

ORIGINAL ARTICLE



Preventing Chronic Emotional Distress in Stroke Survivors and Their Informal Caregivers

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Abstract

Background/Objective: Chronic emotional distress (e.g., depression, anxiety, post-traumatic stress) is common after stroke and interdependent between patients and their informal caregivers. We measured stroke survivors', caregivers', and neurocritical care nurses' views of primary drivers of distress during the stroke experience, and needs and preferences for the structure, topics, mode of delivery, and timing of an intervention to promote emotional recovery.

Methods: We conducted semi-structured interviews with 24 patient–caregiver dyads within the Neuroscience Intensive Care Unit (Neuro-ICU). Additionally, we conducted two focus groups with 15 nurses. Interviews and focus groups were audio-recorded, transcribed, and coded using NVivo 11 (QSR International) software.

Results and Conclusions: The challenges and impacts of stroke most commonly reported by dyads were: uncertainty about future health, fear of recurrent strokes, negative emotions, and role changes post-stroke. Dyads and nurses agreed that resiliency skills such as mindfulness/focusing on the present, problem solving, gratitude/optimism, self-care, interpersonal communication and developing a supportive team of family, friends, and medical staff are beneficial to optimize recovery. The potential barrier to intervention delivery was accessibility, due to challenges of time and travel to appointments. Participants agreed that starting the intervention at hospitalization and continuing via live video after discharge is an ideal delivery modality. Stroke survivors, caregivers, and Neuro-ICU nurses believe that a resiliency skills-based intervention to prevent chronic emotional distress is necessary and urgent. This qualitative study provides valuable information on the challenges faced by dyads, intervention topics to prioritize, and strategies to maximize feasibility, acceptability, and effect.

Keywords: Stroke, Depression, Post-traumatic stress, Caregivers, Nurses

Introduction

Stroke is the 5th leading cause of death and a primary cause of disability among adults in developed countries [1], affecting nearly 800,000 Americans each year [2].

Stroke occurs without warning and often leads to devastating and life-changing consequences. Because stroke may result in death, profound disability, and altered life prospects for survivors, its experience can cause extreme emotional distress for both patients and caregivers. While endovascular and neurocritical care advancements have drastically improved physical and rehabilitation outcomes for stroke patients, there remains an urgent need to address the substantial emotional distress associated with being diagnosed with a stroke, for both patients and caregivers. Indeed, research has shown that many stroke

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patients report clinically a significant emotional distress at hospitalization in the form of depression (10–58%) [3–6], anxiety (12–43%) [3, 6, 7], and post-traumatic symptoms (PTS; 20–29%) [4, 8]. Among family caregivers, rates of depression, anxiety, and PTS (27–60%) [3, 9, 10] are comparably high. Further, these symptoms tend to remain chronic [9, 11, 12] and are interrelated among patients and family caregivers [13, 14], meaning that higher distress in one partner is generally associated with higher distress in the other.

The burden of chronic emotional distress and its adverse effects on patient–caregiver interactions is well documented. Post-stroke emotional distress in patients is associated with poor medical adherence [15], slower recovery [15–17], higher mortality [16, 18], and need of more caregiving assistance [19]. For caregivers, patient distress further increases caregiver distress [17, 20] and their own risk of morbidity [21, 22] and mortality [23]. Higher caregiver emotional distress, in turn, reduces ability to provide high-quality care to patients and negatively impacts patient medical outcomes [20, 24].

These findings demonstrate the urgency of identifying and treating emotional distress early in the stroke recovery process to prevent the downstream effects of increased emotional distress, poor physical recovery, and heightened risk of morbidity and mortality in both patients and caregivers. The initial stroke hospitalization represents a critical, influential time period to intervene strategically to prevent development of chronic psychiatric conditions.

Current psychosocial interventions available for stroke patients or caregivers (e.g., individual psychotherapy) are limited in several ways. First, they are delivered when symptoms are already chronic. Second, they generally address only one emotional illness (e.g., depression, anxiety or post-traumatic stress disorder). Third, they are primarily focused on the individual experience of the patient or the caregiver *outside* of the context of their interpersonal relationship. Emerging research [3, 13, 25] supports the adoption of a *dyadic framework* for understanding post-stroke distress, in which the patient and caregiver dyad is viewed as a unit and emphasis is placed on the interpersonal relationship and the interactions between patient and caregiver coping and emotional factors [26]. This novel framework is consistent with recent American Heart Association recommendations [26, 27] stressing the need for interventions that include *both* patients and caregivers, target patient *and* caregiver outcomes, and utilize a *preventive* approach to chronic emotional distress.

The present study is the first step in building a dyadic psychosocial resiliency program to prevent chronic emotional distress in dyads of patients hospitalized with a stroke and their family caregivers. Our overall goal is to develop an intervention that is credible, feasible,

accessible and relevant to stroke patients, their caregivers, and medical and nursing staff within the neurosciences intensive care unit (Neuro-ICU). We envision the intervention as starting during hospitalization to engage patients and caregivers in attending to emotional distress along with medical care and to best adopt a proactive approach toward future challenges that may be encountered by dyads post-discharge. To inform the development of this intervention we conducted qualitative interviews with patient–caregiver dyads during the first week of hospitalization. We also conducted focus groups with nurses who care for these dyads. The interview and focus group questions were developed using elements from the theoretical response-shift framework to adaptation to acute illness (successful adaptation implies recalibration of values and life goals) [28], the family strength vulnerability model (within dyads relational systems have strengths and weaknesses in how they cope with life events) [29], the dyadic longitudinal model (distress travels from one member of the dyad to the other across time) [30], the resiliency framework (multidimensional factors such as coping, mindfulness, social support work together to facilitate adaptation) [31], and prior quantitative research [3, 13, 25] showing that mindfulness, coping, social support, self-efficacy, and enhancing patient–caregiver bonds are important factors that promote successful adaptation to stroke for both survivors and their family caregivers. The specific aims of the current study were to use semi-structured qualitative interviews with stroke patient–caregiver dyads and focus groups with nurses to determine: (1) perceptions of the psychological challenges and impact of stroke and sources of emotional distress; (2) coping strategies for emotional distress and appropriate points to intervene (e.g., common unhelpful coping styles, misinformation about illness, and poor self-care); and (3) preferences and opinions for the structure, mode of delivery, timing, and topics for a potential dyadic intervention.

Methods

This study took place at an academic medical center's Neuro-ICU between May and July 2017. We conducted 24 qualitative interviews with dyads of patients with stroke and their informal caregivers (e.g., family members or close friends who provide the bulk of unpaid care) [32] during the initial stroke hospitalization within the Neuro-ICU. Subsequently, we conducted 2 focus groups with 15 Neuro-ICU nurses who care for patients and families. Inclusion criteria for patients were hospitalization for ischemic or hemorrhagic stroke or transient ischemic attack, age 18 years or older, the presence of a primary caregiver who would assist with stroke recovery and who was also willing to participate, and clearance

by the medical team. Patients with cognitive impairment or aphasia that prevented independent informed consent and/or verbal participation, as determined by nursing teams, were excluded. We aimed to interview dyads representative of patients with stroke and caregivers that would be able to participate in the intervention that we plan to subsequently develop. Ethics approval was obtained from our institutional review board, and all subjects provided written informed consent. Procedures followed were in accordance with institutional guidelines.

Participant Recruitment

Research assistants screened medical records to identify potential stroke dyads. The nursing team was consulted about each patient's mental status, ability to participate, availability of a caregiver, and best time for recruitment. Study staff approached dyads for participation and conducted screening and consent. Approximately 30 dyads were approached, 26 were eligible, and 24 completed the interviews. Two eligible dyads were discharged prior to the interviews. Two focus groups of nurses ($N=15$) were conducted; one clinical nurse specialist and one nurse director also participated.

Data Collection

We developed a semi-structured qualitative interview guide for stroke patient–caregiver dyads which was linked directly to the study questions and informed by prior research and clinical experience. The interview consisted of 8 targeted content areas: (1) current functioning; (2) most challenging and distressing experiences; (3) impact of stroke; (4) coping with stroke; (5) support resources; (6) interest and content of a dyadic resiliency intervention (topics and skills); (7) preferred structure for the intervention; (8) barriers to participation. The interview content and script was created by the nursing team and 3 clinical psychologists with expertise in qualitative interviews. All interviews were conducted by trained study staff who asked questions, clarified responses as needed, and encouraged discussion. Interviews were audio-recorded and lasted 20–45 min. With nurses, the purpose of the focus groups was to share themes identified in dyad qualitative interviews, including dyads' suggestions for the content and structure of a dyadic intervention, and gather nurses' opinions on implementation strategies and ways to increase feasibility and acceptability of the intervention.

Analysis

Each interview was manually transcribed by trained research staff, and accuracy of transcripts was verified by independent staff raters. One transcript was conducted

in Spanish and was translated by the Spanish speaking psychologist who performed the interview. Data were analyzed using qualitative content analyses and an inductive approach [33] given established knowledge on emotional distress and coping resources in stroke patient–caregiver dyads [3, 9, 13, 25]. Each transcript was thoroughly reviewed and open coded to identify preliminary codes. These preliminary codes were subsequently used to recode the transcripts, and new codes were added if data did not fit the existing codes. In a next step, similar codes were grouped into categories and organized iteratively into mutually exclusive final categories, subthemes, and themes. An accompanying manual was created with information on the coding scheme and an objective definition of each code. Two independent raters conducted coding and resolved discrepancies through analyses of the raw data and input from senior author. Data analysis was conducted with NVivo 11 (QSR International) software [34]. A coding comparison query showed a high level of overall consensus (weighted percent agreement = 99.51%).

Results

Patients and informal caregivers did not differ demographically (Table 1). Overall, participants were middle aged, and a majority were non-Hispanic white, highly educated, and married. The most prevalent diagnosis causing patients to be hospitalized was ischemic stroke (29%). The majority of primary caregivers were patients' spouse/partner (46%). Critical care nurses were mostly women ($N=13$; 86%) and were a representative sample of the nursing team in the Neuro-ICU. The average years of experience of nurses in the unit were 12.3 years and 27.9% of nurses on the unit hold specialty certification, such as the American Association of Neuroscience Nurses or Critical Care Nursing Certification.

Dyad Perspectives

Challenges and Impact of Stroke

Three major themes emerged with regard to the challenges and impact of stroke on patients and their informal caregivers: 1) difficulties managing the uncertainty of the recovery process; 2) difficulties managing emotional distress; 3) sources of emotional distress.

Theme 1: Difficulties managing the uncertainty of the recovery process

This was described by nearly all patient–caregiver dyads as being the most challenging or distressing experience associated with stroke. This uncertainty included recovery both during and post-Neuro-ICU stays. Neuro-ICU-related uncertainty revolved around survival, discharge

Table 1 Demographic characteristics of stroke survivors and their caregivers

Characteristic	Category	M (SD) or N (%)
Age (patient)		58.65 (16.50)
Age (caregiver)		60.54 (10–82)
Gender (patient)	Female	16 (67%)
	Male	6 (25%)
	Missing	2 (8%)
Gender (caregiver)	Female	15 (63%)
	Male	6 (25%)
	Missing	3 (12%)
Diagnosis	Ischemic	7 (29%)
	Hemorrhagic	6 (25%)
	Hematoma	3 (13)
	Missing	8 (33%)
Dyadic relationship	Spouse–spouse	11 (46%)
	Parent–child	9 (38%)
	Extended family	1 (4%)
	Missing	2 (8%)

N = 24 for the entire sample

date, and treatment/test results. One stroke patient shared this concern even while recovering optimally, “Well I think just the whole thing of it, not knowing, you know, it feels like I’m doing exceptionally well. Is that going to stay or change, and, you know, what’s the outcome?” One caregiver stated: “I just want to know what will happen. Nurses and doctors come in and out, he goes for testing and procedures, I don’t know if he is out of the woods yet.” Post-Neuro-ICU uncertainty revolved around long-term consequences of the stroke and fear of recurrent strokes. As one caregiver expressed, “I know she’s getting taken care of, but what’s going to prevent the next one?”

Theme 2: Difficulties Managing Emotional Distress

Both patients and caregivers endorsed distress in the form of anxiety, panic, guilt, sadness, and symptoms of post-traumatic stress. Patients noted panic attacks particularly at night triggered by memories of the stroke onset. Caregivers reported a general sense of anxiety and being “on edge.” Both patients and caregivers noted sadness, crying, and times when they feel hopeless and helpless. One caregiver stated, “I just feel like an emptiness inside of my chest at all times and my heart is always, like, fast-going... Like my, my body’s empty right now, I don’t know why is that? Is that something normally people feel?”

But that’s how I feel, it’s like... Like if I was just like really cold... and just my heart is nervous.”

Theme 3: Multiple Sources of Emotional Distress

Emotional distress was linked to the sudden onset of the stroke, uncertainty about the future, concerns about stroke sequelae, and adjustment to life after stroke. One caregiver stated: “*The fragility of life... you know, I think we just weren’t expecting, we just weren’t expecting for her, she’s young. I just can’t stop thinking about this.*” Several patients shared a feeling of guilt that they might have caused the stroke, “*I was a smoker, I am a nurse, I know this is bad. I feel I brought this on myself,*” and “*I had so much stress in my life, so much. I take care of others but never of me, I know the stress got me.*” Caregivers reported distress associated with navigating work and family while caring for the patient both during hospitalization and after: “*I’m thinking about how am I going to get all this work done when we get home and still take care of him too.*” Patients also noted distress associated with identity and role changes, such as sadness and frustration when transitioning from a caretaker role within the family to patient or one being cared for. This seemed to be particularly salient for women, as it was reported by multiple female stroke survivors. One female patient noted, for example, “*I am the caregiver, I do everything for my kids and my husband. How is he going to do everything? Who am I if I don’t take care?*” Many patients disclosed the desire to remain strong for others, feeling guilty, and concern with being a burden. Table 2 presents these themes and associated quotes.

Coping with Stroke

Most dyads reported using a variety of positive coping strategies. All patient–caregiver dyads identified having a supportive team of family, friends, and medical staff as a critical component of successful coping. Dyads shared that encouragement from medical staff and clear communication were crucial to feeling as if they had a supportive medical treatment team. Dyads noted that problem solving, gratitude, mindfulness, optimism, engagement in hobbies, humor, spirituality, and exercise were strategies that worked for them in the past, but noted challenges implementing them to cope with the stroke. One caregiver stated: “*I think it’s mostly just changing of mindset around not trying to plan or predict the future and just focus on the normal things. But how do you do this? Before I was doing a little bit of exercise, hearing music, or reading the bible, but always entertaining my mind with something... But now, I want to spend all my time with my wife, time is precious, I need to be here for her.*” When specifically prompted about self-care, caregivers reported having difficulty and feeling guilty for getting away to eat or

Table 2 Selected quotes from patient–caregiver interviews and nurse focus groups

Dyad perspectives	
Topic	Quotes
Challenges and impact of stroke	Difficulties managing the uncertainty of the recovery process
	<p>"The challenge right now is the unknown"</p> <p>"I have a fear of not being able to be the way I was, get back to where I was"</p>
	Difficulties managing emotional distress
	Multiple sources of emotional distress
	"Uncontrollable crying, depressed"
	"I hate the idea that people now have to worry about me more than they once did"
	"Being in a hospital is very tiring"
Coping with stroke	Coping strategies
	"I just have to take each day as it comes and keep a good attitude about it. I'm working on that"
	"I try to get in the moment"
	"I just focused on the positive and didn't worry too much about what could have happened"
Preferred structure for a resiliency intervention	Suggested topics
	"Learning more about the condition and research that is being done"
	"Adaptation would be good too...adaptive thinking"
	"Make sure you don't have as much stress and, so, you can do normal living"
	"There's so many other responsibilities and stresses to deal with that it makes it hard to, I'd say, commit with reliability"
Nurse perspectives	
Topic	Quotes
Recommendations	<p>"Staying in the present"</p> <p>"Focusing on the now may keep you from worrying too much, but also you have to appreciate the things that make it better in the future"</p> <p>"Trying to support them and knowing that they're still involved and supporting their loved one by taking care of themselves"</p>
Barriers to effective implementation	"We don't have consistency all the time, like you may work and not be back to work for 4 or 5 days"

take time for themselves, and a desire to stay at the bedside of the patient. Several participants noted that they have few effective coping strategies to rely on. As one caregiver shared, *“So that is my problem. I don’t manage it, ‘cause I manage everybody else’s.”*

Preferred Structure for a Resiliency Intervention Delivery Modality

Dyads suggested that starting the intervention in the hospital and learning skills focused on managing Neuro-ICU-related distress would be helpful. They also noted that they would not want to return to the hospital after discharge and were enthusiastic about the idea of using live video for subsequent intervention meetings post-discharge.

Interest and Opinions

The majority of dyads reported interest in a skills-based intervention. Most agreed that a dyadic intervention focused on helping both patients and caregivers learn skills to manage and prevent emotional distress and improve interpersonal communication would be acceptable and helpful.

Suggested Topics

For the in-hospital sessions, dyads reported interest in learning skills to manage the uncertainty and intense emotions of the stroke experience. Caregivers noted that they would like to be able to engage in more self-care behaviors in the hospital, such as sleeping more, in order to be prepared for discharge. One caregiver said: *“The nurses tell me to go home, sleep, that I will need that after he comes home, but I can’t.”* For the outpatient sessions, patients expressed that they would like to understand why the stroke happened and how to prevent a future stroke. Patients also wanted to learn any strategies that would help them return to day-to-day life after discharge. One caregiver described this sentiment, saying: *“I think now you’re different than you were before, and we need to incorporate that into normal living so when you get back home, we need to be different and make sure you don’t have as much stress... you need to have that adaptation... this is part of who you are now.”* There was wide support among dyads for the following proposed topics of the intervention: (1) adaptive thinking, such as cognitive skills to cope with stress and negative emotions; (2) assistance with managing the uncertainty and worry associated with stroke (one caregiver said: *“It’s a trying experience, any help you can get through the process... you have no idea what’s to come down the road, when you get home”*); (3) mindfulness skills; (4) meaning-making, or making sense of the stroke and its impact on your life; (5) coping effectively with fear of recurrence;

and (6) addressing role changes and patient–caregiver communication.

Barriers to Participation

Dyads expected that others like themselves might have challenges finding time for an additional program both during hospitalization and thereafter. They cited the rapid pace of ICU days, with many appointments and procedures, and the resulting fatigue that patients and families feel. Dyads agreed that integrating the skills program as a typical medical visit and involving nursing staff to identify best timing for in-hospital sessions would work best. Dyads warned us that it may be harder to schedule the visits after hospital discharge, when many caregivers return work. A caregiver noted, *“The hard thing with doing that for a family or someone that’s going through this type of medical condition is really finding the time to make that happen.”* Most caregivers agreed, however, that the option to participate from work via live video, while the patient participates from home, presents a potential solution. Flexibility in intervention timing and mode of delivery was highly recommended to facilitate participation. Live video delivery of the program was considered by many participants to be the only possible way to participate: *“We live far away...and if we had to come here, now that would be some stress;”* *“When we leave, we never want to come back.”* Dyads noted that 30 min was the likely the maximum amount of time that would be feasible for each treatment session.

Nurse Perspectives

Neuro-ICU nurses agreed with themes that emerged from the dyadic interviews and offered additional valuable recommendations for intervention content. Nurses recommended addressing negative thoughts about the stroke and caregiving, such as guilt and self-blame, that add to emotional distress for caregivers. One nurse commented, *“I think part of it is like guilt for, like, if they’re not here then they’re feeling like they’re not actually being like, supportive and present for their sick family member.”* Nurses also suggested teaching patients and families to focus on the present moment and day, rather than constantly evaluating whether the patient is getting better: *“...The fact that they aren’t better right away doesn’t mean things have failed.”* Nurses described the importance of addressing the hardships associated with recovering from stroke, and the challenges patients and caregivers will face in trying to return to how life was before the stroke. One nurse explained, *“People get overwhelmed... Will they get some of these deficits back again? What does the future hold...if you can give people small amounts of information, instead of a lot to process, it’s probably helpful.”* Many nurses felt that an intervention should address

the importance of self-care and the transfer of caregiving responsibilities from the medical staff to family caregivers following discharge. As one nurse stated *“As I explained to them, we’re here now with the patient, but down the line we won’t be, so you need to take care of yourself and get rest, so you’re able to do that.”*

Barriers to Effective Implementation

Nurses were unanimously supportive of the need for the resiliency skills program and supportive of its implementation. Nurses noted that it will be important for them to receive training associated with implementation of the skills intervention so that they can assist with the recruitment and referral process. They noted that potential unwillingness of patients to disclose challenging emotions and concerns to the medical team, and requested learning skills to facilitate communication with patients and families. One nurse stated, *“I feel like none of our patients talk to us, really...I think it’s all new, they haven’t really processed it yet.”* Nurses suggested adding simple, time-saving steps to facilitate intervention delivery, such as a screening tool administered at intake to promptly identify patients who may benefit from a psychosocial skills intervention.

Discussion

Clear evidence for heightened risk of morbidity and mortality associated with chronic post-stroke psychiatric distress in both patients and caregivers means that effective prevention strategies are desperately needed. Given the AHA recommendations for dyadic approaches, and the inter-relatedness of patient–caregiver distress post-stroke, interventions designed to target both patient and caregiver psychosocial needs are necessary. This study gathered detailed qualitative information directly from stroke patient–caregiver dyads at the critical time of hospitalization, and Neuro-ICU nurses who care for these dyads, to better understand factors that influence post-stroke psychiatric distress in order to inform the development of an accessible and feasible resiliency prevention program. According to dyads and nurses, the primary emotional challenges that patients with stroke and their caregivers experience at hospitalization and that need to be addressed by such an intervention were uncertainty about the future, sudden onset of stroke, role changes in relationships and at home, and adjustment to life changes after stroke. Dyads described reacting to these stressors with significant stress, shock, and symptoms of anxiety, depression, and post-traumatic stress. Skills that were thought to assist dyads most effectively in coping with these stressors were having a supportive medical team, problem-solving skills, optimism/gratitude, mindfulness/staying in the present, engagement in hobbies and

self-care, humor, spirituality, and good interpersonal communication. Many dyads highlighted that while they were aware of the utility of these coping skills, they struggled to implement them effectively during the stroke hospitalization. Nurses concurred with this assessment. This feedback reiterates the need for a resiliency skills training program to be integrated with ICU-based medical care and offered early in the hospitalization/recovery process in order to help dyads implement skills that can prevent chronic distress.

In almost all stroke cases, the recovery process extends well beyond the initial hospitalization, with patients often moving into rehabilitation centers and/or intensive rehabilitation regimens at home. For patients who acquire motor and other disabilities at stroke occurrence, the extent of potential recovery is often unknown until months later. As such, themes such as uncertainty about future health, managing emotional distress, and difficult role changes post-stroke that emerge while patients are in the hospital are expected to continue well into the post-hospitalization period. Thus, we believe the themes that emerged in this study regarding psychological distress and coping needs are representative of the longer post-stroke trajectory. In support of this assertion, both cross-sectional and prospective studies in ICU environments have found that emotional distress at hospitalization is the best predictor of chronic emotional distress at 3 and 6 months later [9, 35, 36]. Understanding stroke-related emotional distress at hospitalization—which was the aim of this manuscript—provided valuable information to develop a dyadic intervention that may begin at hospitalization, before emotional distress becomes chronic. Hospitalization represents a critical window of opportunity when we can teach patients and caregivers how to manage the intense emotional distress of the hospitalization, so that they are better equipped to care for themselves and each other after discharge.

The topics proposed as possible content of a skills-based training program—adaptive thinking, managing uncertainties and worry, mindfulness skills, meaning-making, coping with fear of recurrence, and addressing role changes—were widely supported by both dyads and nurses. In terms of structure for a possible intervention program, dyads and nurses agreed that beginning an intervention during the original stroke hospitalization, and continuing after discharge via live video, would offer patients and caregivers the most optimal chances for participation. We plan to utilize this rich, dyad-, and nurse-generated qualitative feedback to design the first skills-based dyadic program to prevent chronic psychiatric distress in stroke survivors and their caregivers, starting with in person sessions at hospitalization and transitioning to synchronous live video sessions after discharge.

This was, to our knowledge, the first qualitative study addressing possible intervention strategies to prevent chronic psychiatric illness in dyads of patients with stroke and their caregivers at the time of the stroke hospitalization. While several psychoeducation, skill building, or combined psychoeducational and skills building interventions exist for stroke dyads [26, 27], none focus on prevention and none are associated with improvement in outcomes for both survivors and their caregivers. Indeed, the majority of existent dyadic interventions are associated with improvement in survivors only, with several studies reporting worsening of caregiver outcomes and, in particular, caregiver social support [26, 27]. By conducting qualitative interviews with both stroke patients and their caregivers, we were able to capture themes to inform intervention modules that address both patient and caregiver needs as well as their interpersonal communication, to increase likelihood of improvement in emotional distress in both members of the dyad.

Notable strengths of the study include the involvement of multiple stakeholders (e.g., caregivers, nurses, patients), and the information gathered on effective implementation strategies from nurses, which directly increased nurse support for championing our effort. Further, the qualitative interview script was guided by recommendations from a systematic review on available interventions for stroke patients and caregivers [27], the several theoretical frameworks, prior quantitative research, and expert feedback from psychologists and nursing team. We were able to recruit and include a heterogeneous sample of stroke patients with regard to sex, stroke type, and stroke severities, and a mixture of spouses, friends, adult–child caregivers. Thus, we believe that this sample provided diverse and varied perspectives, and results are thus generalizable to many stroke survivors, caregivers, and nurses.

It is possible, however, that not all viewpoints and experiences are represented. For example, the perspectives of stroke survivors with major cognitive and speech limitations such as aphasia are not included. While this does limit generalizability of our findings, our sample is representative of the patient–caregiver dyads who would be medically and cognitively able to participate in a resiliency skills program. As our sample included majority female patients and caregivers, it is possible that our results are slight more representative of females. Some private or sensitive difficulties and stressors may not have been disclosed to us by patients or caregivers due to the presence of their caregiver/loved one in the same interview. Additionally, because we conducted all interviews during the initial stroke hospitalization, there may be distinct challenges and concerns that come up farther along the recovery trajectory (e.g., 6 months later) that

we did not capture, such as the effects of acquired deficits on social relationships, longer-term impact of the stroke on family members, and reduction of social support after the initial hospitalization and recovery [37, 38]. Lastly, while reflective of the general patient population of our medical center, the sample was also limited in terms of racial/ethnic and socioeconomic diversity. The socio-emotional needs of these patients and their caregivers could be different from the perspectives included in this report.

Conclusions

This qualitative study provides a first step toward the development of feasible, accessible, and patient-centered interventions for at-risk stroke survivors and their caregivers aimed at preventing chronic psychiatric illness in both members of the dyad. Such dyad-centered skills-based psychosocial interventions administered early in the post-stroke recovery period through a combination of in person and live video sessions, have the potential to dramatically improve both the physical and psychosocial recovery of stroke patients and caregivers. Feedback from dyads and nurses supports efforts toward developing, testing, and implementing psychosocial interventions in this high-risk, underserved population. Randomized controlled trials of dyadic interventions are necessary to provide further evidence on whether improvement of distress symptoms and prevention of long-term psychological dysfunction are possible.

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Authors' contribution

All authors contributed sufficiently to this scientific work and met criteria for authorship.

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Compliance with ethical standards

Conflicts of interest

The authors declare that they have no conflicts of interest.

Ethical approval

The study was approved by our Institutional Review Board ethics committee.

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