

The Impact Caretakers Have on the Recovery Process of Stroke Survivors

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ABSTRACT

This research aims to evaluate the impact of family care on the recovery process of stroke survivors. Using a comparative, evaluative ethnography, two surveys were created (one for stroke survivors and one for caretakers/family members of stroke survivors) to investigate the quality of life of stroke survivors post-stroke. Sixty-five responses were collected from these surveys, and qualitative and quantitative data were evaluated. Analysis disclosed that most stroke survivors experience significant life changes such as identity loss, physical disabilities, and relationship decline as a result of a stroke. With these challenges perceived as prominent in a survivor's life post-stroke, it is recognized that the presence of a caretaker is beneficial. However, the study acknowledged that variation between caretakers' perception of survivors' mental health and recovery process compared to survivors' self-assessments may need further exploration. This study aligns with previous literature as it explores the positive influence of family care and digs deeper into what effects a caretaker will have. It is recognized that although caretakers positively affect recovery experiences, social connections, and more, there are no guarantees in the rehabilitation process. Future research should explore the specific correlations between survivors' and caretakers' interpretations of recovery, as well as look deeper into the long-term effects of a stroke on a survivor's identity and mental well-being. Overall, the conclusions expressed that comprehensive support systems are significant when hoping to enhance the recovery process and improve the quality of life for stroke survivors.

Introduction

It has become apparent that stroke survivors' lives are often altered post-incident. This may be a forever thing, but it may be temporary. What factors take place in a fast and robust recovery? Is family care beneficial? How does the mind of a stroke survivor change? There are so many questions but so few guarantees during this process. My research is aimed to answer all of these questions.

The mental health of stroke survivors and the people around them, such as family, friends, caretakers, and more, all play a part in recovery. A lousy mindset can change the whole process of recovery for the patient. A good mindset and solid mental health can set a patient up for success. One factor that may play into this is family care. There are benefits and downfalls to family care, but the essential question is which will power over one another in the life of a stroke survivor.

While many people have researched the recovery process of stroke survivors, I am explicitly researching the recovery based on how family care has affected them. I will study the recovery process and length, the mental health, and the relationships between survivors and the people around them.

Literature Review

Many authors have concluded that depression occurs in lots of stroke patients during recovery (Northcott, Moss, Harrison, et al. 2016; Medeiros, Roy, Kontos, et al. 2020). The aspect of communication in a patient's social life affects

their mental health (Northcott, Moss, Harrison, et. al 2016). It is explained that a lack of social support and network will often result in depression. This correlates to the article "Post-stroke Depression," as it demonstrates that Post-stroke depression (PSD) is widespread among survivors. It can be associated with higher chances of death, slower recovery, more noticeable cognitive deficits, and lower quality of life than stroke without depression. It also explains the treatments and results of PSD. There are lots of negative results of PSD; some include large or multiple strokes, poor social support, and pronounced disability. Both authors emphasize that mental health is highly affected by stroke patients and can significantly affect their social abilities (Northcott, Moss, Harrison, et al. 2016, Medeiros, Roy, Kontos, et al. 2020). This social decline is often because relationships with people in the stroke survivors' lives tend to fade away.

Various authors have recognized the importance of social interactions and family care during a stroke patient's recovery (Anderson, Whitefield, 2012; Davoody, Koch, Karkau, et al., 2016). Stroke survivors often experience identity loss because their minds change so much (Anderson, Whitefield, 2012). This is why it is so vital that survivors have social support during recovery, as it is the foundation upon which survivors rebuild skills to engage with the world. It was concluded that social support helped them regain a position in society. This was also explained in the article, "Post-discharge stroke patients' information needs as input to proposing patient-centered eHealth services," as the needs of different stroke survivors in different home circumstances are recorded. They conclude that survivors are best off with information about their recovery and healthcare and community services guidance. Both authors show the discoveries of how stroke patients are proven to be more successful in society if they have access to healthcare or family caregivers (Anderson, Whitefield, 2012; Davoody, Koch, Karkau, et al., 2016).

It has become apparent to many authors that relationships in general, whether it be with family members, caregivers, or even friends, are critical and give stroke survivors the best chance of complete recovery (Sarre, Redlich, Tinker, et al. 2014, Young, Lutz, Creasy, et al. 2014). They depend on their relationships with their caregivers or family members and rely on them to support and help them recover (Young, Lutz, Creasy, et al. 2014). There are lots of different relationships that are beneficial for stroke survivors. Friendships are essential during stroke recovery as they spark hope in survivors (Sarre, Redlich, Tinker, et al. 2014). Relationships between family members and stroke survivors can decline as there can be an identity change. This often hurts the recovery of survivors as it holds them back from being themselves and changes their lives. Both authors illustrate the importance of relationships between stroke survivors and people close to them (Sarre, Redlich, Tinker, et al. 2014; Young, Lutz, Creasy, et al. 2014).

Research

Some studies show that caretakers can leave stroke survivors constantly depending on the people around them. This can often result in them being unable to go back to their ways of life pre-incident entirely. However, some data shows that caretakers have brought extreme assistance to stroke survivors as they were able to help survivors through the process of recovery and get them back to normal at a very high speed. So, this leads up to the question, how does family care affect stroke survivors' minds and relationship quality post-incident?

To answer this question, I will analyze my data using a comparative, evaluative ethnography of stroke survivors' lives post-incident. This style of research will help me compare stroke survivors' lives before and after the stroke. It will also allow me to evaluate the customs of these stroke survivors and how they have adapted depending on their resources.

Methodology

The method used for my research was a mixed method. The research heavily uses qualitative data, but some quantitative data is used to analyze people on a scale. The mixed method builds my research as I can study the feelings of people and how their lives have changed on a qualitative basis and group people based on the rankings of their feelings

or rankings of the recovery process on a quantitative basis. I created online surveys, one for stroke survivors and one for caretakers/family members, to collect all of this information. These surveys allowed me to keep interviewees anonymous so they could answer in the most honest way possible when asked personal questions. I gathered this data and compared my results to the results of other researchers. However, I also added to their research as I studied how family care has added to the recovery of stroke survivors.

Qualitative Method

My survey's qualitative questions were short answer questions and multiple choice questions. Throughout the survey, participants were asked personal questions about their life and their feelings post-stroke. The survey for stroke survivors had qualitative questions such as:

1. Do you personally feel a difference in your life since the stroke? Why or why not?
2. How would you interpret your relationships with the people around you?
3. Do you or did you have a caretaker?

The survey for caretakers/family members had qualitative questions such as:

1. Is your relationship with this person weaker post-stroke?
2. How has your life changed as a result of the stroke?
3. Do you believe that the stroke survivor having a caretaker or lack thereof has affected their recovery? Why?

The qualitative method added positively to my research as it allowed me to explore the quality of life of stroke survivors, depending on whether they had a caregiver or not.

Quantitative Method

The survey's quantitative questions were put on a Likert scale where participants would rank their thoughts. These questions asked about the recovery process of survivors and the changes in mental health or ability of stroke survivors or their caretakers. Some quantitative questions that are included in the survey for stroke survivors include:

1. How would you rate your mental health?
2. How would you rate your recovery?
3. How would you rate the support from people around you during your recovery?

Some quantitative questions that are included in the survey for caretakers/family members include:

1. How would you rate the change of your relationship with this person?
2. How would you rate the change of ability in the stroke survivor?
3. How would you rate the amount of support that this person has needed?

The quantitative method added to my research positively as it allowed me to group people based on the statistics of their recovery. The data helped me differentiate between stroke survivors who had or have caretakers and stroke survivors who don't have caretakers.

Survey

The survey started by informing all participants that it was voluntary and anonymous. No identity information was recorded, such as names, emails, phone numbers, or more. Using the survey as my primary source of data gathering was a good choice for my research project. It was easy to create and a quick way to collect information, as participants only had to answer and submit a few questions. The survey was an ethical choice because I was candid with my intentions and stayed true to my word as I kept every answer extremely anonymous. Choosing to do an interview or to observe stroke survivors secretly would have been less ethical as I would have had to be very secretive and not express my intentions.

Rejections

While choosing the methods I would use for my research, I had to study each technique and find the best fit for my project. I had to reject some methods and narrow it down to using a survey with both qualitative and quantitative questions. Some of these methods that I rejected include interviews, records, and experimental groups. Data from interviews could have worked for my study, but interviews are only sometimes reliable because participants might feel pressured to answer a certain way. Using records such as videos, pictures, audio, or textual evidence wouldn't resonate with my study. I am researching the lives of stroke survivors in the present time, so using records from the past wouldn't do my study any good. Lastly, an experimental route wouldn't fit my research because no experiment needs to occur. The use of surveys seemed to be the best-fit research method for my study as it could be sent out to a large number of people, ensuring more reliable results and was an easy fit for the data I needed to collect as it asked simple questions and that could give me results very quickly.

Results

Among the two surveys sent out, sixty-five responses were recorded. Thirty-nine people responded to the survey for stroke survivors. Twenty-six people responded to the survey for family members or caretakers. Results from the survey for family members/caretakers showed that all of the quantitative questions, questions where people rated their feelings on a scale, were answered by all twenty-six participants. However, the qualitative questions, where people had to write out short answers, had a variety of responses but only partial participation. Results from the survey for stroke survivors showed that neither quantitative nor qualitative questions had full participation. All of this was taken into consideration as I recorded my data to answer my research question, "How does family care affect stroke survivors' minds and relationship quality post-incident?" All of these responses are used to find the benefits and downfalls of family care and to find a better interpretation of what allows stroke survivors to return to the life they knew pre-stroke. This data provides information to allow a smoother recovery process for stroke survivors in the future as there is an idea of what helps and does not. My findings did help prove my hypothesis to an extent.

Stroke Survivor Survey Results

How long ago did you have your stroke?
39 responses

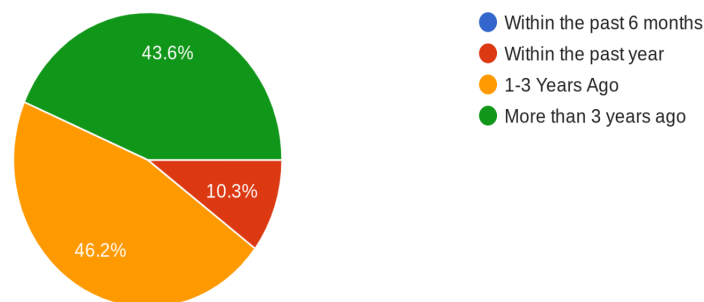


Figure 1. Time Passed Since Stroke. This shows the responses to the question, "How long ago did you have your stroke?" The data shows that the time since participants had the stroke varies. This can explain why different people are in various stages of the recovery process. Most participants have been in recovery for a while, as their stroke happened at least a year ago.

Did you work after your stroke?

38 responses

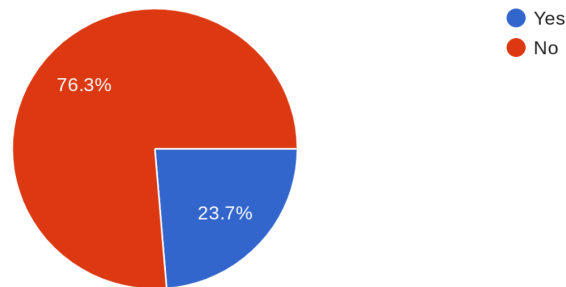


Figure 2. Employment. This shows the responses to the question, "Did you work after your stroke?" This data indicates most participants were unemployed after a stroke, but about ¼ could work again.

Does the participant have physical disadvantage due to stroke?	Frequency	Examples
YES	37/39 = 94.9%	"Hemiparesis (left side paralysis of arm and leg). Doctor says I have vascular dementia" "I have brain damage and am partially disabled. I can walk short periods."
NO	2/39 = 5.1%	"No, I am able to do everything I did before my stroke."

Figure 3. Qualitative Data Recording Physical Disadvantages. This shows that lots of stroke survivors experience physical disadvantages. 94.9% of participants wrote that they experienced some disability, whether it be mental or physical. Only 5.1% of participants came out of recovery entirely unharmed.

Do you or did you have a caretaker?

39 responses

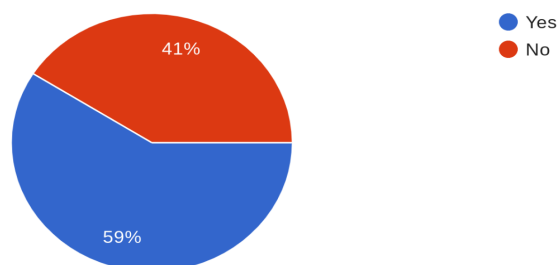


Figure 4. Caretaker Involvement. This shows the responses to the question, "Do you or did you have a caretaker?" This data shows that lots of participants had a caretaker, but 41%, almost half, did not.

How would you rate your recovery?

39 responses

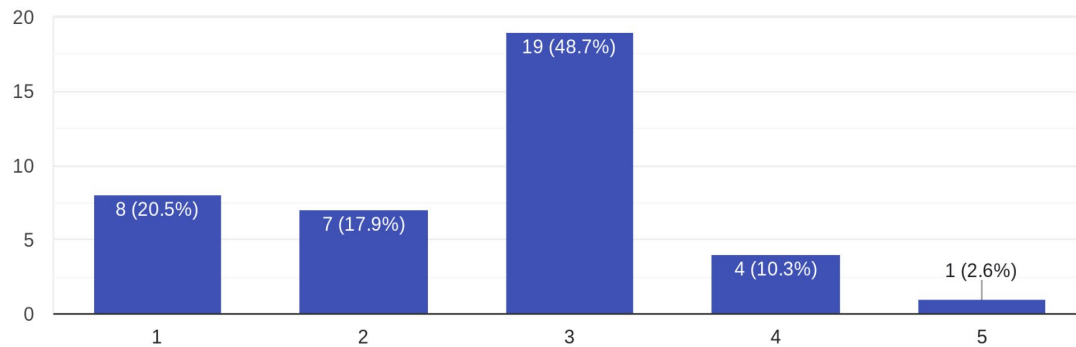


Figure 5. Recovery Process. This shows the responses to the question, "How would you rate your recovery?" The graph explains how stroke survivors rated their recovery on a scale between 1 being a slow/hard recovery and 5 being a fast/easy recovery. Most participants rated their recovery as 3 out of 5.

If you do/did have a caretaker, do you believe that you are at an advantage?

30 responses

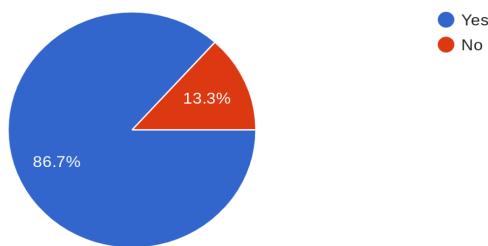


Figure 6. Advantages of Caretakers. This shows the responses to the question, "If you do/did have a caretaker, do you believe you are at an advantage?" This data indicates that a great majority of stroke survivors who did have caretakers believed that it was beneficial.

Family Member/Caretaker Survey

What is your relation to the stroke survivor?

26 responses

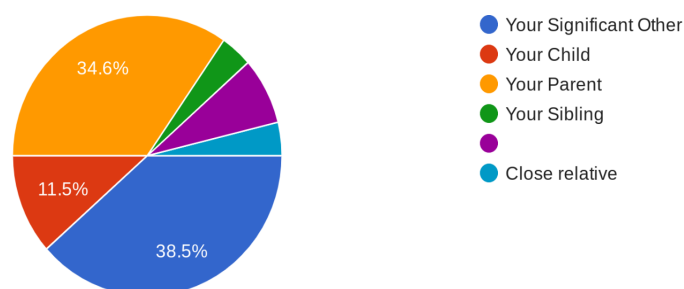


Figure 7. Relations. This shows the responses to the question, "What is your relation to the stroke survivor?" This data shows a variety in caretakers' relations to stroke survivors. Significant others or children of stroke survivors mainly took this survey..

Comparisons Between Figures 8 and 9

Do you consider yourself close with this person?
26 responses

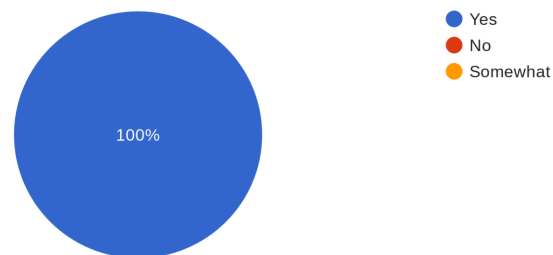


Figure 8. Relationship Status. This shows the responses to the question, "Do you consider yourself close to this person?" The data shows that 100% of the participants answered that they have a close relationship with the stroke survivor.

Is your relationship with this person weaker post-stroke?
26 responses

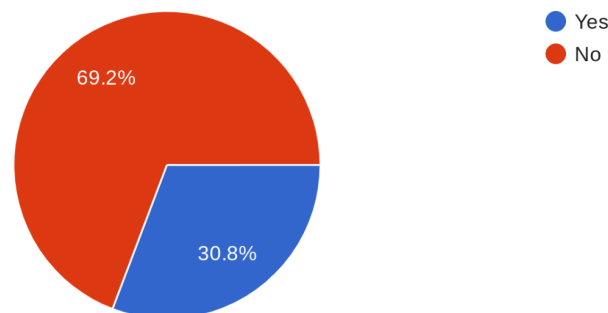


Figure 9. Change in Relationship. This shows the responses to the question, "Is your relationship with this person weaker post-stroke?" The data explains that although all twenty-six participants consider themselves close with the survivor, 30.8% have recognized that the relationship has weakened.

Comparisons

	Life Changes	Frequency	Examples
Stroke Survivor	YES	37/39 = 94.9%	<ol style="list-style-type: none"> 1. "I'm not as outgoing and get frustrated easily. Talking and keeping up with conversation is difficult." 2. "Yes, a whole different person. Miss the old me." 3. "Yes. I feel lost. I am not the person I was pre-stroke and I miss being able to do the things I once did."
Caretaker	YES	21/26 = 80.8%	<ol style="list-style-type: none"> 1. "I have become more of a caretaker than a spouse." 2. "I don't do as much with my family and friends. I feel like if I'm not there with him, something will happen." 3. "I'm now taking care of someone else, reduced income, reduced time to myself, Loss in partner as I knew him."

Figure 10. Qualitative Data Recording Dramatic Life Changes of Stroke Survivors and Caretakers. This shows that both stroke survivors and caretakers of stroke survivors feel as though their lives have changed as a result of the stroke. 94.9% of stroke survivors said that there has been a dramatic change in their way of living since having the stroke, and 80.8% of caretakers said the same thing.

Comparisons Between Figures 11 and 12

How would you rate the mental health of the stroke survivor?

26 responses

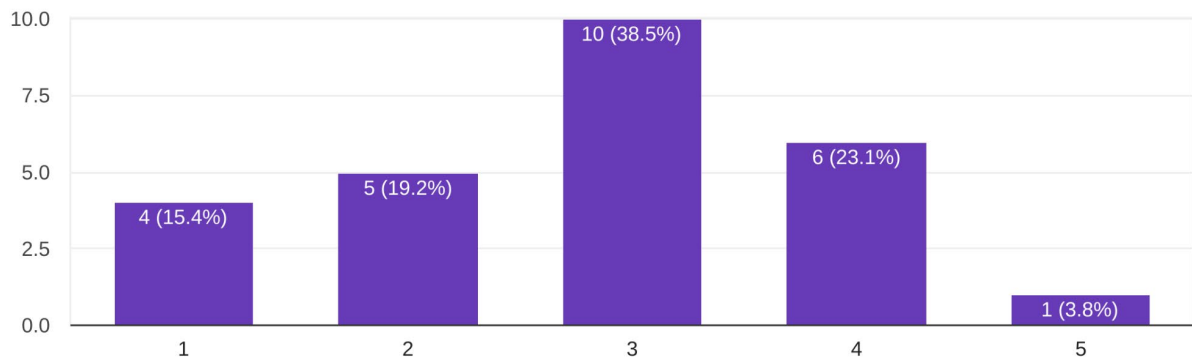


Figure 11.

How would you rate your mental health?

39 responses

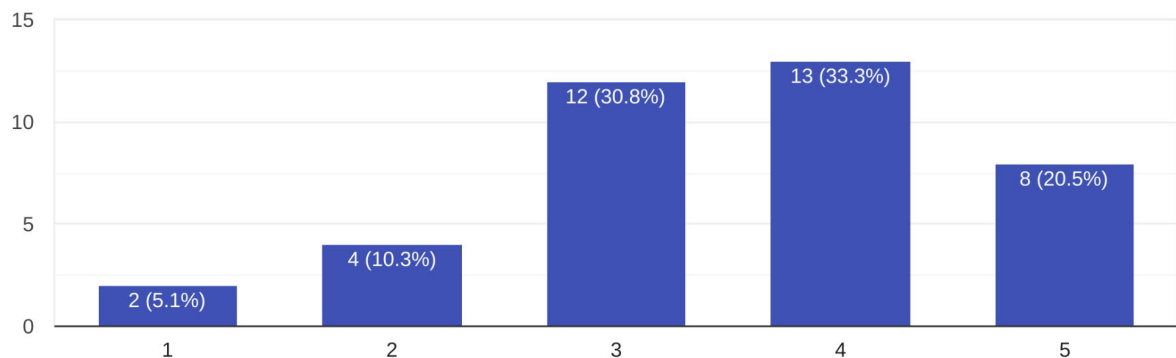


Figure 12.

Figure 11. Caretaker Interpretation of Stroke Survivor Mental Health. This shows the responses to the question, "How would you rate the mental health of the stroke survivor?" This graph explains how caretakers rated the mental health of stroke survivors on a scale between 1 being struggling and 5 being thriving. The majority of caretakers rated stroke survivors' mental health as a 3 out of 5. **Figure 12.** Stroke Survivor Interpretation on Their Own Mental Health. This shows the responses to the question, "How would you rate your mental health?" The graph shows how stroke survivors rated their mental health on the same scale. The majority of stroke survivors rated their mental health between 3 and 4 out of 5.

Comparison of Figures 13 and 14

How would you rate the amount of support that this person has needed?

26 responses

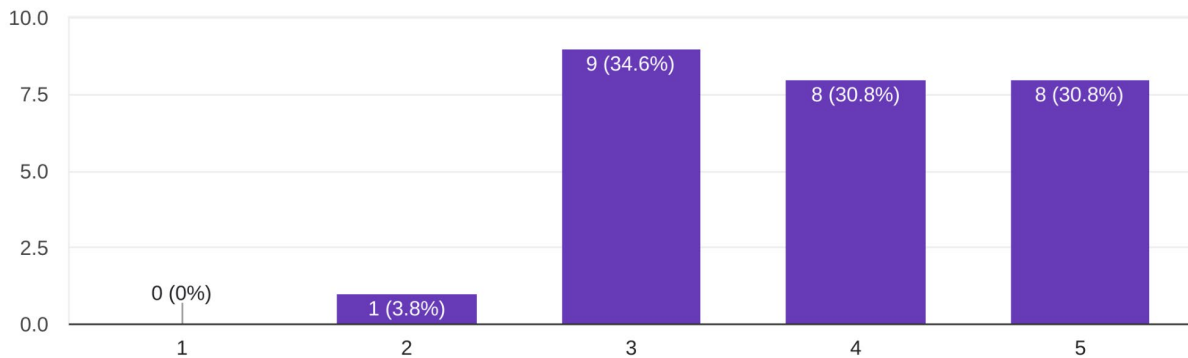


Figure 13.

How would you rate the support from people around you during your recovery?

39 responses

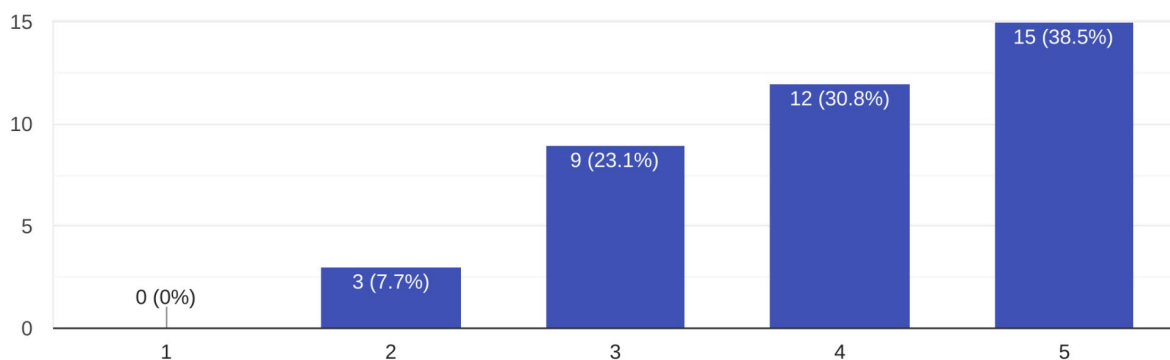


Figure 14.

Figure 13. Caretaker rating of support given. This shows the responses to the question, "How would you rate the support this person has needed?" The graph explains how caretakers rated the support the stroke survivor needed on a scale, with 1 being no support and 5 being an extreme amount of support. Most caretakers rated the support between 3, 4, and 5 out of 5. **Figure 14.** Stroke Survivor Rating of Support Received. This shows the responses to the question, "How would you rate the support from people around you during your recovery?" The graph shows how stroke

survivors rated the support they received on the same scale. Most stroke survivors rated the support received a 5 out of 5.

Discussion

The results from this research prove that the quality of life for stroke survivors undergoes significant changes after experiencing a stroke, but having a caretaker gives an advantage during recovery. Results showed that even survivors who had a stroke three or more years ago continue to face challenges. Survivors explained that their lives are much slower, complex, depressing, and exhausting. When stroke survivors were asked, "Do you personally feel a difference in your life since the stroke? Why or why not?" about 94% of participants felt like entirely new people, as I explained before. Some examples of responses were:

Participant 3	Participant 9	Participant 21
"Yes. I was very active physically, now I am severely limited with hemiplegic and spaciality"	1. "Yes. I'm always tired and have to have my caregiver help me do simple tasks like putting on a bra or clean up. I'm uncoordinated and unbalanced but can still walk. My memory is all REALLY bad. I lose and forget things pretty quickly"	"Yes. Loss of job; first year I battled a sense of identity. If I can be a good husband or father. Doing better now but still improving my mindset."

Figure 15. Only 2 out of the 39 survivors responded that their life did not change, and their responses were:

Participant 7	Participant 38
1. "Not really. I wasn't working before either"	2. "No, not big changes."

Figure 16. Going back to day-to-day working life for stroke survivors is very rare. Having a stroke is a life-changing experience, and side effects may continue throughout the rest of the survivor's lifetime. Most stroke survivors who seem to have significant life changes are also struggling with their mental health. Mental health plays a huge role in recovery, and this data shows that most survivors struggle greatly, and it sets them back in recovery. Although the recovery process seems to be hard, results have shown that no matter what, caretakers are recognized as beneficial during this time. Most stroke survivors rated the support they needed and received in recovery very high. However, no matter the support from people around them, the recovery process seemed to be rated as very slow and complicated. About 40% of participants explained that they were not entirely done with recovery even after having the stroke over a year ago. While the lives of stroke survivors are proven to be altered in this research, relationships between stroke survivors and the people around them also seem to be at risk. When stroke survivors were asked the question, "How would you interpret your relationships with the people around you?" responses varied. There were quite a few people

who responded simply with "Good," "Fine," or "Normal." However, there were a vast number of responses that resembled difficulty. Some responses were:

Participant 2	Participant 5	Participant 18
"It's pretty sad truthfully not being with my ex fiancé and my kids"	"My friends have all disappeared. I can't visit them and after several years, they no longer visit me."	"I keep to myself."

Figure 17. The strength of relationships could be seen as an outcome of the stroke survivors' mental health. When stroke survivors rated their mental health lower, they also responded that relationships were declining. Data shows that stroke survivors who were in bad places mentally, struggling with identity, and at a physical disadvantage seemed to have lost a strong connection with the people around them. In both surveys, participants were asked to rate the mental health of stroke survivors. When caretakers rated the mental health of stroke survivors, the graph was skewed to the left, meaning they were rating mental health more as struggling than thriving. When stroke survivors rated their mental health, the graph was skewed more toward the right, indicating better mental health. The caretakers seem to underestimate stroke survivors. For future studies, it could be essential to analyze this and find out exactly why caretakers, people who are spending a tremendous amount of time with the survivor, are rating the survivor's mental health lower than what the actual survivor interprets it as. Another aspect that both caretakers and stroke survivors were asked to rate in the survey was the amount of support given or received during the recovery process. Caretakers rated the support the stroke survivors needed very high, indicating that a significant amount of support was given. Stroke survivors also rated this very high. With both caretakers and stroke survivors rating this support with high numbers, it can be assumed that for stroke survivors to have a strong recovery, their support system needs to be very strong.

My research somewhat contradicts previous research in this field when talking about the mental health of stroke survivors during recovery (Northcott, Moss, Harrison, et al. 2016; Medeiros, Roy, Kontos, et al. 2020). Although my research did indicate that stroke survivors are in a rough state of mind during recovery, none of the participants talked about having PSD (Post-Stroke Depression). I did expect the participants to rate their mental health lower, but most results show high ratings of mental health. This may be because most of my participants also stated they had family and caretakers around them, but their study did not measure that. Although my research does contradict this study to an extent, my research does align with previous studies about family care and social interactions during recovery (Anderson, Whitefield, 2012; Davoody, Koch, Karkau, et al. 2016). Responses did show that survivors felt a loss of identity after their stroke because their minds had gone through such a traumatic event. My research and previous research have concluded that allowing these survivors to establish social connections with people around them will enable them to regain that sense of identity and their true selves. My research and previous studies show that a caretaker's presence significantly influences stroke survivors' recovery (Sarre, Redlich, Tinker, et al. 2014; Young, Lutz, Creasy, et al. 2014). Both caretakers and stroke survivors rated the support they needed during recovery very high and explained that they had gotten farther in recovery solely because of the help from caregivers.

While there are many similarities between my research and previous studies, there are also some disparities. The stroke survivors who responded to my survey seemed to be in a better state of mind than those studied in other research (Northcott, Moss, Harrison al. 2016; Medeiros, Roy, Kontos, et al. 2020). My data has concluded that stroke survivors' minds and relationships with people around them are altered by stroke. However, with the involvement of a caretaker, there are higher chances of a more fulfilled recovery. While I can conclude this from my research, studying

such a complex process, such as a stroke survivor's recovery through a survey, may only grasp some of the specific details that could help me answer this question.

Conclusion

My hypothesis, expecting the help of caretakers in a stroke survivor's recovery process to be highly beneficial and give stroke survivors a fast and easy recovery, has been proven in some measure. From the results of my survey, I concluded that the process of recovery for stroke survivors can never be predicted. There is no exact way to ensure a strong recovery, even with the help of a caretaker. The distinction between the recoveries of people with and without caretakers is obvious. Since 59% of the participants had caretakers, and about 87% of those said that caretakers were extremely helpful, the ratings for the ease of recovery would be higher. However, results from other questions in the survey explain that no matter if the survivor had a caretaker or not, they were still struggling physically, mentally, socially, and more. Although caretakers do not guarantee a strong recovery, they are recognized as huge contributors. Not only did stroke survivors explain the advantages of caretakers, but caretakers were also asked what they thought was beneficial for stroke survivors in the recovery process. 24/26 caretakers responded, explaining that even though survivors may not have made a full recovery and continue to struggle, they have seen so much improvement and can recognize that the care they give these survivors dramatically benefits them. Using a mixed method did advance my research as it broadened the spectrum of results I could receive. My research was more heavy on using qualitative data as most questions on the survey asked participants to express their feelings. However, rating concepts such as emotions and relationship changes on a scale added greatly to my study.

Limitations in Research

The results from my research using a survey successfully helped answer my research question, but there were a few limitations within my study that should be discussed. First, there is no way to ensure complete honesty when using surveys as a research method. Although I did take precautions, such as making the surveys optional and anonymous to avoid dishonesty as much as possible, there still is no guarantee. Second, there was no way to pair a specific stroke survivor with their caretaker in the surveys while keeping anonymity, so all of the data was not correlated in a way where I could see how one person's recovery was self-rated and rated by their caretaker. Not all questions were answered correctly or answered in full by all participants. While there are limitations, the data I did receive gave me enough information to make conclusions about the research.

Implications

It can be concluded that family care and the support of a caretaker are critical during the recovery process of a stroke survivor. This research allows caregivers and family members to gain a deeper understanding of the challenges faced by stroke survivors. With the knowledge that mental health strongly influences recovery, it could be beneficial to incorporate mental health programs in rehabilitation centers. During rehabilitation, emphasis on physical therapies is essential to regain the survivor's full ability. Identity loss among stroke survivors seems to be very common and highlights the necessity for very personal and empathetic care during the recovery journey. Intensive care for most stroke survivors may extend past their recovery process. The minds of stroke survivors seem to be forever altered in many different ways. So, survivors should have access to ongoing mental health resources and caregiver assistance even after their immediate recovery in order to create a stable life post-stroke. The recovery process for stroke survivors is not as extensive of a topic of conversation as it should be. They need more awareness and help to recover to the best of their ability.

Future Research

Research that could be done to advance my findings is focusing on how stroke survivors and their specific caretakers compare different aspects of recovery. I could not pair survivors with their caretakers, so I could not find a particular correlation between their interpretations of recovery. This study could be interesting to see how they see the recovery differently and what ideas both have to improve. This may help find a specific plan for each survivor that incorporates both recovery ideas. It could also be helpful for researchers to focus more on the study of identity loss and how it plays a role in their lives after recovery. The participants from my study who explained a feeling of identity loss said that they were able to overcome it, but there may be instances for other people where they aren't able to overcome it. Studying identity loss in stroke survivors that continues throughout the rest of their lives could be essential to help find a way to limit it. Another section of research could focus on the recovery process based on the type of stroke and the cause of it. This may allow for a different point of view when asking the questions in the survey. Some people may consider their stroke more mild than others, so it could be helpful to see how the recovery process for different levels of strokes contrasts. A mixed method could benefit all of these studies as it would allow questions to be asked and understood differently. Recording data in a way where people can express their feelings through words and rate their recovery process or specific aspects of relations and feelings adds to the research. This broadens the results and allows more room for different interpretations.

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