

Abstract

Background: Approximately one-third of stroke survivors develop post-stroke depression (PSD), with over 50% of cases going untreated. PSD has been linked with poor cognitive and social functioning and an increased risk of stroke mortality. A survey was conducted to identify stroke survivors' mental health challenges to develop initiatives enhancing their quality of life and reducing their risk of further health complications.

Methodology: A survey was distributed in-person at Northwestern Medicine Lake Forest Hospital and online through a SurveyMonkey shared by Stroke Survivors Empowering Each Other (SSEEO), Inc. There were 42 anonymous participants, all of whom were stroke survivors. Participants were administered a six-question quiz, all questions requiring Yes/No responses with elaboration encouraged if the participant responded 'Yes'. These questions focused on potential emotional, behavioral, and communicative challenges; the number of strokes participants experienced; and antidepressant usage. The survey was conducted in both English and Spanish.

Results: 88% of participants reported feeling overwhelmed, socially isolated, and/or anxious following their strokes. Of those who responded 'Yes', 51% reported not seeking out or being offered support from their providers. 86% of participants reported that their ability to participate within their family or community changed. 83% of participants reported that their sense of independence changed. 71% of participants reported facing communication challenges. 48% of participants reported being prescribed antidepressants.

Conclusions: Analysis of the data indicates that stroke survivors face significant mental health challenges. Most participants reported feeling overwhelmed, isolated, and/or anxious. However, the majority did not receive or seek out support, nor were the majority prescribed antidepressants. This demonstrates a distinct need for more support services to be made available to stroke survivors. Specific areas of focus should be helping survivors regain independence and increasing community participation, specifically through helping them regain their ability to drive and making it easier for them to leave their homes.

Methodology

There were 42 participants in the survey, with all personal data kept anonymous. A six-question survey was conducted both in-person at Northwestern Medicine Lake Forest Hospital and online through a SurveyMonkey shared by Stroke Survivors Empowering Each Other (SSEEO), Inc. This survey was sent out in SSEEO's newsletter and was posted on social media. All participants were administered a six-question quiz, all of which consisted of Yes/No questions with elaboration encouraged if the participant's response was 'Yes'. Both English and Spanish versions of the survey were made available, with a Spanish translation available on the SurveyMonkey and a Spanish translator used in the hospital. All participants were stroke survivors who were either members of SSEEO and/or patients at Northwestern Medicine Lake Forest Hospital. All respondents also attended outpatient clinics with regular checkups, as all SSEEO members attend various outpatient facilities.

The six questions, as worded on the survey, are listed below:

- "Have you felt overwhelmed, socially isolated, and/or anxious following your stroke? If so, have you sought support from or been contacted by your healthcare providers?"
- "Has your ability to participate within your family or community changed? If so, please share any ways in which physical, cognitive, and/or sensory limitations may have played a role in this."
- "Has your sense of independence changed following your stroke, and if so, how has this impacted your daily life?"
- "Have you faced any challenges with effective communication post-stroke?"
- "Have you had more than one stroke? If so, how many?"
- "Have you been prescribed antidepressants after your stroke? Other than medication, what strategies (if any) have you found most effective in dealing with social and emotional struggles?"

Completing all of the above questions with Yes/No was required in order to successfully submit the survey; however, elaboration into answers was not required. Additionally, elaborations provided by the participants were thematically categorized and organized for each question in search of commonalities. This consisted of grouping activities into categories (i.e., golf, playing darts, etc. into 'hobbies') and searching for keywords in the responses to each question (i.e., driving, slurred speech, etc.) Using the Yes/No responses, percentages of participants who responded either 'Yes' or 'No' were calculated for each question.

Results

Have you felt overwhelmed, socially isolated, and/or anxious following your stroke? If so, have you sought support from or been contacted by your healthcare providers?

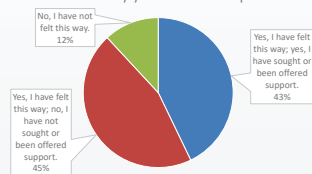


Figure 1: General Mental Struggles & Support

- 37 out of 42 participants (88%) felt overwhelmed, socially isolated, and/or anxious following their strokes.
- Of the 37 who responded 'Yes', 19 (51%) stated that they had not sought out or been offered support from their providers.
- Common themes reported among those not receiving support was feeling abandoned and having trouble reaching out to others for support.
- Among those who had received support in some capacity, a common theme was receiving it through their physicians, psychiatrists, and/or therapists.

Have you faced any challenges with effective communication post-stroke?

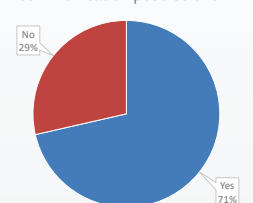


Figure 4: Effective Communication Challenges

- 30 out of 42 participants (71%) reported facing communication challenges
- Common themes were slurring speech and being unable to find the right words.

Has your ability to participate within your family or community changed? If so, please share any ways in which physical, cognitive, and/or sensory limitations may have played a role in this.

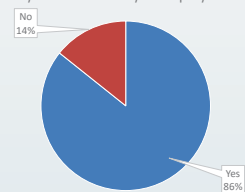


Figure 2: Family & Community Participation

- 36 out of 42 participants (86%) reported that their ability to participate within their family or community changed.
- Common themes seen in elaboration were fatigue, inability to travel, inability to participate in hobbies, and feeling disconnected from friends and family.

Have you had more than one stroke? If so, how many?

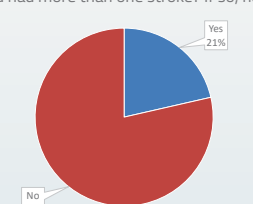


Figure 5: Number of Strokes Experienced

- 33 out of 42 participants (79%) only experienced one stroke, while 6 experienced two strokes, 1 experienced three, 1 experienced six, and 1 experienced eight.
- Among the 9 participants who had experienced >1 stroke, 7 (78%) responded 'Yes' to Q1, 7 (78%) responded 'Yes' to Q2, 8 (89%) responded 'Yes' to Q3, 8 (89%) responded 'Yes' to Q4, and 4 (44%) responded 'Yes' to Q6

Has your sense of independence changed following your stroke, and if so, how has this impacted your daily life?

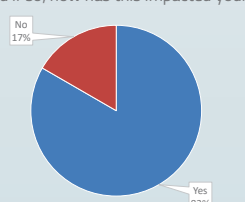


Figure 3: Sense of Independence

- 35 out of 42 participants (83%) reported that their sense of independence changed.
- A common theme seen in elaboration was being unable to drive/leave the house often.

Have you been prescribed antidepressants after your stroke? Other than medication, what strategies (if any) have you found most effective in dealing with social and emotional struggles?

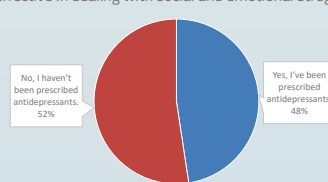


Figure 6: Anti-Depressant Usage & Coping Strategies

- 20 out of 42 participants (48%) reported being prescribed antidepressants.
- Aside from medication, common coping strategies mentioned were therapy and various forms of exercise.

Limitations

Sampling bias could contribute to the data as many participants learned of the survey through the SSEEO newsletter and, as such, were members of SSEEO. Stroke survivors who are members of a support organization might have received more supportive services in the past, which could have affected their current abilities and feelings; on the flip side, these individuals might have joined due to being more harshly affected by their stroke than other survivors. Additionally, social-desirability bias may have played a role in the participants' responses. The participants may have felt compelled to present themselves and their symptoms in the best light instead of being wholly truthful. However, the survey was completed anonymously to minimize participants behaving this way.

Conclusion

The ultimate goal of this study was to identify the mental health challenges stroke survivors face in order to develop initiatives to enhance their quality of life and reduce their risk of further health complications.

By assessing these various areas that stroke survivors often struggle in, it may be possible to improve the quality of resources made available to stroke survivors.

Across the board, analysis of the data indicates that stroke survivors face a variety of mental health challenges. The plurality of participants reported feeling overwhelmed, isolated, and/or anxious, yet the majority also did not receive or seek out support. This demonstrates a clear need for more support services to be readily made available to stroke survivors. Embedding mental health services within stroke clinics could be a potential solution. Specific areas of focus should be helping survivors regain independence and fully participate in their communities. This can be done through implementing programs that help stroke survivors return to driving and make it easier for them to leave their homes to travel and participate in community events. Antidepressants are prescribed at lower rates than participants reported facing mental health struggles, which is also something to consider going forwards.

Future Studies: In future studies, it would be beneficial to reach a larger, more diverse group of stroke survivors by including communities outside of the SSEEO group and the clinic. It would also be beneficial to collect demographic data, such as data on geographic location, race, and types of stroke experienced. Collecting antidepressant adherence data would also be useful in analyzing mental health struggles. Additionally, focusing on the specific areas of struggle participants mentioned when elaborating on their responses would be useful. For example, future studies could focus on stroke survivors' inability to participate fully in their communities due to various factors such as their inability to drive and difficulty participating in hobbies.

References

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