 (3.9%)

the interviews (Graneheim et al., 2017). Deductive content analysis supports consideration of data in a new context (Catanzaro, 1988; Elo & Kyngas, 2008). Codes were identified based on the selected quantitative survey questions that addressed loneliness, social needs, stress, and mental health, dyad-external networks, and dyad-social network. To support qualitative rigor, a constant, thoughtful process was used to review interview transcripts. Authors Bristol, Mata, Mickens, Terrill met as a team to develop and finalize the codebook based upon the identified codes. Interviews were divided among the team members and were coded based on the established codebook. Member checking was used to review application of the codebook. The team met regularly to discuss and review the differences in coding or the emergence of new codes until consensus was reached (Creswell & Poth, 2017). Triangulation of the quantitative survey questions and interviews occurred to support development and refinement of themes (Morse, 2015).

Results

Participant Characteristics

Participating caregivers ($n=82$) who completed the survey were predominantly women (85%), White (90.4%), non-Hispanic (95.8%), and had at least a college education (74.0%). Nearly half were older (44% over the age of 60) and most were married (78%). The sample included those caring for parents/parents-in-law (45.1%), spouses/partners (26.8%), children (18.3%), and other family members such as siblings and grandparents (9.8%). Over half of participants (53.2%) provided more than 20 hours of care per week. Most care-recipients were older than 60 years (63.8%), lived with the

caregiver (73.4%), and most had neurological conditions (40.6%) and other chronic conditions such as diabetes, heart disease, or cancer (24.8%).

Quantitative Findings

Most participants (92.5%) reported that their experience as a caregiver changed due to COVID-19. Table 1 details changes and challenges reported by caregivers. Caregivers (83.3%) reported increased stress during the pandemic, and over half (53.4%) felt that they did not have adequate support for their mental, emotional, and spiritual health. Notably, 76.7% reported feelings of loneliness during the pandemic, with 21.9% feeling lonely every day.

Qualitative Findings

The subsample ($n=27$) of caregivers who participated in interviews was predominantly women (78%) and more than two-thirds were in their 60s or older. The subsample included those caring for parents/parents-in-law (56.7%), spouses/partners (20%), children (20%), and other family members (3.3%), most of whom had neurological conditions (53.1%) and other chronic conditions (18.8%).

The qualitative findings provide insight into how social connections changed during the pandemic, echoing the high rates of loneliness, isolation, and stress evident in the quantitative survey. Interview transcripts provided details regarding how caregivers' social interactions and relationships were affected during the COVID-19 pandemic. The themes identified converge (e.g., increased social isolation and increased caregiving role/burden), extend (new role in enforcing COVID-19 restrictions, types of social support lost), and contradict (examples of the dyad relationship

growing closer) findings from the quantitative analysis. The main themes are (1) defining boundaries to protect the care-recipient, (2) intentionality in social interactions, and (3) loss of social resources.

Theme 1: Defining Boundaries to Protect the Care-Recipient

Caregivers overwhelmingly acknowledged the need to establish and define boundaries between the care-recipient and their external social support network to reduce potential exposure to COVID-19 and maintain care-recipient health. With less access to formal or informal supportive services, caregivers felt solely responsible for ensuring the care-recipient avoided becoming ill. For example, a caregiver stated:

I guess, with COVID, I have to keep a little bit of a closer watch on him. If the doorbell rings, he'll go to the doorbell and forget that he shouldn't answer the door or let people in, so a greater watch with it. I monitor his health really closely...because we don't want him to have to go into an emergency room...I would not be doing that quite as intensely if COVID weren't here. (CG22)

Caregivers typically felt they had a responsibility to follow the established COVID-19 precautions over the wishes of others.

To combat potentially high-risk actions of the care-recipient, caregivers sought to educate and emotionally support them. This was especially evident when the care-recipient displayed hesitancy toward following recommended COVID-19 precautions. By maintaining trust between and seeking to demonstrate why boundaries were sought, caregivers (in some cases) were able to establish a closer relationship with the care-recipient. For example, one caregiver stated:

She's come to trust me more, about the information that I give her about— if it's too dangerous to go get her haircut, or if other extended family members, if we don't know for sure where they've been, that maybe it's not the best idea for them to come to her house. (CG20)

Tensions often emerged as caregivers sought to follow COVID-19 guidelines, while addressing opposing opinions from some members of their external network. Caregivers felt they had to serve as the final arbiter between external social networks and the care-recipient and following COVID-19 precautions to maintain social distance and to follow stay-at-home orders. One shared:

My other brother, he was like, "Oh, yeah, we'll just come over." He didn't think it was a big deal. He's like, "Oh, we're not sick." So they would try to come over, and then I would get in a fight

with them, and say, "No, you can't come over." [...] That was definitely managing risk of exposure. (CG15)

As new boundaries were established relationships with the external social network suffered and exposed family tensions.

Theme 2: Intentionality in Social Interactions

The pandemic restricted opportunities for social interactions for both caregivers and care-recipients, which prompted caregivers to intentionally seek out opportunities for social connections. Many caregivers described an increasing burden of being the sole source of social interaction for the care-recipient and seeking opportunities for supporting care-recipients' social connection needs.

Outside of the caregiver-care-recipient relationship, caregivers also experienced restricted access to their support network. Whether it was spending more time with the care-recipient or spending less time with family, friends, and other support systems, caregivers observed that they were being more intentional in their social interactions.

Subtheme: Intentionality within the caregiving relationship

Caregivers reported being more intentional in their communication and actions with their care-recipient. However, finding opportunities for social interactions were challenging. One caregiver shared:

She just sits at home all day. And I've been trying different things. [...] I can't take her places that I used to be able to take her. Grocery shopping was very much a social activity for her. And she had friends all through the grocery store. (CG18)

Caregivers struggled to provide the same level of social interactions experienced by the care-recipient pre-pandemic. A caregiver reported:

I try to provide stimulation and interest and I feel like I do a good job, but there's so much more that, you know, regardless of how hard I try, I can't be everybody else. (CG5)

Another shared

I'm the number-one person that has to try and calm her down, to convince her kids that "This is what she needs from you right now,"... I'm the one that's got the brunt of all of it because I'm trying to get them to "Please pay attention to your mom." (CG4)

Subtheme: Intentionality with external network

The pandemic introduced new challenges for interacting with external support networks, for both caregiver and care-recipient. Caregivers described still wanting to establish

and maintain supportive networks outside of the caregiver–care-recipient relationship, but to do so required them to be more intentional with whom and how they might interact.

Many participants expressed missing organized social events, such as in-person church services or support groups. Particularly the casual face-to-face encounters that used to facilitate connections at these gatherings were no longer available. A caregiver stated:

It has changed a lot just because of all church services being cancelled. You would see people at least once a week, and you'd say "Oh, how you doing?" and stuff like this, and now you have to reach out a little bit more, [...] to say "Oh, how are you doing?" And I've even had to say "Hey, I'm struggling. Can you just talk to me?" And so it's been harder [...] but it is still possible. You just have to be more proactive to reach out because they're probably struggling too. (CG28)

Caregivers found that they had to be more intentional about reaching out and checking in with each other. Several participants described having to be inventive in creating opportunities for social interactions that maintained social distance. One participant described:

People are—and have been—really starved, socially. So we've had a number of occasions where we'll circle up the chairs outside, and have visits, and laugh, and talk, and that's helped, too, because everybody's in the same boat, and misery loves company. (CG21)

Caregivers without a strong, clearly established support network prior to the pandemic struggled to maintain connections during the pandemic. Caregivers whose external networks fell apart due to social isolation found it difficult to know how to find or build social connections.

As participants navigated these challenges with members from the external network, many found they needed to increase the frequency of interaction, which may have increased the overall quality of interactions. For example, one participant commented, "Everything is centered around my home right now [...]. There are great things about it, too. I think there are connections I'm making with my kids that maybe I wouldn't have otherwise." (CG26) These new interactions with external networks were occurring via phone, letter, email, and videoconferencing, rather than in-person.

Theme 3: Loss of Social Resources

Overwhelmingly, participants identified that access was limited to formal and informal resources, relationships, and services resulting in increased caregiving-related workload and burden. For example, some participants reported they struggled to find home health services they could trust to allow into the home environment during the pandemic.

Others shared the loss of in-person support groups. One caregiver stated:

They were saying that sometimes there's a group [...], they're trying to figure out a way to gather at a park and sit far enough away with masks and stuff to have some kind of face-to-face, but again for me I work full time and then I don't have coverage to go and do that, I can't leave Mom alone ever. (CG8)

Subtheme: Increased Caregiving Role

The loss of formal services and access to their informal supportive arrangements led to greater isolation for both caregiver and care-recipient, echoing the high levels of reported loneliness in the quantitative survey. Caregivers felt responsible for creating new activities in the home to replace the lost social connections; many spent increased time interacting with the care-recipients. As a result, many caregivers were taking on new and greater caregiving duties, while adjusting to other personal changes (e.g., working from home and cohabitating with care-recipient) and their own changes in social connections. A caregiver shared how assuming additional care duties represented a key challenge of COVID-19, "Probably having to do pretty much everything myself, not being able to utilize other family members, grandchildren, [...] to help. That might be the hardest part" (CG19). As caregiving responsibilities increased, stress levels also increased as evident in the quantitative survey findings.

Discussion

The health of the care-recipient has been demonstrated to be associated with the mental health status of the caregiver (Pristavec, 2019). Therefore, considerations of the lasting impact of social isolation resulting from COVID-19 should be recognized. As evident in the quantitative findings, caregivers reported loneliness as a key aspect of caregiving during COVID-19. During interviews, caregivers agreed, sharing that the loss of superficial, everyday social interactions negatively impacted mental health and coping as caregiving duties increased. This suggests that caregivers are especially vulnerable to changes in their social networks due to the emotional and instrumental support provided that previously offset the stresses of long-term caregiving.

Family relationships, social support (Yu et al., 2015), and satisfaction with life (Fauziana et al., 2018) have been associated with positive mental health outcomes for caregivers. However, the circumstances of the pandemic heightened caregivers' role as an "enforcer," whereby caregivers had to enforce COVID-19 precautions for both the care-recipient and external network, resulting in tensions between themselves, the care-recipient, and the external social networks. Stressors such as family conflict during COVID-19 have been

associated with increased caregiver adverse health effects (Beach et al., 2021). In our study, caregivers reported the heightened responsibility of the enforcer role decreased social connection with extended family members and influenced feelings of isolation and stress. Maintaining positive family relationships and social connections may be unattainable during a pandemic. As care-recipients depend on caregivers for high quality care, caregivers may be unable to address care-recipients' needs, resulting in potentially increased use of healthcare services, such as placement of the care-recipient in long-term care facilities.

This study found that the pandemic also supported some positive changes in the care relationship, echoing other discussions regarding how families drew closer during the pandemic (Lightfoot et al., 2021). In our study, the actions caregivers took to educate care-recipients about why COVID-19 behavior was needed tended to promote a positive outcome such as increased trust in the caregiver. Caregivers also frequently noted a closer relationship with the care-recipient, which may be due to more time spent together and opportunity for intentional, often reciprocal interactions as well as feeling more appreciated by the care-recipient. These findings could be significant as existing research suggests that mutuality and gratitude are related to improved caregiver outcomes, including better emotional health and decreased caregiver burden (Amaro, 2017; Park & Schumacher, 2014).

The COVID-19 pandemic illustrates the importance of considering the support available to caregivers and how caregivers seek out social connections. Healthcare professionals should recognize caregivers represent a potentially vulnerable group during events such as a pandemic and assess for caregivers' potentially unmet social needs (Dang et al., 2020; Steinman et al., 2020). Increased screening, support, and education are necessary to help caregivers address the care needs of the care-recipient (Dang et al., 2020). Addressing social needs aids in caregivers supports the health needs of the care-recipient, such as aiding in management of the care-recipient at home and decreased use of healthcare services (Dang et al., 2020).

In addition to formal services, caregivers rely upon more informal forms of social connections (e.g., church attendance and shopping) and these may also be restricted during a crisis (D'herde et al., 2021). Similarly, to other individuals during the pandemic, caregivers described an increased use of technology to connect with fellow caregivers and family members. However, most caregivers acknowledged that communication over technology occurred with individuals they had a relationship with prior to the onset of the pandemic. During the pandemic, more individuals became comfortable using technology to connect with friends, family members, and healthcare providers. Telehealth emerged as key tool to help connect individuals and healthcare professionals. Telehealth has the potential to support family-centered care (Brody et al., 2020).

However, telehealth has been found to not meet the needs of caregivers providing care to complex individuals (Kowanda et al., 2021). Further consideration of how to incorporate social needs assessment in the delivery of care during a pandemic is needed. To ensure that social connections can be maintained, it is important to recognize the potential negative impact on both formal and informal connections and to explore alternative ways in which the social needs of caregivers are included during assessments of the health and wellness of the dyad.

Limitations

This study provides a unique look at caregivers' social connections during a pandemic. Previous focus has been placed on describing the influence of social isolation. However, the unique needs of caregivers may not be well understood. Using a mixed-methods design supported a richer understanding of caregivers' and care-recipients' experiences during COVID-19. Additionally, it is unknown what the long-term relationship status is between caregivers and care-recipient. Other limitations for this study include the homogenous sample of primarily white, female caregivers.

Future Directions

This study highlights the need for healthcare professionals' recognition of the need to assess caregivers' social needs. The COVID-19 pandemic exposed the importance of establishing a strong, existing social support networks as a potential buffer against social isolation. While it is unknown how caregivers will return to normal, we have more knowledge about the intricacies and nuances of social support that sustain and support caregivers during, before, and beyond the pandemic. Thus, future directions could then be reframed in terms of how research and theory about social support can adopt these expanded notions of social support and highlight the importance of healthcare professionals' recognition of the role social connection plays in supporting positive health outcomes for the caregiver and care-recipient.

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ORCID iD

Alexandra L. Terrill, PhD  <https://orcid.org/0000-0002-2698-7435>

Supplementary Material

Supplementary material for this article is available online.

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