

Stroke Family Caregiver Life Changes From the COVID-19 Pandemic

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ABSTRACT

BACKGROUND: Stroke family caregivers were already struggling with unmet needs and changes in their own lives from providing care. The COVID-19 pandemic added further stress and disruption to their lives. The purpose of this study was to describe life changes in 17 stroke family caregivers specifically resulting from the COVID-19 pandemic. **METHODS:** This study was conducted as a secondary data analysis from an ongoing randomized controlled clinical trial testing feasibility of the Telehealth Assessment and Skill-Building Kit (TASK III). Using a multimethod design, both quantitative and qualitative data were analyzed to determine caregiver life changes. Quantitative ratings regarding life changes were obtained using 17 items adapted specifically for COVID-19 from the Bakas Caregiving Outcomes Scale. Rigorous content analysis procedures for the qualitative data were guided by a start list of codes based on the 17 items, with additional themes possible. Representative quotes were selected based on author consensus. **RESULTS:** Findings revealed both negative and positive life changes from the COVID-19 pandemic. Negative life changes included such things as disrupted daily routines, limited access to healthcare providers and resources (eg, food, masks, hand sanitizers), reduced family and social contact and activities, decreased emotional well-being, and problems with performing caregiving activities for the survivor. Positive life changes were increased use of the Internet and videoconferencing, closer relationships with friends, and learning how to access needed resources in new ways. **CONCLUSION:** Stroke family caregivers experienced both negative and positive life changes specifically as a result of the COVID-19 pandemic. Responses further indicated that COVID-19 affected most caregivers in different ways and an individualized approach is needed in dealing with caregiver life changes.

Keywords: COVID-19, family caregiver, quality of life, stroke, technology

Stroke remains the second major global cause of death and leading cause of disability affecting more than 104 million people.^{1,2} An estimated 7 million US adults have had a stroke resulting in complications such as diminished motor functioning, cognitive impairment, aphasia, incontinence, falls, seizures, and depression.² Although many stroke survivors receive inpatient rehabilitation and skilled care, family caregivers provide most of the required long-term care once discharged to the home setting. As a result of these extra responsibilities, family caregivers

experience numerous unmet needs including the lack of caregiver education and training, financial issues, poor access to services and resources, difficulty managing the survivor's personality and emotional changes, and dealing with the survivor's physical limitations.³ Unmet needs of stroke caregivers involve taking care of oneself and managing one's own emotions during the process,³ especially anxiety and depressive symptoms.⁴

With the COVID-19 pandemic, stroke family caregivers had a dramatic increase in unmet needs.⁵⁻⁷ Despite stroke care best practices to maintain the provision of comprehensive care across the care continuum during the pandemic,⁸⁻¹⁰ caregivers have reported delayed communication with healthcare providers, inadequate caregiver education in preparation for discharge, and lack of training to provide rehabilitation care at home, as well as the added stress of sanitizing and protecting their loved ones from COVID-19.^{7,8} Because of a wide variety of unmet needs both before and after the COVID-19 pandemic,³⁻⁷ caregivers have experienced considerable life changes.^{6,7,11,12} Life changes are defined by the Bakas Caregiving Outcomes Scale (BCOS) as changes in social functioning, subjective well-being, and health specifically as a result of providing care.¹¹ The BCOS consists of 15 items rated on a scale from -3 (changed for the

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This study was supported by the National Institutes of Health, National Institute of Nursing Research (R21NR016992; PI, Tamilyn Bakas; <https://clinicaltrials.gov/ct2/show/NCT03635151>).

The authors declare no conflicts of interest.

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<https://doi.org/10.1097/JNN.0000000000000654>

worst) to +3 (changed for the best), with 0 meaning the item did not change.¹¹ Strong evidence of internal consistency reliability and content, construct, and criterion-related validity have been reported for the BCOS.¹¹ Studies using the BCOS have reported negative life changes in stroke caregivers, such as decreased time for family and friends, reduced level of energy, and diminished physical and emotional health specifically as a result of providing care.^{11,12} Under normal circumstances, stroke family caregivers experience substantial life changes, but these changes may be further magnified with COVID-19 when more demands are placed on caregivers' ability to provide care.^{11,12} The purpose of this study was to describe life changes in stroke family caregivers specifically as a result of the COVID-19 pandemic.

Methods

This study was conducted as a secondary data analysis from an ongoing randomized controlled clinical trial testing feasibility of the Telehealth Assessment and Skill-Building Kit (TASK III). In this study, the Telephone Assessment and Skill-Building Kit (TASK II) for stroke family caregivers¹³ was enhanced to a TASK III version¹⁴ that was delivered based on caregiver technology preferences. During the last few months of the TASK III feasibility trial (August–December 2020), 17 stroke caregivers provided ratings about how their lives changed specifically as a result of the pandemic using a COVID-adapted version of BCOS.¹¹ A multimethod design was used to investigate stroke caregiver life changes based on both quantitative and qualitative data analyses.¹⁵ All participants gave consent before the start of this study, which was approved by an institutional review board.

Data Collection. The 15-item BCOS¹¹ was adapted to determine possible life changes in stroke family caregivers specifically as a result of the COVID-19 pandemic. Eleven items from the BCOS were used, with 6 new or adapted items added. These 17 items were grouped according to 4 major themes: routines and access to resources; family, friends, and videoconferencing; survivor relationship and caregiving activities; and caregiver health and well-being. All participants were asked to rate the items using a response scale used in the original BCOS.¹¹ Responses were recoded as $-3 = 1$, $-2 = 2$, $-1 = 3$, $0 = 4$, $+1 = 5$, $+2 = 6$, and $+3 = 7$ so that positive numbers were obtained for analysis. As caregivers were responding to the 17 items by telephone interview, they were encouraged to elaborate about their responses for each item and gave permission for their responses to be recorded and later transcribed for analysis.

Data Analysis. Descriptive statistics (mean [SD], median, range, frequency [percent]) were used to

summarize sample characteristics for stroke caregivers and survivors. Quantitative ratings from the 17 items adapted from the BCOS were summarized using descriptive statistics. Rigorous content analysis procedures for the qualitative data were guided by a start list of codes.^{15–17} The start list of codes were the 17 items adapted from the BCOS, with additional categories possible for themes that emerged that were different from the 17 items. Representative quotes were selected and placed in a matrix table with the 17 items, along with any other themes that emerged.¹⁵ Findings were interpreted by matching quantitative ratings with the qualitative quotes. The first author placed the quotes into the table with the 17 BCOS item ratings. The coauthors independently reviewed and confirmed the coding process in the table based on the transcripts. Consensus was reached related to the selection of representative manuscript quotes presented. Trustworthiness was addressed according to the qualitative criteria: credibility, reliability, and confirmability.^{15,17,18} Credibility was demonstrated by an audit trail when investigator bias was minimized by tracking each step of the coding process and decisions made during analyses.¹⁷ By confirming the consistency of procedure, analyses, and conclusions, reliability was addressed.¹⁸ Finally, confirmability was achieved by triangulating qualitative responses with the quantitative ratings from the COVID-adapted BCOS provided by the caregivers.^{15,17}

Results

Table 1 summarizes sample characteristics for the participants. Of 17 stroke caregivers, 7 were spouses, 6 were adult children/in-laws, and 4 were other relatives or close friends. Family caregivers tended to be younger on average than the survivors, with more than three-fourths of caregivers being female. Survivors were more evenly split between males and females. Most caregivers were White, with more than one-fourth being Black or African American. None of the participants were Hispanic. In this sample, the average years of education was 16 and almost half of the caregivers worked full-time or part-time. Although most caregivers rated their perceived incomes as comfortable (Table 1), more than one-third had only enough to make ends meet, and 1 participant was not able to meet expenses. On average, stroke survivors had 3 chronic conditions compared with caregivers who averaged 1 chronic condition. On the basis of Stroke Specific Quality of Life proxy scores, survivors were mildly to moderately impaired. Five caregivers and 3 stroke survivors reported a history of depression.

The wide range of responses for each of the 17 items underscored the diversity of perceptions that the caregivers had regarding life changes during the

TABLE 1. Sample Characteristics (N = 17)

Caregiver and Survivor Characteristics	Mean (SD)	Median	Range
Caregiver age, y	54.5 (18.7)	57.0	24–85
Survivor age, y	71.3 (19.0)	71.0	33–98
Caregiver years of education	16.1 (2.9)	16.0	12–23
Survivor years of education	15.0 (3.0)	14.0	12–20
Caregiver number of chronic conditions	1.1 (1.8)	0.0	0–5
Survivor number of chronic conditions	3.1 (1.2)	3.0	2–5
Survivor total SSQOL proxy score ^a	3.4 (0.6)	3.4	3–5
Thinking	3.3 (1.0)	3.3	1–5
Language	4.3 (0.9)	4.6	2–5
Vision	4.7 (0.5)	5.0	3–5
Energy	2.5 (1.2)	2.3	1–5
Physical function	3.7 (0.9)	3.9	2–5
Mental function	3.2 (0.9)	3.1	2–5
Role function	2.3 (1.2)	1.8	1–5
	n (%)		
Caregiver sex			
Male	4 (24)		
Female	13 (77)		
Survivor sex			
Male	8 (47)		
Female	9 (53)		
Caregiver race			
Black or African American	5 (29)		
White or Caucasian	12 (71)		
Caregiver perceived income			
Do not have enough to make ends meet	1 (6)		
Just have enough to make ends meet	6 (35)		
Comfortable	10 (59)		
Caregiver employment			
Full-time or part-time	8 (47)		
Unemployed or retired	9 (53)		
Type of relationship			
Spouse	7 (41)		
Adult child or adult child-in-law	6 (35)		
Other relative or friend	4 (24)		
Caregiver history of depression	5 (29)		
Survivor history of depression	3 (18)		

^aStroke Specific Quality of Life (SSQOL proxy): lower scores indicate more impairment.

COVID-19 pandemic (Table 2). Most items ranged from 1 (changed for the worst) to 7 (changed for the best), with a score of 4 meaning “did not change.” When caregivers were asked, “In general, how has your life has changed as a result of the COVID pandemic,” the mean score was 2.8 and best reflected in the comment “Everything in my life changed simultaneously with COVID.” The 17 items and corresponding representative quotes were grouped according to the 4 themes mentioned previously.

Routines and Access to Resources. The most negative change revealed was “daily routines” that had the lowest mean rating for this category (3.4), with some caregivers having ratings as low as 2. This finding was supported by caregivers who said, “We have to be more playful and mindful of when and how you’re spending your time” and “Because of all the cleaning, it’s increased my burden at work, also increased burden at home.” Another caregiver said, “Since I work in healthcare, when I go home, I have to like to change all my clothes, and need to find time to shower. I have to be careful when I get home so I’m not bringing it to people at home.” Another prominent negative life change was reduced access to healthcare (mean, 3.5), for instance, “It’s hard to get any information [from healthcare providers] now because of COVID,” and “It changed particularly at the beginning because we all went into lockdown.” Access to food and other needed items was impacted (mean, 3.7) as evidenced by the comment, “When you got everything you need and everything you want, and then all of a sudden you don’t have it.” One caregiver viewed access to food as changing for the best saying, “My son has done all of my grocery shopping.” Use of the Internet to order items improved slightly (mean, 4.4), although 1 caregiver acknowledged some delays in orders at the beginning. Surprisingly, on average, financial well-being changed slightly for the best (mean, 4.0), although some caregivers rated their financial well-being as low as 1 (changed for the worst). One caregiver stated, “The only thing that’s really changed, my business that I own, so that’s gone downhill a little bit because of social distancing, but not enough to financially impact me because it’s not my main source of income.”

Friends, Family, and Videoconferencing. Social activities were limited because of COVID (mean, 2.5), exemplified by statements such as “It’s impacted our lives because we are not with people that stimulate you. We’ve had our birthdays through the front window,” and “I live in a cul-de-sac with about a dozen houses, and want to get together with the neighbors, but you really can’t do it.” Other caregivers responded, “It certainly takes more effort to talk to people because you have to make plans about where you are going to

TABLE 2. Life Changes as a Result of the COVID Pandemic (N = 17)

As a result of the COVID pandemic...	Mean (SD)	Median	Range
Routines and access to resources			
My daily routines	3.4 (1.4)	3.0	2–6
My access to healthcare (eg, doctor, dentist, eye or therapy appointments)	3.5 (0.6)	4.0	2–4
My access to food (eg, grocery, shopping, finding needed items, buying)	3.7 (0.8)	4.0	3–6
My use of the Internet to order items (eg, groceries, household goods)	4.4 (1.0)	4.0	3–7
My financial well-being	4.0 (1.2)	4.0	1–6
Friends, family, and videoconferencing			
My relationship with friends	4.0 (1.4)	4.0	1–7
My social activities with friends	2.5 (1.1)	2.0	1–5
My relationship with family	3.9 (1.6)	4.0	2–7
My family activities	2.6 (1.5)	2.0	1–7
My use of videoconferencing to connect with others (eg, Zoom, WebEx, Skype)	4.7 (1.3)	5.0	1–7
Survivor relationship and caregiving activities			
My relationship with the survivor	4.2 (1.4)	4.0	2–7
My caregiving activities for the survivor	3.7 (1.3)	4.0	1–7
Caregiver health and well-being			
My emotional well-being	3.5 (1.3)	4.0	1–7
My ability to cope with stress	3.9 (1.1)	4.0	2–7
My level of energy	3.5 (1.0)	4.0	2–6
My physical health	4.1 (0.7)	4.0	2–5
In general, how has your life changed as a result of the COVID pandemic?	2.8 (1.3)	3.0	1–7

Note. Items were rated on a scale from $-3 =$ changed for the worst to $+3 =$ changed for the best, with $0 =$ did not change. Responses were recoded ($-3 = 1, -2 = 2, -1 = 3, 0 = 4, +1 = 5, +2 = 6, \text{ and } +3 = 7$) so that positive numbers were obtained for analysis; same response scale used for the original 15-item Bakas Caregiving Outcomes Scale.⁵

meet, if it is outside and all of that kind of stuff,” and “It’s just staying connected to people which is I think really important in crises, but also in general.” As far as family activities (mean, 2.6), caregivers said, “Not being able to see my daughter has been extremely hard” and “You just can’t do the things you wanna do like Thanksgiving, a big family dinner.” Regarding videoconferencing (eg, Zoom, Webex, Skype) to connect with others (mean, 4.7), participant statements revealed some positive life changes and willingness to try new things to maintain some normalcy and stay connected, for example, “I didn’t know it [videoconferencing] existed before COVID and then a family member started trying to hook us up” and “My mom has gone back to [church] fellowship by Zoom.” Another caregiver stated, “We listened to it [church] on the YouTube on Sunday morning, but it’s not like being at church and participating with other people in your congregation.”

Survivor Relationship and Caregiving Activities. Regarding relationship with the survivor (mean, 4.2), a spouse caregiver shared, “My husband spent an entire month in the hospital alone [during the COVID pandemic] and I feel like that has done more to his mental health, therefore in turn affecting the rest

of the family.” Caregiving activities were impacted as well (mean, 3.7). One particular statement that stood out was, “He was really sick, throwing up, and had a fever, so I assumed he had COVID, so I locked him in our bedroom. We were all pretty sick a while ago.” A spouse caregiver shared, “I couldn’t take her to church, and I couldn’t take her anywhere, and so she didn’t interact, and so it was hard for her and still is.” Another caregiver said, “This COVID has made my situation of me caretaking for my grandpa even more isolating.”

Caregiver Health and Well-being. The impact of the COVID pandemic on caregiver health was minimal on average (mean, 4.1), although some caregivers said their physical health changed for the worst. One of the caregivers said, “I’m just thankful that I haven’t gotten it [COVID] yet.” Level of energy for caregivers changed for the worst (mean, 3.5). Caregivers’ emotional well-being (mean, 3.5) also suffered, with 1 caregiver sharing, “I feel like my anxiety is through the roof.” Although the ability to cope with stress was negatively affected (mean, 3.9), 1 caregiver indicated the pandemic produced a positive change, the strength of her faith. This is reflected in her statement,

“Well, I think it brought me closer to God. He is in control, and I think this is another way of proving it.” Another caregiver stated, “I am not worried (about getting COVID), I just can’t let it control my life.” So, in essence, how the caregivers framed the situation affected their coping and response to the COVID pandemic.

Discussion

Adding to the body of nursing knowledge, the findings from this study highlight the additional struggles that caregivers faced during the COVID pandemic. On top of many existing unmet needs, caring for a stroke survivor during the pandemic resulted in new unanticipated challenges. Caregiving for many is almost a full-time job resulting in a restructured life, altered relationships, and psychological and physical challenges.¹⁹ The pandemic created numerous disruptions in areas such as daily routines, access to resources (healthcare, food, household items), financial well-being, relationships and activities with family and friends, survivor relationships, and caregiving activities, as well as caregiver anxiety, health, and well-being. Because almost 30% of the caregivers in this study reported preexisting depression, this could have further affected their responses to these factors, how they coped, and their own physical health.²⁰ Consistent with findings from Sutter-Leve et al,⁷ 1 caregiver revealed how the survivor being hospitalized during the pandemic led to very negative mental health consequences that ultimately affected the entire family.

This study is unique in that it measured life changes related to COVID-19 and identified both areas that were negatively affected, but more importantly, those that changed positively. Positive changes were the increased use and confidence with videoconferencing to connect with family, friends, and church services. Caregivers learned how to be creative and access needed resources in different ways (ordering groceries, masks, hand sanitizers, etc). Irani et al²¹ discovered the important attribute of resourcefulness that served to mediate family caregiver stress and self-rated health for those experiencing the pandemic. They highlighted the potential benefit of resourcefulness training to improve family caregiver well-being during times of crisis and social isolation; thereby, helping to address some of the barriers such as heightened stress with 24/7 care, insufficient caregiver training, and decreased resources identified others.^{6,7} During the pandemic, Paletz²² offered several strategies, such as telephone- and mailed-focused educational interventions, which was also supported by Bakas et al.^{5,14} Within the emerging literature, especially during a pandemic, social support and connectedness served as a strong predictor of caregivers’ quality of life and health promotion activities.^{21,23–25} In this

study, 58% of caregivers indicated their perceived financial status was “comfortable,” which suggests these family caregivers may have had more access to resources that could enable more positive outcomes. However, other caregivers may have struggled financially and did not have had access to such resources.

Limitations

Findings should be interpreted with caution because these stroke caregivers were receiving support from an ongoing intervention trial. Plus, the caregivers were primarily White and female and had many years of education. The sample size was small and not sufficient to assess the psychometric properties of the 17 items adapted from the BCOS; however, quantitative ratings were analyzed at the item level providing a unique view of stroke caregiver life changes during the pandemic. The questions used to gather the qualitative data did not permit in-depth reflection from the caregivers. Collectively, these factors limit the generalizability of the study findings but do indicate additional investigation is warranted.

Conclusion

For the 17 stroke caregivers in this study, both negative and positive life changes were identified specifically as a result of the COVID-19 pandemic. Several negative consequences were disrupted daily routines, limited access to healthcare providers and resources, reduced family and social contact and activities, decreased emotional well-being (eg, anxiety), and problems with performing caregiving activities for the survivor. On the other hand, positive life changes were increased use of the Internet and videoconferencing, closer relationships with friends, and learning how to access needed resources in different ways. Responses indicated that COVID-19 affected caregivers in different ways and an individualized approach in dealing with caregiver life changes resulting from the pandemic and other future events is needed.

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