

The Caregiver Experience After Stroke in a COVID-19 Environment: A Qualitative Study in Inpatient Rehabilitation

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Background and Purpose: Stroke is the leading cause of disability in the United States. Two-thirds of stroke survivors will require caregiver assistance. Evidence suggests the mental health of caregivers is closely related to patients' health outcomes. The timing of this study intersected with the beginning of the coronavirus disease-2019 (COVID-19) pandemic that required strict social distancing and hospital visitor policy changes. This study aims to answer the primary research question: What is the level and nature of stress experienced by caregivers of persons with newly-acquired stroke in the inpatient rehabilitation setting and how has the COVID-19 pandemic impacted the caregiver experience?

Methods: Recruitment occurred from a single inpatient rehabilitation facility. Participants were administered the Perceived Stress Scale and then completed qualitative semistructured interviews. The investigators used a phenomenological, iterative approach to collect and analyze qualitative data. The data were independently coded and categorized before consolidated into primary themes and subthemes.

Results: Eleven informal caregivers' perspectives generated 13 subthemes across 4 primary thematic categories: COVID-19 impact, concerns of the caregiver, coping strategies, and important aspects of the caregiver experience. COVID-19 social distancing necessitated new visitor policies, which presented additional challenges for caregivers.

Discussion and Conclusions: Caregiver attendance at therapy sessions and frequent, direct communication between staff and caregivers improved caregiver readiness for family member discharge following inpatient rehabilitation. This study shared perspectives from a distinctive time during the COVID-19 pandemic. If visitation for multiple therapy sessions is prohibited, we recommend taking alternative measures to keep the caregiver involved in the plan of care.

Video Abstract available for more insights from the authors (see the Video, Supplemental Digital Content 1, available at: <http://links.lww.com/JNPT/A326>).

Key words: caregiver stress, CVA, discharge, inpatient rehabilitation, pandemic

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INTRODUCTION

Stroke is the leading cause of adult disability in the United States.¹ Every year roughly 795 000 people experience stroke and about one in every 20 of these individuals will die from its consequences.^{1,2} Approximately two-thirds of those who survive will experience mobility deficits requiring rehabilitation.³ According to the Medicare Payment Advisory Commission, stroke is the leading cause of admission to inpatient rehabilitation.⁴ Following discharge from inpatient rehabilitation, most of these patients require ongoing assistance from a caregiver.

Informal caregivers, usually friends or family members, play an integral role in the inpatient rehabilitation setting supporting the patient as well as preparing them for dismissal to home.⁵ A growing body of research demonstrates that mental health and wellness of the caregiver is intimately linked with the patient's functional and health outcomes.^{6–8} A study by Em et al⁵ concluded that reduced caregiver mental health is correlated with reduced functional outcomes in persons who suffer cerebrovascular accident (CVA), indicating that caregivers who are not emotionally well might negatively impact the patient's rehabilitation. An article by Kuzuya et al⁶ reported that increased stress or caregiver burden was correlated with increased hospitalization and mortality in community-dwelling older adults. Similarly, Isik et al⁷ published an article correlating reduced caregiver mental health with increased patient mortality in the neurodegenerative population. This evidence supports the need to increase awareness and assessment of caregiver mental health to optimize patient success.

Currently, there is literature published examining caregiver mental health and stress levels in the outpatient setting for persons with stroke.^{9–11} In inpatient rehabilitation, there are studies looking at the quality and nature of mental health in caregivers of patients with traumatic brain injury^{12,13} and spinal cord injury,^{14,15} but none examining caregivers of CVA, the most common cause for admission. Therefore, the purpose of this study was to answer the primary research question: What is the level and nature of stress experienced by caregivers

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of persons with newly-acquired stroke in the inpatient rehabilitation setting?

The development of this original research question occurred prior to the onset of the coronavirus disease-2019 (COVID-19) pandemic in the United States. Following dramatic changes in rehabilitation unit visitor policies in response to a need for social distancing, the investigators created an addendum to their question to include the following: How has the COVID-19 pandemic affected the experiences of caregivers of persons with newly-acquired stroke?

METHODS

This phenomenological study was undertaken with ethical approval from the Mayo Clinic Institutional Review Board. Participants were recruited by criterion sampling via in person and telephone from the Mayo Clinic, a large academic medical center in the Midwest region of the United States. This sampling approach was chosen to best gather a broad sample of caregiver experiences with key baseline characteristics.¹⁶ Inclusion criteria for participation in the study were adults who identify as the primary informal “caregiver” or “support person” to individuals with a primary diagnosis of newly-acquired stroke admitted to the inpatient rehabilitation unit. Those who were caregiving for individuals rehabilitating after a second or later stroke or were hired as formal caregivers were excluded. Non-English-speaking caregivers were excluded due to lack of translation services. Data collection began in February 2020 and was concluded in April 2020. Recruitment was terminated once the data reached a point of saturation. Saturation was defined as the cessation of novel thematic material found during data analysis.

After providing written informed consent, each participant was administered the Perceived Stress Scale-10 (PSS-10), either in person or over the telephone. The PSS-10 is a widely-used outcome measure to appraise stress in adults and is validated to be distributed in person, mailed, or by telephone.^{17,18} The measure is scored from 0 to 40, with ranges from 0 to 13 considered “low stress, 14 to 26 considered “moderate stress,” and 27 to 40 considered “high stress.”^{17,18} Following completion, participants engaged in qualitative interviewing where each was asked a series of semistructured interview questions (see Appendix 1, Semi-structured Interview Questions, Supplemental Digital Content 2, available at: <http://links.lww.com/JNPT/A327>). All interviews were conducted within 72 hours either prior to or following dismissal by one of the coinvestigators, R.S.L. or E.P., who completed training in qualitative research interviewing. Each interview was completed individually by one coinvestigator, recorded digitally, and then transcribed verbatim by the alternate coinvestigator.

An iterative approach was used to examine the data, analyzing each participant’s experiences immediately following collection of responses. In qualitative research, this approach allows investigators to use what emerged from the data to inform subsequent sampling decisions (purposive or theoretical sampling) and interview questions (reflexivity).^{16,19} Two of the investigators (R.S.L. and E.P.) independently examined the emerging data and clustered them into categories which they placed in a coding section. Codes were then clustered into

preliminary categories and then further reduced into primary thematic categories and subthemes. The primary thematic categories were determined based on the number of participants who spoke about the theme as well as frequency of mentions. Analyst triangulation was used to illuminate blind spots in data interpretation. The investigators then combined their independent interpretations into a collaborative analysis. As a final check, the collaborative results were reviewed by a third member of the research team (A.R.) for thematic categorization and reduction of redundancy.

RESULTS

Eleven informal caregivers of persons with newly-acquired stroke participated in this study. Eight participants were females and 9 were spouses of the person with newly-acquired stroke. See Table 1 for additional characteristics. Four primary thematic categories with 13 subthemes emerged from data analysis. The 4 primary thematic categories are impact of the COVID-19 pandemic, concerns of the caregiver, coping strategies, and important aspects of the caregiver experience. Representative quotes from participants are included in Table 2 to describe each subtheme. These quotes were selected from among those that were supportive of each subtheme because they best represent the collective descriptions shared by participants.

COVID-19 Impact

The timing of this study coincided with the first wave of the COVID-19 pandemic in spring of 2020. In an attempt to reduce the spread of the virus, the institution instigated a strict “no visitor” policy, with the exception of crucial family training that was to take place on their day of discharge or soon before. This visitor policy change had a great impact on the caregivers in this study, leading to the primary thematic category: COVID-19 impact. Subthemes included competency of care, feeling unprepared for discharge, communication challenges, and caregiver suggestions.

Table 1. Participant Demographics

Characteristic	Number (N = 11)
Relationship to patient	
Spouse	9
Sibling	1
Child	1
Gender	
Female	8
Male	3
Race	
Caucasian	11
Total length of stay in inpatient rehabilitation	
0-7 d	1
8-14 d	2
15-21 d	4
22-28 d	2
29-36 d	1
37-48 d	1
Type of stroke	
Ischemic	6
Hemorrhagic	5

Table 2. Representative Participant Quotations

Thematic Category	Quotation
1. COVID-19 impact	
A. Competency of care	A. <i>I gathered up all his dirty laundry and put it together and it sat there for two days. Even though there was a note on it . . . when it comes to his care, I'm not afraid at all of the care I'm going to be giving him. (Participant 4)</i>
B. Unsure of patient progress and preparedness for discharge	A. <i>The concern was, I was his primary caregiver even though he had medical staff and whatever. I was the one who did almost everything. He would wake up in the middle of the night and he would holler and I would go get the urinal. I would help him do that kind of thing . . . a nurse didn't do that, a PCA didn't do that. (Participant 6)</i> B. <i>I don't know if she can go down stairs! If ya'll tell me she can, hey great! But my mental picture is from what she's been describing still having problems with that left leg, stairs are not going to be something that she's going to want to try. (Participant 11)</i> B. <i>I'm supposed to learn speech cognitive therapy, OT, PT . . . all these different things from specialists who have had at least 4 years of college if not more . . . 6 years of training for this stuff and I'm supposed to learn everything I need to do for his rehab because they said outpatient therapy is out for 8 weeks! And be able to help him advance as much as possible because once he hits the 3 to 6 month mark, you reach a plateau generally. (Participant 4)</i>
C. Communication challenges	C. <i>I haven't been able to be there . . . at first I was having to call to see how everything was going . . . to see how he was doing because no nurses or anything were calling . . . I think it would've been a lot different [to visit]! Because I could be there everyday and get updates and talk directly to the staff and to my husband and just be there for him. So that's been stressful for him and for me that I can't be there. (Participant 7)</i> C. <i>I didn't know if his phone was by him, because I could call directly in his room but . . . I don't want him to get flustered to reach for it and fall out of the chair . . . I didn't want to wake him up if he had just fallen asleep or if he was in the middle of eating. (Participant 4)</i>
D. Caregiver suggestions	D. <i>call in the beginning more . . . in the first week, so I'd know what was going on. (Participant 7)</i>
2. Concerns of the caregiver	
A. Functional prognosis	A. <i>[What] I was perhaps concerned about was "will he ever be able to get the use of his left side?" (Participant 3)</i> A. <i>just him not being able to make a full recovery . . . so he could do daily living things . . . go back to work, drive again . . . (Participant 7)</i>
B. Patient safety once home	B. <i>but, will he comply with waiting till I'm next to him to move? . . . he is in a new environment so he knows those are the rules here but that has never been a rule at home that he needs someone to go with him when he is going from room to room. So, that's kind of a fear. (Participant 1)</i>
C. Recurrence	C. <i>Well, I suppose there's always a chance she could have another one. That's probably my main concern. They don't seem to find any reason that she had one. (Participant 9)</i>
3. Critical aspects of the caregiver experience	
A. Attending therapy sessions	A. <i>The support I've had from the therapists has been [critical]. What they've done, when they've done it, what parts they start with first . . . and what they're finding is assisting and what has been working for him . . . I just soak all that up like a sponge. (Participant 4)</i>
B. Clear and timely communication	B. <i>They would call me every Wednesday and Friday . . . update me on her progress and that was very appreciated to be able to participate in listening and have them call me. (Participant 8)</i>
C. Relationship with staff	C. <i>I like the fact they try to get to know him as a person . . . they can tell what things are probably gonna work well with him . . . taking a personal interest in finding out who he is, how he thinks and maybe what methods are probably going to work . . . finding out what he wants to be able to do when he's done. And working towards those things, [goals]. (Participant 2)</i>
4. Coping strategies	
A. Physical preparation around the home	A. <i>I think doing the physical preparations at home have helped me . . . as I've been going home at night and trying to do little by little to make things safe for him, I think that makes me feel more confident that "okay, I can do this". (Participant 1)</i>
B. Education about the condition	B. <i>I knew that stroke meant a blood [clot] in the brain, but, I never thought about the impact of the brain around that clot . . . I just never thought "oh there's damage there." So it's been this learning curve for me going "oh, it's a brain injury." And, I never was aware of that before so . . . in the last two weeks I've learned it. But, I think the reading has helped me too . . . (Participant 1)</i>
C. Support from family and friends	C. <i>We have many, many friends and that's been absolutely wonderful support. (Participant 3)</i>

I'm supposed to learn speech cognitive therapy, OT, PT . . . all these different things from specialists who have had at least 4 years of college if not more . . . 6 years of training . . . and I'm supposed to learn everything I need to do for his rehab because they said outpatient therapy is out for 8 weeks. (Participant 4)

Competency of Care (Table 2, Section 1A)

Many caregivers were unable to visit their loved one in the rehabilitation hospital following their admission because of visitation policy restrictions due to efforts to prevent the spread of COVID-19. These changes impacted caregivers' ability to witness the care provided to their family member. Caregivers discussed concerns over how well their loved one was taken

care of in their absence from the rehabilitation hospital. Participants spoke about stroke-related communication challenges and highlighted how the challenges impacted their loved one's ability to ask for help or use the restroom.

Unsure of Patient Progress and Preparedness for Discharge (Table 2, Section 1B)

Caregivers reported feeling out of touch with their loved one's progress when unable to attend multiple therapy sessions. Many spoke about not knowing the abilities of their loved one and what assistance will be required when they return home. This poor understanding of their loved one's abilities created hesitation in their own ability to assist or continue rehab at

home. Caregivers voiced feeling inadequate compared with the skilled therapists. They voiced how they felt multiple therapy sessions were required to be able to continue rehab in the home following discharge.

Communication Challenges (Table 2, Section 1C)

Participants voiced challenges in contacting members of the care team, receiving updates or information from the care team, and contacting their loved one. Caregivers felt like an inconvenience to providers while experiencing difficulty reaching members of the care team, oftentimes requiring multiple phone call exchanges before connecting with providers. These calls were not scheduled, which created difficulty for the caregivers to plan their day around waiting for a return phone call. Additionally, they reported that it was difficult to contact their loved one. Many voiced challenges about talking to their family member who had new cognitive or communication impairments. Others were fearful that calling their loved one might cause them to do something unsafe.

Caregiver Suggestions (Table 2, Section 1D)

In response to the unexpected impact of the COVID-19 pandemic, the researchers asked for suggestions from caregivers to improve their experience. The caregivers highlighted the need for scheduled phone calls, especially early in the rehab stay, from all members of the care team and recommended more frequent video conference or footage from therapy sessions to appreciate functional progress.

Concerns of the Caregiver

This thematic category includes descriptions of the concerns of the caregiver. The subthemes in this category include participants' concern over functional prognosis and fear of stroke recurrence.

... but, will he comply with waiting till I'm next to him to move? ... he is in a new environment so he knows those are the rules here but that has never been a rule at home that he needs someone to go with him when he is going from room to room. So, that's kind of a fear. (Participant 1)

Functional Prognosis (Table 2, Section 2A)

A broad range of functional impairments often follow CVA.⁵ Caregivers voiced uncertainty over whether their loved one would have long-term impairments such as unilateral hemiparesis or an inability to ambulate. They also experienced fear of the possibility of not returning to work or hobbies pre-stroke.

Patient Safety Once Home (Table 2, Section 2B)

A concern shared among participants was patient safety and fear of their loved one falling after discharge from the inpatient rehabilitation unit. Caregivers recognized the importance of 24-hour assistance or supervision depending on the level of impairment. Participants spoke about how they were concerned their family member may not make safe choices when away from the controlled environment of the inpatient rehabilitation setting.

Recurrence (Table 2, Section 2C)

Fear of recurrence of the stroke was spoken about frequently. The fear of experiencing a subsequent stroke was greater when there was an unknown cause of the initial CVA.

Critical Aspects of the Caregiver Experience

This primary thematic category included subthemes of attendance at therapy sessions, timely communication and participation in team rounds, and relationships with staff members. Participants recognized that this was a time of rapid healing and functional progress for their family member. Value was placed on attending therapy sessions to learn skills and witness their family members' improvement. The relationships built between providers and families were instrumental in the caregiver experience. Frequent and timely communication was highly coveted.

The support I've had from the therapists has been [critical]. What they've done, when they've done it, what parts they start with first ... and what they're finding is assisting and what has been working for him ... I just soak all that up like a sponge. (Participant 4)

Attending Therapy Sessions (Table 2, Section 3A)

Caregivers appreciated learning techniques to assist their family member during skilled therapy sessions. They also highly emphasized how important it was to learn about the condition from each therapy discipline. Some took notes and videos to document exactly what they were learning during their time attending therapy sessions.

Clear and Timely Communication (Table 2, Section 3B)

Participants emphasized the fundamental requirement of timely and direct communication between therapists, physicians, and nurses to relay information regarding progress, prognosis, and dismissal planning. Caregivers appreciated bi-weekly team rounds, but, even greater emphasis was placed on frequent phone calls from providers outside of these designated meetings.

Relationship With Staff (Table 2, Section 3C)

Caregivers appreciated personal relationships developed with therapists, nurses, and physicians. Relationships developed when members of the care team intentionally spent time with the caregiver and family throughout the rehabilitation stay either during therapy sessions or outside of scheduled visits.

Coping Strategies

This primary thematic category, coping strategies, included subthemes of physically preparing their home for the patient's dismissal, learning more about stroke, and support from family and friends.

I think doing the physical preparations at home have helped me ... as I've been going home at night and trying to do little by little to make things safe for him, I think that makes me feel more confident that "okay, I can do this." (Participant 1)

Table 3. Perceived Stress Scale-10 Outcomes

Participant #	Score	Interpretation
1	8	Low
2	19	Moderate
3	4	Low
4	16	Moderate
5	NA	...
6	12	Low
7	25	Moderate
8	8	Low
9	9	Low
10	23	Moderate
11	16	Moderate

Abbreviation: NA, not available.

Physical Preparation Around the Home (Table 2, Section 4A)

Caregivers found it therapeutic to make physical changes around the home in preparation for dismissal. Participants frequently spoke about a variety of home modifications including minor changes such as removing throw rugs, picking up dog toys, and installing grips on the floor in the shower, as well as greater changes such as installing grab bars in the bathroom, railings along the stairs, or a ramp for safer entry into the home. Participants used recommendations from providers as well as personal judgment when completing the home modifications.

Education About the Condition (Table 2, Section 4B)

Learning more about CVA provided a sense of relief for caregivers. Participants spoke about realizing the stroke injured an area of the brain, which has direct control of specific movements. Many voiced new understanding that the brain controls the contralateral body resulting in hemiparesis. Participants appreciated learning about the typical healing progression and expectation for recovery following stroke.

Support From Family and Friends (Table 2, Section 4C)

Caregivers voiced benefiting from emotional support from family and friends following their loved one's stroke as well as during inpatient rehabilitation.

Perceived Stress Scale-10

Ten of the participants completed the PSS-10, and 1 participant declined. The scores obtained from these participants ranged from low to moderate stress levels with a mean score of 14 (see Table 3 for details). These results indicate no participants in this study felt their stress was at a high level within 72 hours of dismissal.

DISCUSSION

The significance of this study lies in the unique perspectives it shares from a previously unspoken sample of the population of caregivers of people with newly-acquired stroke. Additionally, it captures the experiences of a group during a novel time in health care history where hospitals were making rapid visitor policy changes to provide increased social distancing in response to the COVID-19 pandemic. The varying

perspectives of these informal caregivers were, in a large part, shaped by these policy changes. Caregivers spoke frequently about their concerns related to their loved one's quality of care, prognosis, safety once home, and fear of recurrence. Caregivers described being uncertain about whether the patient was receiving adequate care, particularly after visitor restrictions changed due to the COVID-19 pandemic. They frequently spoke about concerns related to patient functional outcomes and their fear the patient would not be safe once home. They also discussed their concerns about whether the patient may experience a subsequent CVA. Caregivers coped with these fears by preparing the home for the patient's dismissal from the hospital, learning more about the condition and receiving support from family and friends.

Caregivers spoke about the most important aspects of their experience. Participants used the word "critical" when describing the opportunity to attend therapy sessions. They highlighted how important it was that the staff members take the time to build a relationship with them and communicate in a clear and timely manner. Once the COVID-19 visitor restrictions were initiated, this communication became even more critical. Caregivers spoke about feeling like an "inconvenience" when they called as well as being unable to get ahold of health care team members. They also discussed how their inability to witness the patients' progress made them feel anxious and unprepared for dismissal.

Our findings were consistent with other studies in several ways. The importance of caregiver social support systems through friends and family has been highlighted in previous work by Hanson et al¹¹ in 2019 studying caregivers of patients with traumatic brain injury and polytrauma. Similarly, they discussed how family attendance of therapy sessions for training was highly valued. In this study, we found that caregivers found it comforting to seek out additional education about their loved one's condition. Bakas et al¹⁰ came to this same conclusion in a study examining stroke caregiver needs following hospital dismissal.

However, perhaps due to the timing of our data collection that coincided with the beginning of the COVID-19 pandemic, our study reports differences from other research. The visitor policy changes that took place at our institution and others throughout the country accentuated the importance of in-person communication with clinicians and observation of therapy visits to assist caregiver feelings of readiness for dismissal home. Those who experienced the visitor policy change during their family member's stay were more likely to speak about the stark contrast between seeing their loved one's progress on a daily basis and only receiving intermittent phone calls as updates. They highlighted that this negatively impacted their mental health and increased their stress levels. Given the necessity to maintain social distancing to prevent the spread of COVID-19, coinvestigators inquired about suggestions to improve the caregiver experience despite these restrictions. Caregivers highlighted the need for scheduled calls and updates from all members of the health care team. Multiple participants spoke about wishing they had a direct way to contact providers. They also mentioned how greatly they appreciated video footage of the patient's progress.

Implications

Due to the timing of the study, the participants shared a distinctive experience related to the COVID-19 pandemic and its effect on the caregiver experience. While the findings may not be fully generalizable because of the small sample size and regional focus, one can use these perspectives to gain insight on how to develop and maintain optimal caregiver experiences in the inpatient rehabilitation environment.

The caregivers who participated in this study greatly appreciated the ability to attend therapy sessions reporting that it helped them visualize their family member's progress as well prepared them to better assist their loved one upon discharge. When they were unable to attend due to COVID-19 visitor policy restrictions, they discussed, at length, how this negatively impacted their perception of being prepared for dismissal home. In the inpatient rehabilitation unit setting, if the caregiver is unable to regularly attend therapy sessions, therapists or rehabilitation facilities could consider finding an alternative to supplement this absence such as frequent phone calls or video. The phone call or video conference could double as an opportunity to discuss and clarify expectations for functional prognosis to improve caregiver confidence.

Regarding communication, therapists should not be the only providers updating the family. Nurses and physicians can also be communicating with family, providing the reassurance needed to know the patient is safe and well taken care of. Moreover, education of the primary diagnosis was a critical piece of the caregiver's experience, so a regular phone call may provide a time to share additional resources to satisfy this need.

Limitations

Although the findings of this study present valuable perspectives of caregivers during a unique time in global health care history, there are limitations inherent in its qualitative design. Due to its small sample size and regional representation, this sample may not fully represent the voices of caregivers who represent minority populations. This study was performed at one inpatient rehabilitation facility, so various qualities of the caregivers experience may not be translatable to other hospitals. The timing of the study, during a pandemic, may have increased the caregivers' baseline stress, meaning that our quantitative data captured by the PSS-10 and interviews may not adequately represent their stress related solely to the stroke.

Considerations for Future Research

Future studies including various rehabilitation centers across the country may provide a more diverse perspective of the caregiver experience. A survey that screens a large number of participants about the validity of these claims over several centers and regions may be helpful in generalizing the findings of this study to a broader population. Additionally, many of the caregivers made suggestions for how to improve their experience. It would be beneficial for future studies with quantitative designs and larger sample sizes to evaluate the success of these recommendations with clear pre- and postintervention analyses.

CONCLUSIONS

Following stroke, healing occurs for both the patient and their caregiver. The rehabilitation setting is a unique place for this healing, in part, because of the personal connections made between the patient, caregiver, and care team. In the current state of the rapidly changing COVID-19 environment, we recommend that members of the health care team consider how maintaining a high-quality caregiver experience may influence their patient's outcomes.

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If you have questions about the open positions or the application process contact a member of the Nominating Committee:

- Tara McIsaac at tmcisaac@atsu.edu
- Alicia Flach at adflach@mailbox.sc.edu
- Leslie Wolf at leslie.wolf@ohiohealth.com

