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Stroke Survivors: Needs, Wellness and Warning Signs in a Stroke Support Group Population

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Abstract

Aim: This study was designed to investigate needs of stroke survivors in stroke support groups, including their knowledge of warning signs, and the effectiveness of their care provider in acquiring rehabilitation services, from the perspective of the stroke survivor.

Background: According to the Centers for Disease Control and Prevention (CDC), almost 800,000 patients have a stroke each year, with 140,000 patients dying annually. Survivors are at high risk of a second stroke. Patients may have a host of differing needs to both maintain wellness and acquire the necessary knowledge to identify and prevent a secondary stroke. Research about the perspective of stroke survivors in a stroke support group concerning their needs, caregiver satisfaction, and wellness, is limited and in need of further study.

Design: A five-question pilot survey.

Methods: This study was conducted in the Stroke Survivors Empowering Each Other (SSEEO) stroke support group, a national stroke support network. Questions asked about patient knowledge of stroke warnings signs, their wellness needs, and the helpfulness of their caregivers in acquiring both. The study had 52 participants from 80 total invitees, a response rate of 65%, evenly distributed from ages 20 to 83. Forty-two respondents were survivors of an ischemic stroke, while 10 were survivors of a hemorrhagic stroke. There were 25 women and 27 males who participated in the study, and all were computer-literate and active members of the stroke survivor network. Forty-eight of the participants directly responded while a caregiver aided four respondents in accessing the study. Members suffered from a broad range of disabilities, including motor and minor language deficits.

Results: Patients reported a high level of knowledge of warning signs (95%); however only about half (53%) had ever had warning signs discussed with a care provider. Patients reported physical therapy (26%) and increased support group interaction (17%) as their primary needs. A majority of patients (52%) were somewhat or not-at-all satisfied with the assistance of their caregiver in achieving their wellness needs.

Conclusions: Patients reported a general lack of satisfaction with caregiver information about warning signs and in achieving wellness needs. However, patients said that they knew the warning signs of a stroke irrespective of their caregiver helpfulness. Patients reported primary needs for physical, speech and occupational therapy.

Clinical Implementation: Caregivers should consider increasing the amount of time spent discussing stroke warning signs with their patients. Caregivers should also consider attempting to ask stroke survivors as to their perceived needs actively and try to resolve them.

Background

Almost 800,000 patients suffer a new or recurrent stroke each year, with 140,000 patients dying each year [1]. The disease is broadly widespread, one of the most significant causes of death in the Western world, and a leading reason for adult placement in extended care [2]. These patients develop a wide range of social, economic, mental and physical needs [3], and may suffer from ailments including speech impediments, cognitive deficiencies, as well as a loss of social and familial connections [4]. In addition, survivors have an increased risk of recurrent strokes after their initial stroke [5].

After such an event, family and clinical caregivers may become primary caregivers for stroke victims [6]. The influence of caring for a stroke survivor may result in deleterious effects on these caregivers, such as negative impacts on mental health [7]. As a result, studies have noted the growing usage and effectiveness of stroke support networks, which may provide a host of educational and social support functions to survivors [8]. Survivors may also suffer a lack of continuous rehabilitative and psychological support, which may increase the importance of a social support group for stroke survivors [9]. These groups may even aid in rehabilitation with essential bodily functions such as eating and swallowing [10], displaying their important and growing roles in stroke survivor care.

The vast majority of research identifies the needs of stroke survivors through both a caregiver's [11] and clinicians' [12] perspective. A recent scoping review conducted by the National Institute of Health on research concerning needs of stroke survivors have highlighted the need for and importance of new studies which primarily use the perspective of stroke survivors directly, as well as integrates caregiver perspectives in instances where survivors may suffer cognitive deficiencies which impair them from an effective response [13]. In addition, additional research notes the need for research concerning the needs of survivors within stroke support group populations [14]. Current studies have primarily focused on informal support networks and highlight the importance of assessing the impact of a formal and established support network on the needs of stroke survivors [15]. These studies have also primarily focused on stroke survivors' perspective of specific disorders post-stroke [16], as opposed to beginning to investigate their general needs.

Aim

This study was designed to investigate needs of stroke survivors in a stroke support group, including their knowledge of warning signs, and the effectiveness of their care provider in acquiring rehabilitation services, from the perspective of the stroke survivor. The study utilizes the perspective of stroke survivors within stroke support groups, filling the need outlined by the literature referenced earlier, and framing the study's results as distinct from the pre-existing literature.

Methods

Design

The survey was conducted through the one-time

administration of a five-question quiz, of which the first two questions asked about their most pressing needs after a stroke. The next two questions asked for their knowledge of stroke warning signs, and whether their care provider had discussed these warning signs. Patients could also choose not to respond to questions. Each response was then categorized and computed as a percent out of the total responses. There were fifty-two anonymous participants, which included but were not limited to stroke patients, caretakers, and more.

All respondents were members of the SSEEEO support group. The SSEEEO is a stroke outreach and support group based in the Greater Chicago land area [17]. It maintains contacts with its survivor network and regularly hosts calls to aid care providers in improving their treatment of stroke survivors.

The questions were developed in consultation with the SSEEEO board, based on suggestions and feedback which the SSEEEO board had received from its members. This consultation period concluded with the piloting of these questions in four support group meetings, in order to assess whether patients and caretakers could sufficiently respond to the survey questions. The reviewers present during these meetings included the executive board of the SSEEEO, which is composed of former stroke survivors, current care providers and physicians, and ethics consultants. The board ranges from ages 27 to 72, and is comprised of four men and five women.

The study was initially sent to 80 patients through the SurveyMonkey distribution service. The survey was linked through the SSEEEO emailing list, which is only comprised of current SSEEEO members and the board. All patients were members of the SSEEEO support group, and all personal data was kept anonymous. The survey was conducted online through SurveyMonkey [18], with responses through all 50 states.

The online questionnaire was chosen for a variety of reasons. Firstly, the majority of SSEEEO members already use the online SSEEEO website in order to communicate with the stroke survivors' network; therefore, an online survey was most predictable to ensure the largest sample size. Online survey distribution methods have been effectively used in past stroke survivor studies [19], as well as highly effective for communication within stroke support groups [20]. Further results display that online distribution methods are effective for the reporting of personal needs of stroke survivors [21]. Second, the physical addresses of SSEEEO members are unknown to the board, as part of SSEEEO's commitment to personal anonymity, which precluded the possibility of other survey mediums. Third, the SSEEEO is a broad national stroke survivor network, and in-person interviews would be impossible given the expenses required to achieve such an outcome. Therefore, online survey distribution was the most promising review method.

Ethical considerations

After undergoing this initial stage of development, the final questionnaire underwent an ethics review period. This

period consisted of six meetings where the executive board, who discussed whether the questionnaire intruded on patient-doctor confidentiality, whether the questions were answerable by stroke survivors, and whether the survey's distribution method was efficient and limited bias. As part of informed consent, participants were informed that their participation would be anonymous and that they could choose to opt out of the survey if they desired.

Measures

All patients were asked the two primary wellness questions:

1. "How helpful have your physicians/care providers been with helping you improve your wellness after a stroke?"
2. "What are your primary need(s) to maintaining wellness after a stroke?"

The wellness questions assessed whether care providers had resolved perceived needs after a stroke. The first question was asked to identify whether care providers had been helpful in aiding survivor wellness after a stroke. The second question was designed to see if the care provider had different perceived needs, and in conjunction with the third question, see if care providers would help fill those needs as a result.

In addition, patients were asked two warning sign questions:

3. "Has your care provider discussed stroke warning signs with you?"
4. "Do you know the warning signs of a stroke?"

The warning questions were designed to test for a patients' knowledge of warning signs and their literacy in identifying the onset of a second stroke. The third question was designed to assess whether care providers had adequately discussed the warning signs of a stroke with the stroke survivors. The fourth question was designed to determine whether participants had independently acquired the knowledge of warning signs. Patients were allowed to choose as many responses as they wished for question one, which was done in order to collect knowledge of the multifaceted needs of stroke survivors. The remaining four questions only allowed one answer.

Finally, a fifth question to identify respondents was also used:

- 5 "Please tell us about yourself."

The final question was designed to help provide demographic data as to whether a stroke survivor was directly answering the study, or whether a care provider was assisting them during this survey.

Results

Demographics

There were fifty-two anonymous participants, including but not limited to stroke survivors and caretakers. Patients were also allowed to skip questions. None of them skipped question

1, while ten skipped question 2. Patients could write in their responses in addition to the responses provided initially in the survey. The SurveyMonkey data was conducted independently of any significant health systems. All patients were members of the SSEEO which standardized the prior knowledge held by survey participants. All respondents also attended outpatient clinics with regular checkups, as all SSEEO members attend these facilities.

The survey respondents were composed of survivors evenly distributed from ages 20 to 83. Forty-two respondents were survivors of an ischemic stroke, while 10 were survivors of a hemorrhagic stroke. There were 25 women and 27 males who participated in the study, and all were computer-literate and active members of the stroke survivor network. Forty-eight of the participants directly responded, while four respondents were aided by caregiver access the study and help comprehend its questions. Members suffered from a broad range of disabilities ranging from walking difficulties, minor language deficits, major motor deficits, and spasticity.

Responses

The direct results of the study are detailed in the figures 1-5.

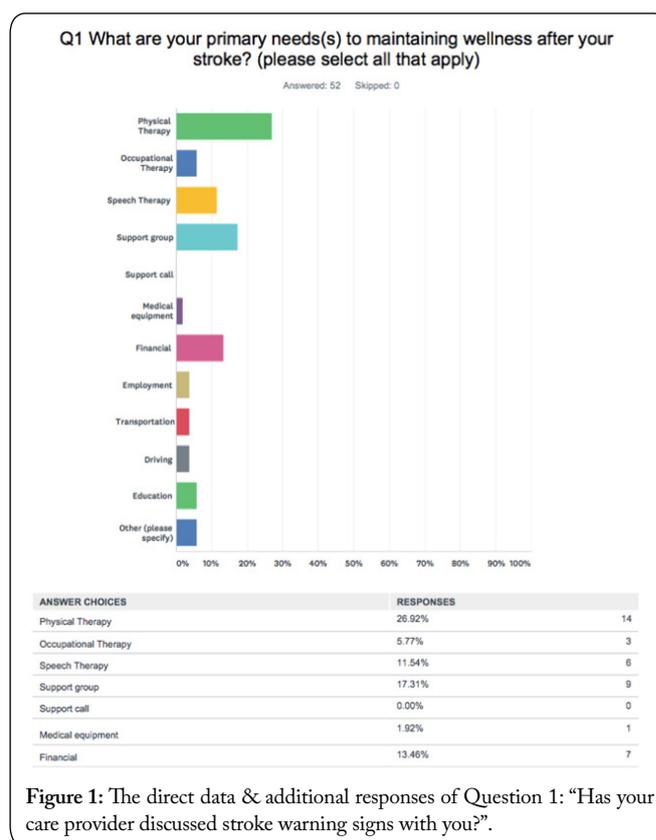


Figure 1: The direct data & additional responses of Question 1: "Has your care provider discussed stroke warning signs with you?"

Discussion

The study also only featured a simple five-question response, which may imply to some that the study lacks robustness. However, given that the study was responded to by stroke survivors, as well as caretakers acting on behalf of stroke survivors, a longer or more complex questionnaires

risks not only disincentivizing participation, but becoming incomprehensible given the possible cognitive impairment which stroke survivors may suffer. Given the population being questioned, the simplicity of the survey's questions is appropriate. Studies validate the effectiveness of this short questionnaire as effective when combined with an already social-integrated population, such as members of a stroke survivors' group [22].

integration of stroke survivor and care provider perspectives on their needs, wellness, and knowledge of warning signs, as well as the stroke survivor perspective on their caregivers' effectiveness. Most studies, as detailed in the introduction, also cite informal stroke support networks, which makes this study unique regarding helping study the needs and wellness in a formally established, regularly communicating community such as SSEEO. Furthermore, the majority of literature on the topic is primarily on specific disorders from which patients may suffer post-stroke, which makes this study distinct concerning the focus on the general needs of stroke survivors within the formally established support group population.

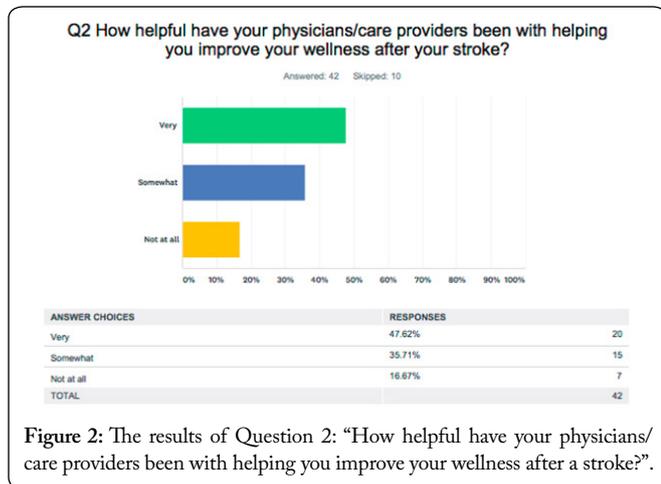


Figure 2: The results of Question 2: "How helpful have your physicians/care providers been with helping you improve your wellness after a stroke?"

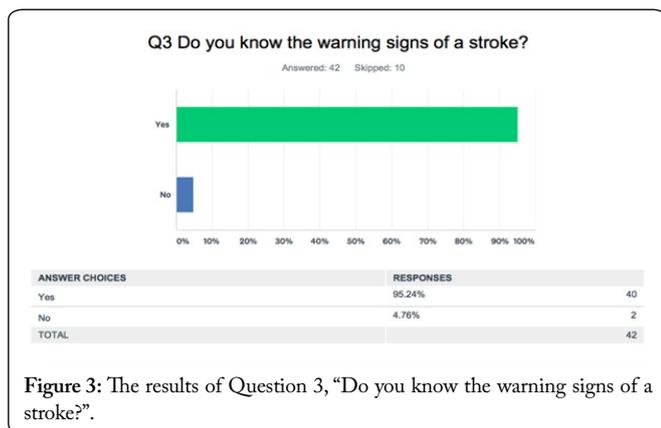


Figure 3: The results of Question 3, "Do you know the warning signs of a stroke?"

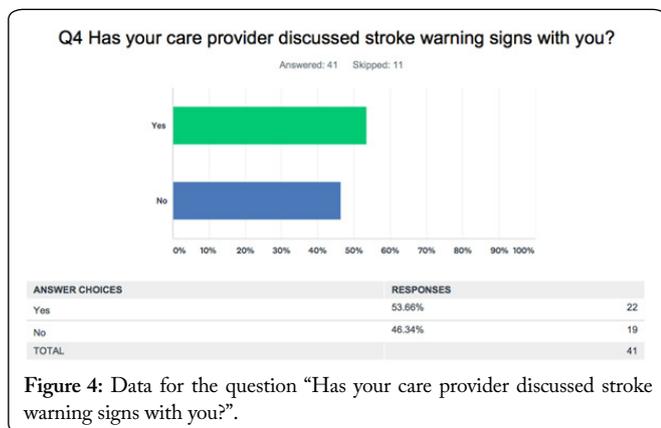


Figure 4: Data for the question "Has your care provider discussed stroke warning signs with you?"

The study places itself within the literature in a field of research which most reviews of literature deem unresearched, as detailed in the introduction. The studies cited above cite not only a need for new studies to perform concerning the

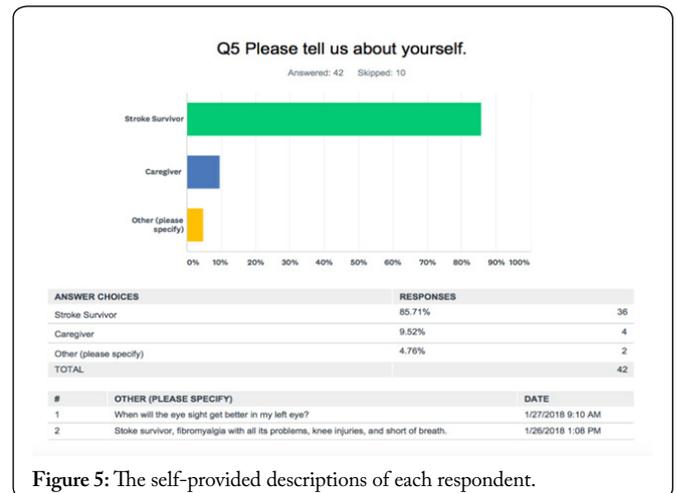


Figure 5: The self-provided descriptions of each respondent.

Limitations

The survey also suffered from certain limitations and technical errors. These technical errors included a single incident in which the patient wrote yes or no as an additional response because they were unable to select the yes-or-no response. Beyond this response, other methodological limitations were present. While the study was able to provide specific gender and stroke-type breakdowns, the study's anonymity regarding specific disability breakdown may have limited the study's generalizability. This anonymity leaves open the possibility that the prevalence rate of specific stroke disabilities may have affected the individual needs of survivors and their ability to comprehend caregiver treatment and warning signs, which would have altered the results.

The optional nature of the survey invites nonresponse bias. The study was initially sent to 80 members of the SSEEO chosen at random. Of these 80, 52 responded to the survey, yielding a response rate of approximately 65%. Out of the fifty-two respondents, none chose to skip Question 1. Ten of the 52 respondents of them decided to skip Question 2, yielding a response rate of approximately 80.7% for that question. Ten of them decided to skip Question 3, producing an identical response rate. Eleven chose to skip question 4, yielding a response rate of approximately 78.8%. As the nature of stroke warning signs is a uniform necessity for all stroke, this result implies that these ten respondents did not wish to share their results, which may be correlated with a negative response and lack of care-provider interaction over wellness needs.

Implementation and clinical practices

Assessing these various factors may help contribute to specific patient care plans and improved future consultation with health providers. These results may also help display the effectiveness of stroke support groups as a supplemental tool for stroke patients. Finally, this study may help provide some useful findings for how care providers should communicate information about stroke warning signs, as well as other important pieces of information, with stroke patients. In addition, the fact that all stroke survivors studied were a part of the SSEEEO support group may indicate that patients may have had greater knowledge about the warning signs, and treatment options post stroke than those who do not belong to such groups.

The results of the warning signs questions may indicate that care providers should spend more time discussing the warning signs of a stroke with their patients. These results may also suggest that they should conduct assessments the survivor knowledge of warning signs, and consistently provide reminders to ensure that patients are well-prepared to deal with a second stroke. These results may also indicate that caregivers and survivors should seek out secondary sources of information, such as a survivors' group, to reinforce the knowledge provided by physicians and other primary care providers.

The wellness results may indicate that primary care providers should spend more time communicating with stroke survivors to see if they perceive that their needs are being met. These results also reinforce the concept that primary care providers should ask stroke survivors about their most pressing need, as well as elaborate the rationale behind the primary care decisions to help stroke survivors feel as if their care needs are being met. These results may also indicate that a more multifaceted approach, including many different types of therapy and rehabilitation, may prove more effective in meeting perceived stroke survivor needs.

Conclusion

This study sought to investigate the needs of stroke survivors, their knowledge of warning signs, and the effectiveness of their care provider in acquiring rehabilitation services and knowledge of warning signs, from the perspective of the stroke survivor. This study utilized a five-question format in attempting to achieve its objectives.

In future studies, we would seek to compare patients who are not part of a stroke survivor's group like SSEEEO and those who are not. This goal is present for several reasons. Firstly, stroke survivors' groups provide free education to stroke survivors within their network, thus providing patients with new insights into their primary needs. Secondly, such a study could also compare the various services provided by a stroke survivors group and display their effectiveness. Thirdly, such a study could even compare the geographic services of a support group to survivors located nearby against those who are far away. An alternative route for future studies could examine specific types of strokes, and if survivors have a difference in

needs and warning signs between different types of stroke.

These new types of studies could prove essential for future investigations of stroke survivors' perspectives of their various needs and the knowledge that these survivors possess of stroke warning signs.

Acknowledgement

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