

Grief and Loss Associated With Stroke Recovery: A Qualitative Study of Stroke Survivors and Their Spousal Caregivers

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Abstract

Despite a focus on physical and cognitive outcomes, stroke survivors are also impacted by emotional and mental health challenges. Additionally, their caregivers may experience decreased well-being due to increased burden and role adjustment. A small body of literature characterizes this experience as a form of grief and loss. This study seeks to explore experiences of grief and loss reported by stroke survivors and caregivers, using Holbrook's 4-stage bereavement model. This cross-sectional, qualitative study was conducted among adult stroke survivors ($n = 9$) and their spousal caregivers ($n = 5$). Focus groups on experiences of recent hospitalizations and transitions home were transcribed, coded, and thematic analysis was conducted, identifying a major theme of loss. Data were reanalyzed guided by Holbrook's model. Common themes were losses and changes experienced by patients/caregivers, disbelief, and lack of understanding. Subthemes of denial and confusion were present. Less prevalent themes were loss of existing support systems and silver lining. Stroke survivors and caregivers experienced a range of negative emotions, impacting behaviors, self-perception, roles, and social support. Awareness of these issues can improve practice with those affected by stroke.

Keywords

qualitative methods, patient expectations, behavioral health, caregiving, challenges

Introduction

Stroke affects 800 000 individuals in the United States per year (1). For those who survive a stroke, long-term disability is common (1). Although there is a robust amount of research on physical and cognitive outcomes for stroke survivors, there is substantially less work regarding the emotional and mental health outcomes of stroke survivors and their caregivers (2,3). Research on the mental health of survivors indicates that depression (4–6) and anxiety (7) are common. Stroke's suddenness (3), an unclear prognosis, and functional changes contribute to survivors' stress, anxiety, and depression (8). Caregivers experience increased demands and decreased well-being related to caring for their loved one. Caregiver impacts include high burden and strain (9–13), decreased quality of life (14), difficulty in role adjustment (15), and relationship problems with the survivor (16).

Experiencing Outcomes of Stroke as Grief and Loss

A small body of literature characterizes the experiences of the stroke survivor as a form of grief and loss (17). A case study of

a survivor with aphasia found that the themes that emerged (identity, existence, normalcy, emotions, and adjustment) shared an “overarching theme” of “disenfranchised grief” (18, p. 227). A number of losses (ie, identity, relationships, body autonomy, and independence) may be experienced and grieved by the stroke survivor. A study of 9 survivors with depressive symptoms described “losing oneself” through increased emotionality, exhaustion, and “feeling like a nobody” (7, p. 1731, p. 1732). Roman (19) makes the distinction between depression and grief, arguing that grieving this loss of self is a component of recovery and reports the experience of a grieving process in several cases of survivors with depressive symptoms. In a qualitative meta-synthesis, themes including loss of confidence, independence, and self were

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Table 1. Themes and Subthemes of Grief and Loss.

Theme	Subtheme (if applicable)	Definition	Bereavement model stage (29)
Lack of understanding	Confusion	Participants identify a problem and don't believe it is stroke related	First—Crisis
	Denial	Participant underestimates the impact of stroke and/or challenges of recovery	Second—Denial
Loss of existing support systems		Participants identify previous existing support	Third—Anger
Loss/change for caregiver		Caregiver identifies a challenging loss or change in their life as a result of the stroke	Third—Anger
Loss/change for patient		Patient identifies a challenging loss or change in their life as a result of the stroke	Third—Anger
Silver lining		Unexpected benefits of the situation or things that they now view as positive	Fourth—Adjustment

identified within 9 studies (20). “Activity loss,” such as loss of identity, independence, and loss of relationships that were previously important, was identified in interviews with survivors (21, p. 443). Lanza (22, p. 767), a nurse and stroke survivor, writes “I do not think that a person who is not a stroke survivor has any idea of the magnitude of the loss.”

Caregivers may also experience grief and loss as they adjust to the changes in their loved one and in their relationship. In interviews with female spouse-caregivers of stroke survivors, spouses experienced grief associated with role and relationship loss (23). In a series of focus groups involving caregivers, discussion of loss emerged in 2 themes: “transition” and “impact of stroke” (24, p. 421). Caregivers described the loss of the relationship they once had with the survivor, as well as a loss of a planned future (24). Rademeyer et al (25) examined poststroke family dynamics in one family, identifying shared experiences and changes that impacted the stroke survivor and family members. Olivier et al (26) identified “grief” as a subtheme in their hermeneutic phenomenological study of the experience of 3 family members of a stroke survivor. In a survey of 46 female caregivers of survivors within 3 to 12 months of a stroke, themes included (27) “struggling to cope and adapt to irreversible losses” and “losing the life that once was” (27, p. 5). McCurley et al (28) completed interviews with 24 stroke survivor and caregiver dyads, finding that their challenges around future uncertainty, emotional distress, and role changes were intertwined. They suggest that a focus on psychosocial interventions that ameliorate emotional distress (which can encompass grief and loss) is necessary in the poststroke recovery period. Although there is a limited amount of literature, often with small samples, it appears that grief and loss impact both survivors and caregivers.

Bereavement Model

Holbrook's bereavement model is specific to adjustment to stroke and is used to describe patterns associated with 4 stages of grief (Table 1) (29) among survivors with sequelae. These stages are used to examine experiences of stroke

survivors' loss of physical functioning, identifying experiences which correspond to the grieving process (17,29). As is typical in models of grief (30), not all stroke survivors will experience all of the stages or experience the stages in the order described in the model (31). Despite some acknowledgment of grief and loss as a component of stroke survivorship and caregiving in the stroke recovery literature, there have been few attempts to apply this model to the experiences of stroke survivors or caregivers. We aim to explore the experiences of grief and loss reported by stroke survivors and their spousal caregivers, using the 4-stage bereavement model framework.

Method

Design

This cross-sectional, qualitative study was conducted during 2015 and 2016 in one US state. Data discussed here come from focus groups that were part of a larger parent study aimed at improving care transitions for stroke patients and their caregivers (32).

Sample

Participants were recruited from 4 hospitals in 2 regions of the state. Both regions are midsized cities and have a hospital with Comprehensive Stroke Center certification. A convenience sample was obtained with assistance from stroke unit personnel at each hospital. Participants were eligible if they met the following inclusion criteria: 18 years or older; hospitalization for acute ischemic or hemorrhagic stroke in the previous 6 months; patient returned home after their stroke; or they were a caregiver to a patient who was participating in the study. Participants were not recruited as dyads, individuals without an identified caregiver were eligible for participation. Participants self-selected into the study based on interest in participating and availability during scheduled focus groups. Tables 2-4 describe the sample demographics and participant characteristics. Caregiving dyads, when present, were all heterosexual married couples.

Table 2. Summary of Demographic Information of Stroke Patients and Caregivers.^a

Variable	Frequency	Percentage
Role		
Stroke patient	9	64.3
Caregiver	5	35.7
Gender		
Female	7	50
Male	7	50
Age	33-87 years old Mean = 66.9; SD = 14.19	
Race		
White	12	85.7
African American	2	14.3
Yearly income		
Less than \$30 000	1	7.1
\$30 000-\$49 000	9	64.3
\$50 000-\$69 000	3	21.4
\$70 000-\$89 000	1	7.1

Abbreviation: SD, standard deviation.

^an = 14.**Table 3.** Summary of Demographic Information of Stroke Patients.^a

Variable	Frequency	Percentage
Gender		
Female	4	44.4
Male	5	55.6
Age	33-86 years old Mean = 63.1; SD = 14.48	
Race		
White	8	88.9
African American	1	11.1
Education		
First-eighth grade	1	11.1
Some college	5	55.6
Four-year college	1	11.1
Postgraduate	2	22.2
Type of stroke		
Ischemic	5	55.6
Hemorrhagic	3	21.4
Unknown	1	11.1
Days in hospital	3-31 days Mean = 11.3; SD = 11.4	
Discharge disposition		
To home-no services	4	44.4
To home-outpatient services	2	22.2
To inpatient rehab	3	33.3

Abbreviation: SD, standard deviation.

^an = 9.

At the time of this study, all of the stroke survivors had some level of continuing physical or cognitive impairment.

Four focus groups, 2 in each location, were conducted with patients and caregivers combined. However, the qualitative data utilized in this article were derived entirely from the first focus groups in each location. Participants were provided a \$50 stipend to cover travel, parking, and to thank

Table 4. Summary of Demographic Information of Caregivers.^a

Variable	Frequency	Percentage
Gender		
Female	3	60
Male	2	40
Age	62-87 years old Mean = 73.8; SD = 11.97	
Race		
White	4	80
African American	1	20
Education		
High school	1	20
Some college	3	60
Four-year college	1	20

Abbreviation: SD, standard deviation.

^an = 5.

them for their time. A university-affiliated institutional review board reviewed and approved this project.

Procedures

Eligible participants who were recruited by stroke unit personnel were sent letters with the date, time, and location of the focus groups. When participants attended the group, study staff discussed consent and provided opportunities for participants to ask questions about participation. Written consent was collected, and participants were provided a copy of the consent form. Focus groups were recorded, and each lasted approximately 90 minutes.

Measures

Researchers collected basic demographic information and information about patients' most recent stroke. Discussions were guided by a study-specific interview guide (Table 5), created by the study team to better understand adjustment in the poststroke period. Participants were prompted to share their most recent stroke hospitalization experience and were asked about challenges related to their transition home.

Analysis

Focus group recordings were transcribed verbatim and speakers were identified by first name. Data were coded independently by 2 coders with the assistance of Atlas.ti software (version 7.5.18). Analysis of codes followed thematic analysis (33,34) to identify and categorize patterns in the transcripts related to poststroke recovery and the transition home. Through an iterative process 2 coders came to agreement on themes/subthemes. Initial analysis identified several major themes, with an unexpected majority related to loss or grief. A secondary analysis of the data related to grief and loss was completed through application of the Holbrook model (29) and is the focus of this manuscript. Grief/loss themes, subthemes, and definitions are presented in Table 1.

Table 5. Focus Group Questions and Prompts.

Welcome everyone and thank you for participating today. We'd like to spend the remainder of the time talking with you about your recent stroke and the transition from the hospital or other rehab facility back to your, or a caregiver's, home. Please use your first name only when you answer, to protect confidentiality, and remember to tell us whether you are a patient or a caregiver.

Question	Possible prompts and follow-up questions
	General stroke and transition experience
1) Can you tell us briefly about your most recent stroke?	<ul style="list-style-type: none"> – When did the stroke occur? – What type of stroke was it? – How long did you spend in the hospital?
2) What conversations did you have with the health care providers (nurses, doctors, therapists) in the hospital about planning your discharge from the hospital?	<ul style="list-style-type: none"> – Did you go straight home from the hospital or did you spend time in rehab facility? – What type of provider spoke with you about this? Did any one person take the lead on this? – Who else from your family/friends were involved in these discussions? – Did you and your support system find these conversations helpful? How so, or why not?
3) Describe what happened when you were discharged home?	<ul style="list-style-type: none"> – What information was lacking? – Did you have any trouble adapting? – Did you have any help when you got home? – What were your chief concerns when you were discharged home? – How was this experience similar or different for your partner? (patient or caregiver)
4) From your perspective, what were the main challenges that you had to face when you got home?	<ul style="list-style-type: none"> – What specific problems did you face? – How many of these were unanticipated prior to leaving the hospital? – Did you feel that you were adequately prepared for these challenges? – Did you find any resources to help with these problems/challenges? – How was this experience similar or different for your partner (patient or caregiver)
5) Thinking back, what would have been the single biggest thing that someone could have done to help you during this period?	<ul style="list-style-type: none"> – Is there any specific thing that the hospital could have done to assist in your transition home? – Who else could have helped you?
6) Thinking back, after you got home from the hospital what information did you lack regarding stroke?	<ul style="list-style-type: none"> Information needs – When did you first identify that you needed this information?
7) What informational resources have you found that were helpful to you and your caregiver?	<ul style="list-style-type: none"> – Informational resources could include explanations about stroke, or rehabilitation care, or descriptions of medications that stroke patients take to prevent stroke recurrence. – How did you find this information, if you did? – Who took responsibility for finding it? (Pt, cg, other)? – What information has been the most helpful to you?, To your caregiver/family?
8) Having gone through this, what are your main concerns today?	<ul style="list-style-type: none"> Current chief concerns and wrap up What about medications? Safety? Return to work or normal social roles? Stress/being a burden? Stroke recurrence
9) If you were to describe your feelings about this transition experience in key words or phrases what would they be?	Identify which 2 or 3 of these items are the most meaningful to you
10) Thank you very much for your time. Before we finish, is there anything you would like to add to help us better understand the transition home after a stroke?	

Results

Prevalent themes were lack of understanding and losses and changes experienced by patients and caregivers. Within lack of understanding, we identified subthemes of denial and confusion. Themes that were evident, but less prevalent, included: loss of support systems and identification of silver linings. Participants did not identify many positives regarding their current situation, the theme labeled silver lining.

Lack of Understanding (Holbrook's²⁹ First and Second Stages)

Patient and caregiver lack of understanding emerged from the data as confusion that a stroke was occurring and denial related to severity and the need for ongoing services. Several dyads recounted that in their initial reactions to stroke-like symptoms they did not think it was stroke. Participants attributed symptoms to food poisoning, stomach upset,

feeling overtired, or allergy. “I figured it was a heart attack or something. And so, I quickly got her 2 aspirins and some water and she poured the water all over herself trying to drink it.” A patient stated:

I didn’t know what happened to me. I just felt instantly drunk. Crawled to the bathroom, threw up a lot, pulled myself up on the sink, looked at myself, and I saw the right side of my head was kind of fading, but I am like “this is terrible food poisoning.”

After confirmation of stroke via diagnostic workup, patients and caregivers still struggled to accept that they, or their loved one, had had a stroke. Patients who perceived themselves to be previously healthy struggled with the notion that they now had a condition that needed attention. A woman in her 40s stated “Look at me. I’m young. I shouldn’t have even had a stroke. When I got home, I thought I was OK. I’m like ‘this stroke wasn’t that bad. I have a little limp, I had these little things, and I thought well I’m OK.” Another said, “I didn’t believe I had a stroke because I had been too active and an outdoorsman all my life and I golf all the time.” For some, this denial led them to question the need for continued therapy and treatment: “I mean we figured, we were running and we’re exercising all the time. We shouldn’t need this [to take aspirin].”

Loss of Social Supports (Holbrook’s²⁹ Third Stage)

Another significant loss was loss of a support system. This theme of loss of existing support systems, such as family and friends, after the stroke contains some powerful data about impact of loss on the dyad. For example:

Our whole lives changed. We don’t—in fact—our social network is gone. We had a big social life [prior to the stroke]. We knew a lot of people because we have traveled a lot and I don’t hear from hardly anybody. And—even family too. And family has kind of been, I think, the biggest stinkers of all.

In discussing the loss of friendships after her stroke one patient said “That’s been months ago and nothing. They haven’t picked up the phone to call me. They don’t know what to say to me and I can’t help them because I don’t know what to tell them.” When a caregiver asked for help soon after her husband’s stroke, she was quite disappointed by the response: “I remember being told, ‘Well I’m so busy. I’ve got things; I’ve got my own problems’. I was beside myself and well, you find out who’s with you and who’s not.”

Loss and Change for Patients and Caregivers (Holbrook’s²⁹ Third Stage)

Although loss and change for patient and loss and change for caregiver are expressed as separate stages in the Holbrook model (29), participants described complimentary experiences in areas such as loss of independence, changes in roles

and relationships, and lack of recovery progress, thus these themes are presented together for the sake of this article. Patient losses centered on physical changes and resulting restrictions to their activities, abilities, and role participation. Many talked about the challenges they experienced related to loss of control of their own body and the frustration or humiliation of having to ask for help. When one patient commented “I still have trouble with my hand. I try to get it in my pocket sometimes and it’s just—my fingers are hanging out and it’s not in my pocket at all. It’s, you know, doing whatever it wants to do, so I get really frustrated sometimes,” another responded “that was the hard part for me because I have always been very independent and doing everything on my own and to have to say ‘I can’t zip my pants up. Can somebody zip my pants?’ it’s very hard, very hard.” Loss of independence was a common concern for patients, but one that many caregivers endorsed as well:

Everywhere I go I have to take him with me. It’s hard for him communicating and trying to say what he’s thinking and get it out. And then it’s hard for me because not only has his life changed, but mine has just flipped completely. The hardest part for me is my freedom being taken away from me.

For some, stroke effects required that they relearn familiar tasks. A caregiver expressed fear that her husband no longer perceived danger and a majority of her day was spent providing or arranging for his 24-hour supervision. Patient frustration was expressed many times with the seeming lack of progress in getting back to their perceived “normal”: “I am still struggling with the drop foot. I feel like Chester on Gun Smoke. And I get frustrated because it takes me twice as long it seems like to do anything.”

Patients and caregivers struggled with changes in their roles—within their dyad, their family, and their profession. One patient stated that the most challenging aspect of her recovery was not being able to cook. She stated “I always cooked Christmas dinner and Thanksgiving dinner and it was always a big ordeal—a big family thing. I always did it by myself. Not being able to do that was really hard.” Patients and caregivers were not prepared for these role changes and the losses associated with them.

When all of a sudden your wife is thrust into decision-making process that she hadn’t done and I had always done. Nobody ever mentioned to us that, “Yeah the dynamics of your relationship are going to change.” Because that is something that no one ever prepares for or even thinks about. You know, “What am I going to do when we reverse roles?”

When her husband returned home after a stroke, one caregiver was surprised by how emotional he was “he’s been my rock and he’s always taken care of me, so this is new for me. And I don’t know how to deal with it.” A caregiver stated “I had to take over all of our bills and I had been the little lady. That was upsetting.” For those patients who had

been working prior to their stroke, they worried about returning to their professional roles. One patient stated, "The question is 'When are you going to be able to return to work and do what you do at a high level?'" while another stated "I was worried about things like depression and just not being able to remember things, and losing function, and not being able to be an accountant ever again."

Identification of Silver Linings (Holbrook's²⁹ Fourth Stage)

A few participants reported positive aspects of the experience of stroke or lessons that they had learned from the experience. One patient described his mindset about recovery as "... if I want to get better... it's only going to happen if I put the energy into doing it." For caregivers, they identified positive aspects of their changed relationship with the patient. One caregiver describes gaining appreciation for what she and the patient had:

As hard as it is, you know, for us during this transition, I have learned not to take him for granted. I have always appreciated the things that he has done for me. But I really appreciate it now because I know that he can't and I know he would if he could.

Another caregiver stated, "We really have more fun together since he stroked out than we had before."

Discussion

Although physical loss was significant, psychosocial loss also had profound impacts on the lives of participants in our study. Recovery can require substantial adjustment, and many felt unprepared and unsupported. Although some in our study were able to find silver linings, for the most part the stroke and recovery process negatively affected their lives. These data raise several concerns that can guide services to those recovering in the community.

Role loss and adjustment to new roles have implications for the survivor and caregiver relationship. Relationship stability is often a strength that those dealing with major illness rely on; however, stroke recovery can threaten this resource. Having to take on new responsibilities can be stressful, and challenges perceptions of self. For several of the dyads we see this reflected in their discussion of how difficult it is to get used to not doing what is expected of them, often along stereotyped gender roles (ie, bill paying, meal preparation). Loss related to work role was observed, with some variability based on life stage of participant. Patients who are still active in the professional world may worry about regaining professional skills and returning to the workforce. For older couples, the challenges associated with age have less to do with career goals and more to do with managing previous expectations of retirement.

Confusion and denial around the identification of stroke symptoms was a common experience among participants, in

some cases delaying care by hours or even days. This finding has implications for how the public is educated about stroke symptoms and the need for quick medical response. Confusion and denial were also present in the understanding of the length and intensity of recovery, as well as the seriousness of the stroke. The challenge for the care team in these cases includes conveying information about expectations of stroke recovery in a way that can be understood by the patient and caregiver.

Social support is an important adjunct to stroke recovery. Many participants experienced painful loss related to family and friend support. The intensity of the recovery and its length were barriers identified in accessing a support system. Lutz et al (35) describe a model for identification of caregiver needs and readiness for caregiving that can facilitate better preparation of stroke caregivers. In addition, Cameron and Gignac (36) make suggestions for supporting stroke family caregivers across the spectrum of care that are responsive to the changing needs of caregivers throughout stroke recovery. It is essential that patients and caregivers alike are educated about the emotional and social aspects of stroke recovery and that loss beyond the physical is acknowledged. Recent findings from the development and pilot study of the program "Recovering Together," a dyadic cognitive behavioral approach, indicate that programs targeting both the stroke survivor and caregiver after discharge and during recovery may have positive effects on resilience, coping, and emotional well-being (37,38).

Holbrook's bereavement model (29) provided a foundation for understanding the grief reactions of the participants in our study. We could identify the model's 4 stages in these data. It is likely that we did not find as much data related to acceptance and adjustment due to the nature of our sample versus the nature of Holbrook's sample (29). She developed this model based on observation of rehabilitation in a previous care generation where inpatient and rehabilitation stays were significantly longer than current lengths of stay. All of our participants had experienced a stroke in the previous 6 months and were still relatively new to the experience. However, a strength of this framework is that it is stroke specific and with modification may be a helpful resource to patients and families along the stroke recovery spectrum.

Our findings need to be considered in light of some limitations. In addition to the considerations of the model fit to recent stroke survivors, our data come from a self-selected sample, all of whom were experiencing sequelae in the form of physical or cognitive impairments. Participants may be more likely to need support or are more likely to volunteer for research studies than the typical stroke survivor. However, a unique strength of this study is the emergence of these grief and loss themes. As the parent study did not include inquiry into the experience of grief and loss that participants in 2 distinct groups identified and discussed themes of grief and loss with no prompting by the research team speaks to the universality of this experience for both stroke survivors and caregivers. Care teams and providers

can use the information presented here to assist patients and caregivers along the spectrum of recovery so that grief reactions are normalized and attended to. Support groups can be useful as well so that patients and caregivers experiencing loss have a place to discuss it and learn that it is a reaction shared by others. Emerging interventions that focus on psychosocial recovery will be important adjuncts to typical recovery services (28).

Conclusion

Grief and loss permeated the recovery period of our participants. Whether it was a loss of function, a loss of friendship, or a loss of role these experiences greatly impacted both patients and caregivers. Although a few were able to glean something positive from their experience, for the vast majority grief and loss negatively affected their lives. This work identifies the value of looking at stroke recovery through the lens of grief and providing increased access to supportive services and interventions. This lens can sensitize providers to the ongoing loss that patients and caregivers contend with during recovery.

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References

- Centers for Disease Control and Prevention. Stroke Facts. 2006. Updated September 8, 2020. Accessed April 11, 2017. <http://www.cdc.gov/stroke/facts.htm>
- Pringle J, Hendry C, McLafferty E. A review of the early discharge experiences of stroke survivors and their careers. *J Clin Nurs*. 2008;17:2384-97.
- National Stroke Association. Post-Stroke Conditions. 2016. Accessed April 11, 2017. <http://www.stroke.org/we-can-help/survivors/stroke-recovery/post-stroke-conditions>
- Glass TA, Dym B, Greenberg S, Rintell D, Roesch C, Berkman LF. Psychosocial intervention in stroke: families in recovery from stroke trial (FIRST). *Am J Orthopsychiatry*. 2000;70:169.
- Gustafson Y, Nilsson I, Mattsson M, Astrom M, Bucht G. Epidemiology and treatment of post-stroke depression. *Drug Aging*. 1995;7:298-309.
- Hackett M, Carter G, Crimmins D, Clarke T, Maddock K, Sturm JW. Improving outcomes after stroke (post) clinical pilot trial results. *Int J Stroke*. 2011;6:19.
- Kouwenhoven SE, Kirkevoold M, Engedal K, Kim HS. Depression in acute stroke: prevalence, dominant symptoms and associated factors. a systematic literature review. *Disabil Rehabil*. 2011;33:539-56.
- Castillo CS, Starkstein SE, Fedoroff JP, Price TR, Robinson RG. Generalized anxiety disorder after stroke. *J Nerv Ment Dis*. 1993;181:100-6.
- Draper P, Brocklehurst H. The impact of stroke on the well-being of the patient's spouse: an exploratory study. *J Clin Nurs*. 2007;16:264-71.
- Jaracz K, Grabowska-Fudala B, Gorna K, Jaracz J, Moczko J, Kozubski W. Burden in caregivers of long-term stroke survivors: prevalence and determinants at 6 months and 5 years after stroke. *Patient Educ Couns*. 2012;98:1011-6.
- Lutz BJ, Young ME, Cox KJ, Martz C, Rae Creasy K. The crisis of stroke: experiences of patients and their family caregivers. *Top Stroke Rehabil*. 2011;18:786-97.
- McCullagh E, Brigstocke G, Donaldson N, Kalra L. Determinants of caregiving burden and quality of life in caregivers of stroke patients. *Stroke*. 2005;36:2181-6.
- Scholte op Reimer WJ, De Haan RJ, Rijnders PT, Limburg M, Van Den Bos GA. The burden of caregiving in partners of long-term stroke survivors. *Stroke*. 1998;29:1605-11.
- Parag V, Hackett ML, Yapa CM, Kerse N, McNaughton H, Feigin VL, et al. The impact of stroke on unpaid caregivers: results from the Auckland regional community stroke study, 2002-2003. *Cerebrovasc Dis*. 2008;25:548-54.
- Visser-Meily A, Post M, Gorter JW, Berlekom SB, Van Den Bos T, Lindeman E. Rehabilitation of stroke patients needs a family-centred approach. *Disabil Rehabil*. 2006;28:1557-61.
- Carlsson GE, Forsberg-Wärleby G, Möller A, Blomstrand C. Comparison of life satisfaction within couples one year after a partner's stroke. *J Rehabil Med*. 2007;39:219-24.
- Alaszewski A, Alaszewski H, Potter J. The bereavement model, stroke and rehabilitation: a critical analysis of the use of a psychological model in professional practice. *Disabil Rehabil*. 2004;26:1067-78.
- Doughty Horn EA, Crews JA, Guryan BA, Katsilometes BM. Identifying and addressing grief and loss issues in a person with aphasia: a single-case study. *J Couns Dev*. 2016;94:225-33.
- Roman MW. Lessons learned from a school for stroke recovery. *Top Stroke Rehabil*. 2008;15:59-71.
- Salter K, Hellings C, Foley N, Teasell R. The experience of living with stroke: a qualitative meta-synthesis. *J Rehabil Med*. 2008;40:595-602.

21. Bourland EL, Neville MA, Pickens ND. Loss, gain, and the reframing of perspectives in long-term stroke survivors: a dynamic experience of quality of life. *Top Stroke Rehabil.* 2011;18:437-49.
22. Lanza M. Psychological impact of stroke: a recovering nurse's story. *Issues Ment Health Nurs.* 2006;27:765-74.
23. Bäckström B, Asplund K, Sundin K. The meaning of middle-aged female spouses' lived experience of the relationship with a partner who has suffered a stroke, during the first year post-discharge. *Nurs Inq.* 2010;17:257-68.
24. O'Brien CL, Moore G, Rolley JX, Ski CF, Thompson DR, Lautenschlager NT, et al. Exploring health care providers' perceptions of the needs of stroke carers: informing development of an optimal health program. *Top Stroke Rehabil.* 2014; 21:421-31.
25. Rademeyer M, Roy D, Gasquoin S. A stroke of grief and devotion: a hermeneutic enquiry of a family's lived experience two years post-stroke. *Nurs Prax N Z.* 2020;36:8-19.
26. Olivier CL, Phillips J, Roy DE. To be or not to be? a caregiver's question: the lived experience of a stroke family during the first 18 months poststroke. *Scand J Caring Sci.* 2018;32: 270-9.
27. Saban KL, Hogan NS. Female caregivers of stroke survivors: coping and adapting to a life that once was. *J Neurosci Nurs.* 2012;44:2-14.
28. McCurley JL, Funes CJ, Zale EL, Lin A, Jacobo M, Jacobs JM, et al. Preventing chronic emotional distress in stroke survivors and their informal caregivers. *Neurocrit Care.* 2019;30:581-9.
29. Holbrook M. Stroke: social and emotional outcome. *J R Coll Physicians Lond.* 1982;16:100.
30. Stroebe M, Schut H, Boerner K. Cautioning health-care professionals: bereaved persons are misguided through the stages of grief. *Omega (Westport).* 2017;74:455-73.
31. Wade DT, Wood VA, Hewer RL. Recovery after stroke—the first 3 months. *J Neurol Neurosurg Psychiatry.* 1985;48:7-13.
32. Reeves M, Hughes AK, Woodward A, Freddolino PP, Coursaris CK, Swierenga SJ, et al. Improving transitions in acute stroke patients discharged to home: the Michigan stroke transitions trial (MISTT) protocol. *BMC Neurol.* 2017;17: 1-15.
33. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* 2006;3:77-101.
34. Hayes N. Theory-led thematic analysis. In: Hayes N, ed. *Doing Qualitative Analysis in Psychology.* Psychology Press; 1997: 93-113.
35. Lutz BJ, Young ME, Creasy KR, Martz C, Eisenbrandt L, Brunny JN, et al. Improving stroke caregiver readiness for transition from inpatient rehabilitation to home. *Gerontologist.* 2017;57:880-99.
36. Cameron JI, Gignac MAM. Timing it right: a conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home. *Patient Educ Couns.* 2008;70:305-14.
37. Bannon S, Lester EG, Gates MV, McCurley J, Lin A, Rosand J, et al. Recovering together: building resiliency in dyads of stroke patients and their caregivers at risk for chronic emotional distress; a feasibility study. *Pilot Feasibility Stud.* 2020;1:1-16.
38. Meyers EE, McCurley J, Lester E, Jacobo M, Rosand J, Vranceanu AM, et al. Building resiliency in dyads of patients admitted to the neuroscience intensive care unit and their family caregivers: lessons learned from William and Laura. *Cogn Behav Pract.* 2020;27:321-35.

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