Stroke Survivors: Needs, Wellness and Warning Signs

Sarosh Nagar

Introduction: According to the Centers for Disease Control and Prevention (CDC) almost 800,000 patients suffer a stroke each year, with 140,000 patients dying each year. Those who survive suffer long-term physical and mental damage, including speech impediments, cognitive deficiencies, and more. Each patient is distinct, thus requiring a distinct treatment option, as well as patients may desire rehabilitation and treatment options outside of those already utilized/suggested by their care provider.

Objectives: An observational study to determine the needs of stroke survivors, their knowledge of warning signs and whether their care provider had been helpful in acquiring the treatment/rehabilitation services that the patients needed and informed them of stroke warning signs.

Design: Online SurveyMonkey distributed through the Stroke Survivors Empowering Each Other (SSEEO) Facebook page and website.

Participants: 52 anonymous participants; not limited to, but including stroke patients, caregivers, amongst others. All patients were members of the SSEEO support group.

Methods: One time administration of a five question quiz, of which focused on two questions related to their most pressing needs after a stroke with two more for stroke warning signs and such knowledge provided by care providers. Patients could choose not to respond to questions. Each response was then categorized, and a percentage of responses against the 52 individuals was computed.

Results: 40 out of the 52 individuals stated that they had knowledge of the warning signs of a stroke, whilst 2 out of the 52 individuals did not, and 10 chose to skip the question. However, out of the 52 individuals, only 22 individuals had been talked to about the signs of a stroke from their primary care physician, whilst 19 had not been talked to and 11 individuals chose to skip the questions. Due to this skip, the induced non response bias leaves open the possibility that a majority of people did not actually know about the warning signs of a stroke. 14 out of 52 survivors desired physical therapy, which was followed by 9 respondents desiring support group, 7 respondents desiring financial aid, 6 respondents desiring speech therapy, 4 respondents each wanted new education, and occupational therapy for their primary priorities. 2 respondents each listed driving, transportation and employment, 1 respondent required medical equipment whilst no respondents desired support. In addition, we received three written responses, which selected multiple categories as their top priority. The first three of these respondents named all of the following as priorities, but could not respond due to technical errors: physical therapy, occupational therapy, speech therapy, support group, support calls, medical equipment. The next respondent named physical and occupational therapy, speech therapy, and a support group as their top priority. The third respondent illustrated a need for all of the categories. No respondents skipped this question. In addition, when asked about the aid their care providers provided after their stroke, 20 respondents said care providers were ‘very helpful’, 15 respondents said ‘somewhat helpful’, and 7 respondents said ‘not at all helpful’, whilst 10 respondents skipped out of the 52 total respondents.

Q1. What are your primary need(s) in managing wellness after your stroke? (please select all that apply)

Exhibit 1 & 2 (above) - The direct data & additional responses of Question 1: “Has your care provider discussed stroke warning signs with you?”

Exhibit 3 (below) - data for the question “Has your care provider discussed stroke warning signs with you?”

Methods

52 participants

All personal data kept anonymous.

Conducted online through SurveyMonkey (responses through all 50 states)

To ensure the most accurate results, all patients were allowed to the 2 primary yes-no questions:

1. “Has your care provider discussed stroke warning signs with you?”

AND

2. “Do you know the warning signs of a stroke?”

Two additional wellness questions were added:

3. “How helpful have your physicians/care providers been with helping you improve your wellness after a stroke?”

AND

4. “What are your primary need(s) in maintaining wellness after a stroke?”

A fifth question to identify respondents was also used: “Please tell us about yourself!”

Patients were also allowed to skipped questions, however none of them skipped question 1, whilst 10 skipped question 2.

Patients could write in their own responses in addition to the responses provided originally in the survey. All patients voluntarily responded as well as the SurveyMonkey data was conducted independently of any major 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 various outpatient facilities. The survey was conducted through an open survey on Facebook, which members of the SSEEO could respond to at any time they choose. In addition, SSEEO members could also administer the survey through a caretaker. The survey also suffered from technical errors, including a single incident in which the patient wrote yes or no as an additional response because the options were not working.

Figure 3 (below) - The logo of SSEEO, who aided in conducting the survey.

Results


Acknowledgements: Christine Winiecki, Michelle Johnson, Phyllis Weiss & members of SSEEO Organization for survey and data collection.

Discussion

The optional nature of the survey invites nonresponse bias, as out of the 52 respondents, 10 of them chose to skip Question 2, related to the aid of care providers in improving wellness, although none chose to skip question 1, or their desired options for treatment/rehabilitation post-stroke. In addition, 10 of them chose to skip Question 3, related to the warning signs of a stroke, and 11 chose to skip question 4, or whether a physician discussed these warning signs. As the nature of stroke warning signs is a uniform necessity for all stroke patients and care provider interactions for wellness are a necessity for stroke patients, this result implies that these ten respondents did not wish to share their results, which may correlate with a negative response and lack of physician interaction over wellness needs.

Figure 4 (above) - the self-provided descriptions of each respondent

Conclusion

Analysis of the data indicates that patients have a plurality of needs and care providers have displayed varying degrees of aid. It also indicates that a plurality of patients have not discussed the warning signs of a stroke with their care providers. However, given the anonymity of patient data, it does not provide the primary factors of a correlation between various factors and level of disinformation.

Future Studies: In future studies we seek to compare patients who are not part of a stroke survivor's group like SSEEO and those who are not.

- Stroke Survivors groups provide regular information to stroke survivors within their network, thus providing patients new insights into their primary needs.
- Such a concept could also compare the various services provided by a stroke survivors group and display their effectiveness.
- Such a concept could also compare the geographic services of a support group to survivors located nearby against those who are far away.
- Future studies should examine specific types of strokes, and if survivors have a difference in needs and warning signs between different types.

The ultimate goal of this study is to assess the needs of stroke survivors after a stroke and the level of assistance provided by patient's care providers in achieving their wellness goals, as well as to assess the knowledge of stroke survivors and the information provided by their care providers about stroke warning signs. Assessing these various factors may help contribute to specific patient care plans and improved future consultation with health providers. In addition, the fact that all stroke survivors were apart of the SSEEO support group indicates that patients may have had greater knowledge about and access to the various treatment/rehabilitation options post-stroke.

References


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