Stoke is 1.45 times more prevalent in rural areas compared to urban areas [1], yet stroke peer support groups in these areas are sparse and understudied. Approximately 41% of North Carolina’s population lives in a rural county [2], and it is estimated that 131,000 people living in rural North Carolina counties have been affected by a stroke [3]; yet, only a few support groups exist across 80 rural North Carolina counties. To the best of our knowledge, there is no single location to find stroke support groups in any region of North Carolina, let alone across all of North Carolina. Even the directories that do list stroke support groups are not always up to date and often include groups that are no longer active.

**Stroke Impact and Recovery**

After stroke, many survivors and their caregivers suddenly face new challenges. Survivors report physical symptoms and both survivors and caregivers report psychological distress [4-9]. As stroke survivors become increasingly aware of their new cognitive deficits and loss of functional abilities, changes in self-concept and adjustment to a new normal occur [4]; however, this can take time and is often accompanied by frustration. Additionally, post-stroke depression affects one-third of stroke survivors [10] and is associated with poor functional outcomes and high mortality rates [11]. Predictors of post-stroke depression include physical disability, stroke severity, cognitive impairment, pre-stroke depression [11], and lack of family and social support [12]. Many stroke survivors do not receive effective treatment because of perceptions that post-stroke depression is inevitable, and that depression will improve as their condition improves. Additionally, physicians may be reluctant to prescribe antidepressants in older patients because of potential side effects [13]. However, research shows that psychosocial intervention is one method of preventing and managing post-stroke depression [11].

Meanwhile, caregivers face increased burden from daily care coordination, isolation from their social networks, and changes in their roles and relationships [14]. Therefore, depression may be more common in stroke caregivers than in stroke survivors [15]. Additionally, stroke survivors and caregivers in rural areas lack access to regular psychosocial and rehabilitation support [16]. Survivors in rural areas are more likely to experience more persistent and severe stroke-related disabilities [17]. A recent study of stroke survivors in rural Appalachian Kentucky found that all participants reported a need for a local peer support group to provide psychological and emotional support. Both stroke survivors

**Perceived Benefits of Peer Support Groups for Stroke Survivors and Caregivers in Rural North Carolina**

Erin R. Christensen, Shannon L. Golden, Sabina B. Gesell

**BACKGROUND** Significant geographical disparities exist in stroke prevalence among southeastern states, including North Carolina. Additionally, stroke is more prevalent in rural areas. Peer support groups play an important role in stroke recovery by providing tools for effective coping, alleviating psychological stress, and creating an outlet for stroke survivors and caregivers. However, their perceived benefits have not been clearly defined for rural stroke survivors and their families.

**METHODS** This qualitative study describes the experiences of survivors and caregivers in rural North Carolina who have participated in stroke peer support groups. Four focus groups were conducted with 32 participants (average age 67 years, 72% female) in 4 rural North Carolina counties, using a semi-structured discussion guide and an inductive coding approach.

**RESULTS** Thematic analysis revealed that participants in rural support groups seek and receive knowledge from their support groups and feel empowered by providing and receiving this knowledge. Shared experiences cultivate a sense of community, and participants viewed support outside of the support group as necessary to their recovery process.

**LIMITATIONS** This study reflects the views of a small group of predominantly non-Hispanic, white stroke survivors and caregivers who voluntarily participated. We did not conduct separate focus groups with survivors and caregivers.

**CONCLUSION** Peer support groups are a sparse, but critical resource for rural stroke survivors and caregivers because they provide information and community that can assist with recovery to health and independence.

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and their caregivers were unaware of any existing local support groups, but were equally interested in them [18].

**Stroke Support Groups**

For many survivors and caregivers, perception of social support is associated with coping effectiveness [19]. People who perceive that they have more social support report better adjustment to daily life with new disabilities and changing roles [4]. In addition, social support has been linked to better functional outcomes for stroke survivors [20] and a greater sense of self-efficacy and self-esteem for stroke survivors and caregivers [19]. Peers are one source of social support. Four key functions of peer support are: assistance in daily disease management, social and emotional support, linkage to clinical care and community resources, and ongoing support [21]. Peer support has been shown to play a role in the management of many chronic conditions including diabetes [22], cancer [23], and depression [24], and has also been shown to benefit caregivers of dementia patients [25]. Peer support groups are one way for stroke survivors and caregivers to receive beneficial psychological and social support after a stroke, and are unique because the shared experiences enable peers to understand others and allow them to provide and receive relevant emotional, affirmative, and informational support [19]. For stroke survivors, providing support for peers has been shown to be beneficial because those providing support enjoy it, feel a sense of personal growth from providing it, and feel they are making a difference in someone else’s life [26].

Stroke support groups are part of comprehensive stroke care [27], but their perceived benefits have not been clearly defined for rural stroke survivors and their caregivers. This study examines the perceived psychological, informational, and social benefits to stroke survivors and family caregivers in rural North Carolina who participated in stroke peer support groups.

**Methods**

**Study Design**

This qualitative study consists of 4 focus groups with rural North Carolina support group participants using open-ended questions to engage participants in discussions about their experiences participating in a stroke peer support group. The study protocol was approved by the Institutional Review Board at Wake Forest University Health Sciences (IRB00040191).

**Study Sample**

The ongoing North Carolina Comprehensive Post-Acute Stroke Services (COMPASS) Study [28] identified 42 support groups statewide that are open to stroke survivors and their caregivers, 7 of which are in rural counties. The North Carolina Rural Center classifies rural counties as counties that have an average population density of less than 250 people per square mile [2]. We identified 5 additional rural stroke support groups in North Carolina through the American Stroke Association [29], National Stroke Association [30], Brain Injury Association of North Carolina [31], Community Care of North Carolina [32], and American Association of Retired Persons (AARP) [33].

We contacted the identified leader of each rural support group via e-mail and 2 follow-up phone calls (see Figure 1). After contacting the leaders of all 12 identified groups, we found that 3 of the groups were no longer active. Of the 9 active groups, 4 support group leaders agreed to invite the study team to their support groups, 3 declined, and 2 did not respond. The group leaders told regular participants when a focus group would be happening as part of their meeting and those who were interested attended. Participation was voluntary, and survivors and caregivers were not required to attend together. Written consent was obtained from all participants after explaining the purpose of the study.

One support group was led by a stroke survivor who was also the primary caregiver for her husband after a stroke, one was led by a nurse who was also a caregiver of a stroke survivor, and 2 were led by nurses who worked in patient education. Focus groups were conducted between October and December 2016 at the same time and location of regularly scheduled meetings to reduce travel burden on participants; they included 32 adult English-speaking stroke survivors and caregivers.

**Data Collection**

A semi-structured discussion guide was developed from existing stroke support group literature [19, 34]. To ensure consistency, one member of the research team (1st author) led all focus groups. Focus groups lasted 30–60 minutes and were audio-recorded and transcribed verbatim. Participants also completed short demographic surveys that included information on age, gender, race/ethnicity, marital status, and employment status. Participant and community identifiers were removed from all data to ensure anonymity. Each stroke support group that participated in the study is, to the best of our knowledge, the only stroke support group in the county and has regular attendees. To protect the members’ and the groups’ confidentiality, the counties included in this study remain held in confidence by the study team.

**Data Analysis**

For consistency, one member of the research team (1st author) conducted the thematic content analysis [35] to code and identify common themes. Transcripts were reviewed, and a preliminary codebook was developed using an inductive (open coding) approach. Questions about coding were discussed with all authors and resolved. Codes were refined and reviewed by all authors for possible connections, resulting in themes. Themes were determined by iterative review of coded text.
Results

Demographics

Participant demographics are shown in Table 1. Participants were an average of 67 years old, female, white non-Hispanic, married, and retired. Support groups had been meeting once a month or once every 2 months for between 6 years and 12 years, suggesting they were well institutionalized. While some participants had been attending their group since it started, or since the time their stroke occurred, most had not been in attendance since the groups initially formed. Typical support group meetings lasted 1–2 hours and included relevant educational presentations and discussion time. For the counties involved, 18%–22% of adults were smokers, 48%–67% had access to exercise opportunities, and 54%–59% had some college education. There were between 27 and 62 primary care physicians in each county [36].

Themes

Three central themes emerged and are discussed below. We include supporting quotations with unique identifiers to show representation across focus groups. “R” represents the respondent, and “G” represents the focus group.

Theme 1: Survivors and caregivers seek and receive knowledge about stroke and stroke recovery from stroke peer support groups. Participants shared that they initially attended stroke peer support groups to learn more about stroke and recovery. Receiving stroke and recovery related knowledge was important to survivors and caregivers, and difficult to locate. As participant R2G1 stated, “We all go different places and do different things but there is not really a great one source; you just can’t go to the kiosk and say, ‘I would like to have all of these resources for stroke survivors.’ It’s just not there.”

Many learned of the support group by word of mouth, either in the hospital, or through friends and family members. Receiving knowledge about stroke and recovery is one reason participants continued to attend support groups. Participant R5G1 noted, “I want to continue to recover. I don’t want to stop. I want to get stronger each day. I want to get all the knowledge I can possibly get.”

In all focus groups, participants reported that the information they received covered multiple stroke-related topics, such as diet, exercise, blood pressure management, stroke prevention and treatment, and stroke research. Having stroke-related knowledge not only made participants feel more informed, but also equipped them with concrete skills they applied at home to further their recovery. As participant R2G2 stated, “We have had different speakers on different subjects... We had a guy who came in and did exercises with us. Of course, we carried that on some at home.” Similarly, participant R1G3 noted, “You discuss things so you can be on

![FIGURE 1. CONSORT Diagram Detailing Focus Group Recruitment](image-url)
the lookout for anything that might be going wrong, or things you need to be looking to get checked out if you are having this symptom or that one that you might not have thought about before.”

Professionals such as physicians, therapists, and dietitians were sometimes invited to share their knowledge at support group meetings, often at the request of group members. Importantly, by meeting with other stroke survivors at different stages of recovery, participants gained knowledge from each other and felt empowered by providing help to their peers. Participant R2G4 said, “Each one of us helped somebody that was having a stroke. If we can do what we do and not be doctors, we can make a big difference right here.”

Theme 2: Stroke support group participants’ shared experiences cultivate a sense of community. Many participants shared feelings of frustration, depression, and isolation. These feelings stemmed from fear, lack of strength, and feeling overwhelmed by the challenges of adjusting to a new normal after stroke. However, sharing their experiences in peer stroke support groups was helpful. Participant R2G1 noted, “I felt that I was a little depressed before I came ... I found that being around other people that’s gone through the same thing helps.” Participant R2G3 said, “It makes you feel like you are not alone. Like there is someone else out there that is having the same problems and concerns that you do. And how they are dealing with it makes a difference.”

Additionally, the shared experiences enabled participants to empathize with each other and led to a sense of trust and understanding in the group. Participants unanimously agreed that they did not want people to feel sorry for them, nor did they want to feel sorry for each other. Rather, they wanted to build a sense of understanding and encouragement. Participant R7G1 stated, “You find very little sympathy, although there is a lot of empathy. That’s why this works so well. The last thing we really need is sympathy. We need people to understand.”

The sense of community was unique to the support group experience, and impacted participants’ lives beyond scheduled stroke support group meetings. Participant R3G2 noted, “I think this group has become more than a support group once per month. They are almost like family ... They have become friends and support outside of the meetings.” Additionally, participant R2G1 stated, “We love the relationships that we are building with other people. Even if we are in a store ... it’s like, ‘oh they are in our stroke group.’ It is important that outside of this room even, it reminds you that there are other people experiencing the same reconfiguration of their life that we are.”

Theme 3: Support outside of the peer support group is critical to recovery. Both survivors and caregivers discussed support systems outside of their support group as being essential to their recovery and well-being. “If I have a problem, the first thing I do is call my daughter or son,” stated participant R1G4. Participant R4G1 stated, “All of these folks have helped me, but I don’t have any problem at all saying ... her [stroke survivor’s wife] devotion is what has gotten me where I am. Everything else played a part, but the support at home is everything.”

Support from family and friends varied, from aiding with rehabilitation activities such as physical therapy to providing emotional support. Participant R3G4 said, “My daughter worked with the occupational therapist taking pictures of my husband from one step to the next to the next so he could have that to go over every so often.” Participant R2G1 noted, “There may be limits to the physical comeback that you can make but as far as keeping yourself positive, which is a constant battle ... this group and other avenues too: church, your other relationships with people ...That’s the biggest thing on keeping your mental positive attitude going, and in the final analysis that’s almost everything.”

Other participants also emphasized the importance of their churches in supporting them and maintaining healthy relationships during recovery. As participant R1G3 stated, “I go to church and my church family has helped me so much just being around other people. Me and my husband don’t have a lot of people that come and visit or anything, so it helps me to get out.”

Discussion

This study suggests that stroke peer support groups in rural North Carolina provide valuable opportunities for stroke survivors and caregivers to gain knowledge and skills from both health care professionals and each other. They help participants better cope with the effects of a stroke, while also building a unique sense of community based on the shared experiences of stroke survivors and their caregiv-
ers. Although participants discussed life after stroke, they did not discuss the uniqueness of the rural experience or compare it to the urban experience.

Because survivors and caregivers in rural areas have limited access to resources, having the opportunity to learn about stroke prevention and recovery from experts was highly valued. Many people expect increased knowledge from attending a support group, and increased knowledge is one way that peer support groups have been shown to mediate stroke recovery [19]. Additionally, fear of subsequent stroke was common among participants, as is documented in other studies [6-9]. Having knowledge about stroke prevention and recovery may be one way that participating in a support group reduces anxiety among participants. Sharing knowledge with other stroke survivors and caregivers gave participants a feeling of empowerment, which may be important in the psychosocial recovery process.

The theme of helping others and building a sense of community among support group participants is consistent with other study findings [4, 19]. Shared experiences enabled participants to feel less isolated [26] by providing them with opportunities to engage with people whom they felt could truly understand their circumstances. Social support provided by peers and close personal relations protects against poor psychosocial outcomes in stroke survivors [20], so presenting survivors and caregivers with opportunities to engage with peers may be another way in which support groups aid in the psychological aspect of recovery.

Both caregivers and survivors emphasized the importance of having a support system at home. While many caregivers provided support for the survivor, caregivers themselves may be lacking adequate support, so providing opportunities for them to learn from and connect with other caregivers is equally important. Additionally, understanding more specifically how support systems at home aid or fail to aid in recovery (e.g., because the caregiving spouse is elderly and also has significant health issues) is critical for being able to provide relevant information and support to caregivers.

Stroke peer support groups are sparse in rural North Carolina and were difficult for the study team to identify despite professional connections, time, and technology. Thus, locating one in these communities may be overwhelming for patients with brain trauma and families in crisis mode. Many stroke support groups meet during early afternoon hours, so the timing may deter working survivors and caregivers from participating. Creating more peer support groups across North Carolina that incorporate participants’ interest and feedback in the creation and implementation of these support groups is critical to developing sustainable groups that benefit and engage participants in ways that promote holistic recovery. In addition to creating new support groups, providers caring for stroke survivors should better link them to existing hospital-affiliated and community-based support groups. North Carolina stroke support groups are listed in an online community resource directory developed as part of the COMPASS Study, at https://www.nccompass-study.org/patients-and-caregivers/resource-directory/. At the time of publication, all stroke support groups listed in this directory are active.

Limitations

This study used a convenience sample of stroke survivors and caregivers who participated in support groups. Individuals who do not attend support groups may have different views or additional needs. Although the results are based on a relatively small sample size which may impede generalizability, the number of focus groups conducted is considered sufficient for discovering 90% of focus group themes [37]. Additionally, having a single coder may have introduced bias.

We did not collect the number of stroke survivors versus caregivers present at each group, nor did we conduct separate focus groups with survivors and caregivers. We also did not examine whether the benefits expressed by rural participants are also expressed by urban participants.

Although most focus group participants in this study were non-Hispanic whites, stroke is more prevalent in non-Hispanic blacks in the rural counties included in this study, and across North Carolina [38]. Therefore, these findings may not reflect the experiences of minority stroke survivors and caregivers. More should be done to ensure that all stroke patients are aware of stroke support groups available so that all can benefit, and future research can include diverse participants, especially those most affected by stroke.

No negative comments were made in any of the groups, but that may be a result of the focus groups occurring during regularly scheduled support group meetings.

Finally, we did not account for the different types of support groups in this study. Some support groups are primarily expressive in nature, while others serve a more educational role.

Future Research

Future studies could examine when support groups are most beneficial during recovery, how and to what extent support group participation mediates recovery and caregiver burden and explore effects of support group participation on functional status and recurrent stroke.

Conclusion

Peer support groups are a sparse, but critical resource for rural stroke survivors and caregivers because they provide information and community, assisting with recovery to health and independence. NCMJ

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