



April 2021

A Qualitative Study Investigating Stroke Survivors' Perceptions of their Psychosocial Needs Being Met During Rehabilitation

Robin A. Wenzel

Midwestern University – USA, rwenzel67@midwestern.edu

Emily A. Zgoda

Midwestern University – USA, ezgoda96@gmail.com

Mia C. St. Clair

Midwestern University – USA, miastclair@gmail.com

Lisa J. Knecht-Sabres

Midwestern University – USA, lknech@midwestern.edu

Follow this and additional works at: <https://scholarworks.wmich.edu/ojot>



Part of the Mental and Social Health Commons, and the Occupational Therapy Commons

Recommended Citation

Wenzel, R. A., Zgoda, E. A., St. Clair, M. C., & Knecht-Sabres, L. J. (2021). A Qualitative Study Investigating Stroke Survivors' Perceptions of their Psychosocial Needs Being Met During Rehabilitation. *The Open Journal of Occupational Therapy*, 9(2), 1-16. <https://doi.org/10.15453/2168-6408.1691>

This document has been accepted for inclusion in The Open Journal of Occupational Therapy by the editors. Free, open access is provided by ScholarWorks at WMU. For more information, please contact wmu-scholarworks@wmich.edu.

A Qualitative Study Investigating Stroke Survivors' Perceptions of their Psychosocial Needs Being Met During Rehabilitation

Abstract

Background: Depression and anxiety can negatively impact one's recovery, outcomes, and quality of life. Even though therapists consider the mental health needs of their clients to be a priority, they are dissatisfied with their ability to completely address these needs. The purpose of this study was to examine the client's perspective regarding the extent to which health care professionals addressed their psychosocial needs after a stroke.

Method: A phenomenological research design was used to collect data from six participants. Interviews and focus group were audiotaped, transcribed verbatim, and thematically analyzed. Member checks, peer-review, multiple coders, triangulation, and expert examination were used to increase trustworthiness of findings.

Results: Five themes emerged. People with strokes: (a) experience an array of emotions, (b) are not likely to initiate disclosure of their state of mental health, (c) feel their psychosocial needs are not being addressed by health care professionals, (d) grieve the loss of prior roles post stroke and work hard to establish a new normal routine and purpose in life, and (e) have suggestions for improved care.

Conclusion: These findings reinforce the importance of addressing the mental health needs of individuals post stroke and the importance of identifying methods to enhance the ability to effectively address the psychosocial needs of clients post stroke.

Comments

The authors report no potential conflicts of interest.

Keywords

occupational therapy, psychosocial, mental health, stroke, rehabilitation, health care professionals

Credentials Display

Robin A. Wenzel, OTD, OTR/L; Emily A. Zgoda, OTD, OTR/L; Mia C. St. Clair, OTD, OTR/L; Lisa Jean Knecht-Sabres, DHS, OTR/L

Copyright transfer agreements are not obtained by The Open Journal of Occupational Therapy (OJOT). Reprint permission for this Applied Research should be obtained from the corresponding author(s). Click here to view our open access statement regarding user rights and distribution of this Applied Research.

DOI: 10.15453/2168-6408.1691

Stroke is the leading cause of serious, long-term disability in the United States (Benjamin et al., 2017). Following a stroke, individuals often face a variety of challenges, including physical, cognitive, sensory, linguistic, and psychosocial difficulties. Currently, the physical, cognitive, sensory, and linguistic effects of a stroke are widely recognized and addressed in rehabilitation; however, the emotional and psychological ramifications of having a stroke are often underdiagnosed and untreated (Miller et al., 2010). This is especially concerning considering as many as 50% of stroke survivors experience psychological or emotional disorders (Hildebrand, 2015). In addition, more than one-third of stroke survivors suffer from clinical depression and nearly one-fourth from anxiety (Mavaddat et al., 2018). Moreover, depression and anxiety from stroke have been linked with decreased functional outcomes and decreased quality of life (Linder et al., 2015). The ability to regain participation in meaningful occupations has been identified as one of the most significant predictors of satisfaction for individuals who have had strokes (Fallahpour et al., 2011). Conversely, individuals' inability to engage in meaningful occupations (occupational gaps occurring after a stroke) is correlated with decreased satisfaction in life (Fallahpour et al., 2011). Considering strokes often negatively impact an individual's ability to perform self-care and independent living skills (Legg et al., 2017), as well as one's ability to engage in various forms of social participation, leisure pursuits, and work (Blömer et al., 2015), it is not surprising that stroke survivors experience an array of psychosocial challenges.

Stroke survivors come into contact with many health care professionals, such as physical therapists, occupational therapists, and speech language pathologists during the rehabilitation process. These skilled health care professionals are able to address the physical, cognitive, sensory, and/or linguistic ramifications of having a stroke (Hoover & Carney, 2014; Lucaci et al., 2018; Quinn, 2016; Schwarz et al., 2017); however, occupational therapists are the only professionals distinctly qualified to address the physical, cognitive, and psychosocial effects of a stroke and the complex interaction that these factors can have on occupational performance (Simpson et al., 2018).

Occupational therapy is grounded in the principle that participation in meaningful activities has the capacity to help individuals who have sustained a variety of physical and psychological illnesses ward off depression and regain self-confidence and self-worth (Christiansen & Haertl, 2014). Occupational therapists use their professional artistry to help facilitate engagement in meaningful occupations to help enhance an individual's sense of purpose, self-worth, and belonging (Wimpenny et al., 2014). Occupational therapy uses a holistic approach to help individuals find their new sense of self and identity, facilitate occupational engagement, pace occupations to support the achievement of client goals, formulate a picture of a possible future, and help clients envision a new horizon (Wimpenny et al., 2014).

The holistic approach that is used by occupational therapists was found to be more valued and to provide more effective mental health interventions in comparison to other treatments, such as short-term psychological-based interventions (Hildebrand, 2015). The literature has also shown that occupational therapists use a variety of intervention strategies to address psychosocial impairments after stroke (Hildebrand, 2015). Although these interventions have been effective in the conventional mental health settings, there is little research on psychosocial, occupation-based interventions that address stroke survivors' mental health throughout the rehabilitation process (Hildebrand, 2015). These findings dovetail with the work of Gibson et al. (2011), who provided evidence that occupational therapy services can enhance community reintegration, the reestablishment of normative life roles, and the reestablishment of a variety of occupations for adults with mental illness.

Occupational therapists have been trained to assess the psychosocial and physical needs in order to improve their clients' quality of life and to enhance their occupational performance (Hildebrand, 2014). Considering the population of people with stroke is one of the largest groups treated by occupational therapists (National Board for Certification in Occupational Therapy, 2012), and that there is a high prevalence of psychosocial issues post stroke (Hildebrand, 2015; Mavaddat et al., 2018), it seems imperative that occupational therapists adequately address the mental health needs of this population. In fact, occupational therapy has published an official statement regarding the promotion of health and well-being (Reitz & Scaffa, 2020).

The literature provides evidence that occupational therapists are not completely addressing the psychosocial needs of their clients post stroke for many reasons. For instance, it has been noted that occupational therapists often overlook the mental health needs of their clients in order to address other competing priorities, such as motor, cognitive, and sensory deficits (Rowland et al., 2008). Wimpenny and Lewis (2015) noted that occupational therapists are sometimes unsure of their role in addressing the mental health needs of their clients. Kneebone et al. (2010) indicated that occupational therapists may not address the mental health needs of patients immediately following the stroke because the symptoms of depression or anxiety may not appear until after the client is discharged. Another potential reason why therapists may neglect the mental health needs of clients with a physical disability and fail to provide holistic care is because of the high productivity demands and the fast-paced environments in which occupational therapists are working with stroke survivors (Munce et al., 2017). For example, Simpson et al. (2018) discovered that the primary factors that influence occupational therapists from being able to fully address the mental health needs of their clients post stroke appear to be related to limited time with a client, increased productivity standards, expectations related to physical recovery, and poor educational preparation. Although there are several studies that have investigated the reasons why it is challenging for occupational therapists to meet their clients' mental health needs, as well as the various methods and interventions therapists have used to address the mental health needs of their clients, there is little, if any, research that has investigated the clients' perception regarding how their mental health needs were addressed after incurring a stroke. Thus, the purpose of this pilot study was to explore the clients' perceptions of how occupational therapists and other health care professionals address their psychosocial needs post stroke.

Method

This exploratory pilot study used a phenomenological research design (Creswell & Creswell, 2018) to collect qualitative data to better understand the stroke survivors' perspectives regarding how health care professionals addressed their psychosocial needs. A phenomenological research design is a method used for individuals to describe certain phenomena or experiences in their lives (Cronin-Davis et al., 2009). This study was an extension of a previous study (Simpson et al., 2018) that investigated the occupational therapists' perspective of mental health practices with clients in stroke rehabilitation. Semi-structured interview questions were used in this study to gather qualitative data from a focus group, phone, and in-person interviews. A qualitative research design (Creswell & Creswell, 2018) allowed the researchers to gain a thorough and in-depth understanding regarding the extent to which occupational therapists and other health care professionals addressed the psychosocial needs of individuals who have experienced a stroke during the rehabilitation process. Thematic analysis was used to analyze qualitative data (Braun & Clark, 2006; Creswell & Creswell, 2018; DeSantis & Ugarriza, 2000). More specifically, the first three researchers individually immersed themselves in the data by "repeated reading" as a way

to gain familiarity and to begin to find patterns (Braun & Clark, 2006, p. 87). Next, these three researchers individually generated initial codes from the data. The three researchers then came together to collaborate to identify patterns in the data, reduce and group codes, and identify themes until consensus was reached. Peer debriefing and expert examination was used throughout the data collection and analysis process. As a result, trustworthiness of data was enhanced through individual coding, peer review, and expert examination. Member checking was also used to increase the overall rigor of this study. Finally, the results of this study were compared with the existing literature as another means to enhance meaning and trustworthiness of the findings. This study was approved by the university's institutional review board.

Participants

Six participants (n = 3 female; n = 3 male) took part in this study. The participants were 6 months to 3 years post stroke. Three of the participants were 3 years post stroke, two were 1.5 years, while the most recent was 6 months post stroke. Half of the respondents were from Illinois, while the others were from Iowa, Texas, and Minnesota. Pseudonyms were used in this manuscript to protect the identity of the participants and to ensure their confidentiality. Two of the participants participated in a focus group, three of the participants participated in a phone interview, and one participant participated in an in-person interview.

Procedures

The semi-structured interview guide was based on the literature, modified according to expert opinions, and pilot tested (Simpson et al., 2018). It consists of more than 25 open-ended questions and covers six main areas (see Appendix). The questions, developed and used with permission by Simpson et al. (2018), were modified to reveal the client's perspective.

Purposeful sampling was used for this descriptive study. Flyers regarding the focus groups were passed out to potential participants at local stroke support groups and posts were made on various social media platforms, such as Facebook and the American Stroke Association's stroke support boards. In addition, information and flyers regarding this research study were provided at an open house for stroke survivors to recruit individuals who fit the inclusion criteria. Flyers were passed out to the participants who attended the open house, as well as to occupational therapists at a local hospital with the agreement that they would hand them out to potential participants. Eligibility required that participants be 3 months to 3 years post stroke, English speaking, at least 18 years of age, and have received occupational therapy services in the United States. Individual interviews were offered for the participants who were interested in the focus group but did not have transportation to attend the focus group. Phone interviews were made available for the participants living outside of the Chicagoland area.

All the participants completed the informed consent process prior to data collection. The focus group (n = 2) met in a reserved and private conference room at a rehabilitation center in Chicago that provided privacy for the participants to share their experiences. The focus group lasted approximately 1.5 hr. The in-person interview took place in a private conference room at a university in the Chicagoland area. Both in-person (n = 1) and phone interviews (n = 3) lasted an average of 1 hr.

The semi-structured interviews, phone interviews, and focus groups were recorded and transcribed verbatim by the researchers. Interview and focus group questions asked about the participants' hospital experiences post stroke regarding their emotions and how their health care team addressed their mental health needs. This questionnaire also included questions about how occupational

therapists addressed psychosocial symptoms, additional supports post stroke, and recommendations specific to occupational therapists (see Appendix).

Results

The interviews provided insight on common experiences that the stroke survivors faced when being treated post stroke. Five themes were derived from the qualitative data analysis: (a) an array of emotions and feelings, (b) participants not likely to initiate disclosure of their mental health state, (c) psychosocial needs are not being addressed by health care professionals, (d) participants grieve the loss of prior roles post stroke and work hard to establish a new normal routine and purpose in life, and (e) suggestions for improved care.

An Array of Emotions and Feelings

All of the participants revealed that the stroke resulted in some sort of emotional reaction. In fact, the majority of the participants experienced a wide range of feelings and emotions after their stroke. They expressed feelings of hopelessness, shock, fear, anxiety, anger, and sadness. The participants frequently compared post stroke symptoms and experiences to an “emotional rollercoaster.”

Most of the participants reported being in shock and denial immediately after their stroke. For example, Christopher, a male who was 3 years post stroke, described his initial experience after a stroke by saying:

First there is denial. “I didn’t have a stroke!” You always hear that. When you’re in the ER, the person next to you just had a stroke and they are denying it and you’re denying it. Your saying: “No! I didn’t have a stroke! I couldn’t have had a stroke!”

All of the participants in this study expressed feelings of sadness, frustration, and/or anger as they reported no longer having the ability to perform the activities in their lives that they once took for granted, including working, socializing, walking, driving, and even smaller tasks like taking the garbage out. Christopher, who took pride in being active and working a physically strenuous job throughout his life prior to his stroke, shared that, “nothing prepares you for that, I mean for the change. You go from being able to do everything for yourself to learning I can’t do the simple things now.”

All of the participants grieved for a variety of losses that their stroke caused them, including their inability to use their arms and legs; control their bowel and bladder; eat solid food; speak coherently; and participate in their previous activities, roles, and routines. The participants reported that mourning was necessary before accepting what the stroke had taken away from them.

The participants reported that their emotions and feelings came on rapidly and unexpectedly after the stroke. Moreover, most of the participants expressed that loved ones may not know how to discuss this profound life transition after a traumatic event such as a stroke, and people looked to health care professionals to address this. For example, Francesca, a woman who was 1.5 years post stroke, shared:

It was so much I couldn’t deal with them [feelings] by myself. It was surprising. I never was the out of control type. My emotions were out of control. They were just tsunamis. I mean just . . . anger and depression, and it was tough. I don’t know how to explain it. It was all the emotions, and people do not want to deal with you, so all you have are the trained professionals.

The participants reported that these emotions were uncharacteristic for them, leaving them unprepared and alone. Francesca continued to describe her emotional experience post stroke when she shared:

Your emotions are out of control and you have to be okay . . . you feel like damaged goods. You feel like something is wrong with you. People don't know how to deal with people who had a stroke. Everybody who has never gone through it or experienced it do not know what to do.

The participants elaborated on how challenging social participation was post stroke. These challenges resulted in their inability to participate in activities in which they previously took part. The physical effects impacted them emotionally, leaving them with feelings of embarrassment and shame for not being able to return to their prior level of activity and participation.

Patients Not Likely to Initiate Disclosure of Their Mental Health State

The participants expressed that they were unaware of their mental health needs early on in the recovery process because health care professionals focused on the physical symptoms. In addition, they were not yet exposed to the spectrum of ramifications from their stroke because they were not in their natural environments. Sandra was 18 months post stroke and exclaimed, “but they [therapists] . . . they didn't spend a lot of time addressing my mental health. But it also could be that I kept to myself.” Other participants surmised that they were unaware of their mental health needs because of feelings of gratitude and hope immediately following their stroke. A few of the participants reported feelings of joy to simply have another day in their life. For example, Devon, who was 3 years post stroke, explained, “I felt thankful I was alive in the first week.” These attitudes of gratefulness prevented about half of the participants from recognizing their mental health needs. However, the other half of the participants admitted to wanting to keep to themselves during this time and were not interested or had difficulty in expressing or communicating feelings to health care professionals.

Most of the participants expressed that they may tell occupational therapists or other health care professionals that they are “doing okay” mentally, though they are not. For example, Christopher emphasized that:

Every patient is going to be different. Some of us are going to be okay. Don't just, because a person seems you know, everything is cool, they're laughing they're joking . . . don't for a minute think that they are okay with what happened to them. Because they aren't. Some of it is, uh, how do I want to put it. It's a defense.

Psychosocial Needs are not Being Addressed by Health Care Professionals

A few of the participants identified that their psychosocial needs were never spoken about in the hospital or rehabilitation settings. The majority of the participants repeatedly stated that they were unaware that health care professionals, such as occupational therapists, were able to evaluate and treat clients' psychosocial needs. The majority of the participants felt that health care professionals avoided addressing psychosocial needs and only focused on the person's physical needs. Christopher vividly described the weight of the topic of mental health he felt during recovery: “It is basically the 600-pound gorilla in the room. You don't really talk about it or you don't look at it, you just want it to stay over there. Nobody is comfortable about talking about it. It's rough.”

In addition, the participants reported receiving no education about their possible physical and psychosocial needs during recovery from the stroke once they were discharged from the inpatient setting. The participants were left to seek out the resources needed to support their psychosocial needs on their own. In particular, all of the participants reported having to seek out stroke support groups completely independently.

Grieving Loss of Roles Post Stroke and Working Hard to Establish a New Normal Routine and Purpose in Life

The participants described that experiencing new physical, cognitive, and/or linguistic impairments made it difficult to participate in valued roles and occupations; at times, preventing them from continuing them altogether. Almost all of the participants admitted that it was a difficult process to establish new meaningful occupations, roles, and routines after their stroke. Michael, a male, 3 years post stroke, described that having expressive aphasia made it impossible to return to a normal workload as a lawyer, which was the reason for an earlier than expected retirement. Michael also indicated that “even participation in meaningful events like Thanksgiving and Christmas are now difficult.” He said, “you don’t think about how having to be on the pureed diet affects your socialization and not wanting to go out to dinner.” Devon explained that post stroke:

I just wanted to get back to my routine. Nothing is normal. Nothing is the same. I mean, yeah, in general you still have the same house, family. I wanted to go back to [my] routine prior to stroke but nothing is the same anymore. It’s just a little, everything is just, you know, a notch different, or two notches different, or whatever.

Sandra said, “I miss being at work. I miss being with people who I thought were my friends.” Karen said:

I love and miss Sudoku; it might not sound significant; but I was a master Sudoku player, I lost my streak of 172 games! I can do things that require logic, like crossword puzzles, but I lost my math function, so I can’t play Yahtzee either.

The loss of important occupations on top of grieving is devastating for clients. Several of the participants acknowledged that occupational therapists could play a vital role in establishing new roles and routines and expressed the desire for more opportunities to focus on that aspect of their recovery. Many of the participants discussed the importance of outings (e.g., going to the bowling alley, driving range and golf course, grocery store) and its aid in reengaging in normal activities. For example, Christopher, who had been in inpatient rehabilitation post stroke, stressed the importance of leaving the rehabilitation setting and doing things in the community when he said:

What I would like to see more with the occupational therapists is the excursions. Excursions help patients create a new sense of meaning during what patients consider a difficult time . . . I like golf . . . she arranged a day trip for me so I could watch my son in a golf tournament . . . she even let me drive the golf cart! It was amazing!”

Similarly, Michael said:

I used to play golf . . . it used to be my hobby . . . the therapist had me swing at plastic balls in therapy. . . I can’t work anymore . . . but I now go to the driving range . . . I am not very good;

but I wasn't good before (laugh) . . . but now it's my favorite hobby . . . I also bought a bike . . . we'll see how the balance goes with that.

Whereas Devon said,

I can't work anymore but I can mow the grass . . . it's a rider . . . it helps my whole outlook on life . . . that you can still do things around the house . . . my wife is younger and still works . . . I am now the one who goes to the store, goes to the dog groomer, post office, or the bank . . . the little things.

Devon further discussed how being able to drive again was key to his ability to establish and enjoy new routines as indicated when he said, "I wasn't driving initially, but now I am . . . I have season tickets to DePaul . . . this is therapy for me . . . it gives me a reason to get up in the morning, get dressed, and out of the house."

Suggestions for Improved Care

All of the participants provided numerous suggestions to improve the care health care professionals provide to better address the stroke survivors' psychosocial needs. For example, the participants reported having heard about strokes but were unfamiliar with the common symptoms and warning signs of a stroke. Francesca shared, "I have no stroke in the family or anything. It was very classic stroke symptoms, but I didn't know." Sandra, like Francesca, shared that she would have liked to have known more about warning signs, even after being medically stable and working toward full recovery. A few of the participants recommended that there needs to be more public education about the warning signs of a stroke, specifically through pamphlets given in doctors' offices and/or classes that are open to the public. However, some of the participants revealed that they received an overload of information in a short time and expressed feelings like Karen, who stated, "it was overwhelming. I received so much . . . too much information . . . in such a short period of time. I couldn't deal with it."

A couple of the participants' suggestions included wanting to have more involvement with professionals who are specifically trained to work with their psychosocial needs. In fact, Francesca declared that it would be helpful if every client could talk to a psychologist or someone with mental health training on a regular basis during the rehabilitation process. She stated, "I would have liked to have had once a week sit down sessions . . . to see how I feel . . . yeah . . . just to get it out . . . you have to adjust to the change . . . yeah . . . once a week . . . that would help a lot." Several of the participants recommended having the family and caregivers more actively involved throughout the therapy sessions. They felt that having family and caregivers present more often during their recovery and rehabilitation process would help increase the social support after being discharged from the hospital and rehabilitation center. Moreover, they felt that active participation of the caregiver during rehabilitation would lead to better caregiver education about what to expect when discharged back home and enable them to better understand how they can assist them in their home environment. For instance, Devon shared that health care professionals "are very good about the family. They involved my son and my wife and my sisters . . . if they were around more in the evaluation and treatment . . . what I needed to work on . . . what I was doing well with, it would have been helpful." Sandra indicated that "it would be helpful if the therapists could create a journal for when family can't be there during the day." Lastly, one of the participants felt it would be helpful to have special training sessions for patients who have younger children:

I have a 12 year old . . . it would be nice if they had something for smaller children . . . just have it for them and for them to get out their feelings . . . she asked me every day, why aren't you working? When are you going to use your arm? And, ya know, I tell her that I may never be able to use it but I can still do things . . . it's a way for her to find out without mom there . . . and express her emotions, too.

Other recommendations included taking time to listen to the clients and not taking short and general responses such as "I'm good" or "I am doing fine" for an answer. It was expressed by multiple participants that they want to be listened to and heard. Francesca expressed the importance of addressing what can be a difficult topic to discuss and said:

Ask about it. It is the same thing as suicide awareness – no one asks people how they are feeling. Do not be afraid to ask how you are feeling. And when people say 'I'm fine' do not accept that for an answer. Um. Because people downplay. To get around that they say, 'some people are afraid of this, some people feel like this' give ideas of what people feel like because if you just ask them how they feel they will downplay it as much as possible.

Devon talked about the importance of giving clients a sense of hope when he said:

New normal means you have to adjust. It is like saying once a junkie always a junkie. Once an alcoholic always an alcoholic. Never tell someone that. That takes away hope. Anyone going through this needs hope. Needs hope that they can get better. Nobody is guaranteed full recovery, and I understand that.

Karen discussed how it is important that the therapists understand and acknowledge clients' losses and help them get back to doing the things that they need and want to do when she exclaimed:

Understand that this is a huge change in someone's life! You fear things. I lost my job . . . everyone is encouraging you . . . but I was wondering how do I actually get to where I want to be? They asked me what my problems were . . . but then they didn't say okay why don't you try this to make this better . . . they just kind of said, oh, it will come back. Don't just say it will come back! Figure out what is going on and set a goal . . . they definitely didn't set any goals related to the (my) issues . . . nor did they help with any of them. I needed help with my computer . . . they told me it was the strength in my fingers, which it wasn't . . . they did send me finger exercises to strengthen them . . . but that wasn't the issue.

Many of the participants expressed the importance of building rapport and showing that you care. Devon proclaimed:

Don't make them (clients) feel that you are a burden. You just want to be accepted. These are still people you are working with. You want to have a relationship . . . those places will destroy you, the spirit in you, or it will make you a fighter. It kept me a fighter . . . encouragement is big! They don't tell you when I do good at something. They just move onto something else . . . tell me what my goal is . . . don't just say do the best that you can . . . tell me if I am close or miss it (the goal).

Similarly, Christopher expressed the importance of building rapport and therapeutic use of self when he said, "they (therapists) helped me understand what I needed to do . . . they had fun with me . . . they

helped me relax . . . whether it be humor, compassion, whatever.” He also was extremely touched and said it was one of the most memorable things in his life when his doctor revealed that he prayed for him: “He (doctor) told me every night I pray to God that He tells me how to fix you . . . I’m balling my eyes out because you never hear that from a medical professional.” Michael echoed these sentiments when he described his relationship with his therapist: “I called her a Drill Sergeant . . . it was a joke . . . it was a compliment. I told her I want her to work me . . . don’t be soft on me . . . she wanted me to get better . . . she really showed she cared.”

Several of the participants had suggestions to enhance leisure and social participation during and after the rehabilitation process. For example, Sandra said, “I think working on my ability to use technology . . . my keyboard, sending emails, and texting on my phone would have been very important . . . keep me in contact with the kids and work.” Michael said that “they need to give us more to do when we are not in therapy.” He exclaimed, “The TV gets boring! The Dollar Tree sells books and crossword puzzles this thick for a dollar! Give us things to do. We might be in there for a month!”

Lastly, the participants in this study shared the importance of having an occupational therapist encourage them, educate them, and provide information about what to expect once discharged from the hospital or inpatient setting. All of the participants indicated that support groups were helpful, and several felt that online support groups can be just as beneficial for clients post stroke as in-person support groups. The participants revealed that online support groups provided helpful information related to medical questions, adaptive equipment, and other resources to use once clients were discharged from the hospital or rehabilitation setting. The participants also expressed that in-person support groups were sometimes discouraging because the people may be at different points of the recovery process, which impacted their own hope of recovery post stroke. Karen discussed the benefits of having a friend who was the same age and who had also had a stroke:

We get together . . . once a week and we spew out what’s our problems and what’s going on . . . we talk about different studies . . . we talk about it all . . . to have a minute to not necessarily feel good . . . some are building up and encouraging . . . but some of them aren’t . . . you just have to have that . . . because not everything you can talk to your family and your friends.

Discussion

This exploratory pilot study examined stroke survivors’ perceptions of their psychosocial needs being met during rehabilitation. The results of this study support the current evidence and provide additional insight into a relatively unexplored topic of interest to occupational therapists and other health care professionals. This study revealed that stroke survivors experience an abundance of emotions and feelings after a stroke; yet, they feel that their psychosocial needs are not being addressed by health care professionals. Moreover, the participants indicated that they are not likely to initiate disclosure of their mental health state; however, they were able to offer suggestions for improved care. In addition, the participants reported that they are grieving the loss of roles post stroke and are working hard to establish a new normal routine and purpose in life, but there is room for improvement in order to help facilitate this process.

The participants in this study expressed a variety of feelings, emotions, and mental health concerns, including feelings of hopelessness, embarrassment, shame, shock, fear, anxiety, anger, sadness, grief, and depression. These findings are consistent with Annoni et al. (2006), who highlighted the wide variety of acute and chronic feelings and emotional disturbances that commonly occur after a

stroke. Moreover, consistent with Miller et al. (2010) and Towfighi et al. (2017), who revealed that the emotional and psychological ramifications of having a stroke are often underdiagnosed and untreated, the majority of the participants in this study felt as though their health care providers typically avoided the emotional and psychological ramifications of having a stroke. In fact, the participants in this study expressed that rehabilitation after a stroke focused on their physical needs and neglected to address their psychosocial needs, which is consistent with Rowland et al. (2008). Likewise, as Kneebone et al. (2010) asserted, some of the participants in this study felt that their health care professionals might not have addressed their mental health during the rehabilitative phase because they were grateful to just be alive and were unaware of their own mental health needs early on in the recovery process. In other words, it is possible that until a stroke survivor has the opportunity to experience the full impact of the stroke on their daily life, the stroke survivors, as well as mental health practitioners, might not be able to identify any psychological needs or concerns. They might not have a clear sense of the comprehensive ramifications of the stroke, including their state of mental health, until after they are discharged (Dar et al., 2017; Graven et al., 2011; Towfighi et al., 2017). Thus, occupational therapists should consider their role in the development and reformation of policies and consider their role in advocating for additional occupational therapy services for stroke survivors after discharge from inpatient or intense outpatient rehabilitation.

Somewhat unique to this study, however, is the fact that the participants reported that they were not likely to initiate disclosure of their mental health state or concerns. In fact, most of the participants in this study stated that they were unaware that health care professionals, such as occupational therapists, were able to address their psychosocial needs. Since uncertainty regarding easy identification of patients at the greatest risk of experiencing depression after the onset of stroke continues to exist (Dar et al., 2017; Graven et al., 2011; Hackett & Anderson, 2005; Towfighi et al., 2017), and since clients might not be forthcoming with their feelings, emotions, and mental health concerns, as indicated by the participants in this study, this might provide another explanation as to why health care providers may overlook mental health issues post stroke. Moreover, these circumstances seem to highlight the necessity of the importance of health care professionals inquiring about their client's mental health on a regular basis throughout their recovery. In fact, one of the participants expressed that it would be helpful if every person post stroke could talk to a psychologist or someone with mental health training on a regular basis during the rehabilitation process. She stated that these sessions would help "just to get it out . . . to adjust to the change." In addition, as the participants in this study indicated, it seems imperative that therapists do not ask generic questions regarding one's state of mental health or accept general responses such as "I'm good" or "I am doing fine." "Do not accept that for an answer . . . because people downplay. To get around that they should say, 'some people are afraid of this, some people feel like this,' give ideas of what people feel like because if you just ask them how they feel, they will downplay it as much."

Furthermore, the findings of this study were consistent with the literature in terms of common experiences people encountered post stroke (Blömer et al., 2015; Legg et al., 2017). For example, the participants in this study revealed that changes in their physical ability and mental health often resulted in having to adjust to new roles, habits, routines, and occupations. Similar to the current evidence, the participants in this study also discussed their struggles with grieving their losses. It is interesting, though, that some of the participants reported that mourning was necessary before they could accept what the stroke had taken away from them. Analogous to Fallahpour et al. (2011), who asserted that the

ability to regain participation in meaningful occupations is one of the most significant predictors of satisfaction post stroke, the participants in this study discussed how they were desperately trying to establish new routines, roles, and meaning in life. In fact, almost all the participants admitted that it was difficult to establish new meaningful occupations, roles, and routines. They reported that “nothing was normal or the same” and indicated that they “wanted to get back to work, be able to socialize with friends, and participate in various activities in the community.” Since Linder et al. (2015) noted that decreased functional outcomes and decreased quality of life are correlated with mental health concerns and Fallahpour et al. (2011) noted that the ability to regain participation in meaningful occupations is one of the most significant predictors of satisfaction post stroke, it seems imperative that occupational therapists prioritize reestablishment in meaningful occupations post stroke. This echoes Reitz and Scaffa’s statement in “Occupational Therapy in the Promotion of Health and Well-Being,” which asserts that “to reach a state of complete physical, mental, and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment” (2020, p. 1). As one participant expressed, therapists need to understand that “this is a huge change in someone’s life” and they need to truly collaborate with their clients regarding goals that are meaningful and specific to them.

Even though Simpson et al. (2018) noted that occupational therapists are skilled, qualified, and motivated to address the psychosocial needs of stroke survivors, the participants in this study “did not feel as though their psychosocial needs were fully addressed,” and they “did not feel that they received enough encouragement” or resources to deal with the complex ramifications of their stroke. Unique to this study are the insights and suggestions for improved care from the clients’ perspectives. For example, in addition to the suggestions discussed previously, the survivors in this study indicated that they “would appreciate more opportunities to have family and caregivers present during their recovery and rehabilitation process.” They felt that these opportunities would help improve their level of support (physical, social, and psychological) after being discharged. They also asserted that these added opportunities for caregiver education would enhance the caregivers’ ability to “be prepared for what to expect when discharged back home.” The participants also declared that “more involvement of family and caregivers during rehabilitation would enable the caregivers to better understand how they can assist” their loved ones in their home environment and be “better able to understand the stroke survivor’s new normal” post stroke. In addition, many of the participants expressed the importance of encouragement, building rapport, and showing that you care. However, the participants asked for treatments that addressed their specific needs and goals as well as the provision of direct and specific feedback regarding performance and attainment of goals. As one participant expressed, “tell us when we do good at something . . . don’t just say do the best that you can . . . tell us if I we are close or if we missed the goal” and another participant exclaimed:

They asked me what my problems were . . . but then they didn’t say okay why don’t you try this to make this better . . . they just kind of said, oh, it will come back. Don’t just say it will come back! Figure out what is going on and set a goal. They definitely didn’t set any goals related to the (my) issues.

Lastly, since the participants in this study expressed the importance of education regarding the common signs and symptoms of strokes as well as a variety of other stroke related topics, and since the participants articulated the value of support groups, it seems imperative that occupational therapists

should not only consider their important role in serving individuals, but also ensure they are actively involved in providing services at the group and population levels (Reitz & Scaffa, 2020).

Implications for Practice

The current evidence, including the results from this study, seem to strongly suggest that occupational therapists should examine their practice to ensure that they are truly holistically treating their clients and fully addressing the psychosocial needs of their clients who incurred a stroke. The majority of the participants explained that it should be the role of the occupational therapist to initiate discussion about the client's current and future state of mental health since it is unlikely that the stroke survivors will initiate conversation about their current life dissatisfaction. It has been suggested that occupational therapists and other health care professionals educate clients on the psychosocial issues post stroke because of the major life changes that one may experience. Providing clients with various resources that they could access throughout the recovery process would also appear to be extremely beneficial. Since depression and other psychosocial issues often occur after being discharged from the hospital, stroke survivors often feel alone and unprepared. Thus, it seems imperative for occupational therapists to provide education regarding what clients can expect after discharge. Occupational therapists should also examine their practice and assess how often they encourage family and caregivers to be present during their recovery and rehabilitation process, since family and caregivers may be instrumental in easing the transition from being a patient in the hospital to being a more independent and self-fulfilled person in the home. Education should not only include the psychosocial ramifications of strokes but also incorporate how stroke survivors can participate and reengage in their meaningful roles and occupations post stroke. As Wimpenny et al. (2014) indicated, occupational therapists can use their professional artistry to help facilitate engagement in meaningful occupations to help enhance an individual's sense of purpose, self-worth, and belonging, which appears to be an area that is not being fully addressed for stroke survivors.

Since the majority of the participants felt dissatisfied with their experiences in rehabilitation and expressed that they felt that their mental health needs were overlooked or not fully addressed, and since the participants admitted to giving short and untrue responses to typical questions related to their mental well-being, therapists need to be more cognizant regarding these issues and should not necessarily take comments such as "I'm good" or "I am doing fine" at face value. Therapists should reflect on their own practice and ensure that they are aware of signs and symptoms of depression and are being attentive to a person's body language, tone of voice, and other subtle signs of mental health concerns, since these factors can also be a determinant of how a client is feeling.

Although the findings of this study reveal that clients are dissatisfied with how their mental health needs are being met, research does indicate that occupational therapists are motivated to create a change. For instance, Simpson et al. (2018) found that occupational therapists do view mental health as an important component to optimal health and wellness for individuals that have experienced stroke. Further, it has been indicated that occupational therapists hope to deliver holistic services to their clients and are motivated to promote physical and mental wellness (Simpson et al., 2018). Because occupational therapists have been trained to assess the psychosocial needs of clients (Hildebrand, 2015), the researchers of this study are hopeful that the dissemination of these findings will motivate therapists to be more aware of these needs and perhaps advocate for additional occupational therapy interventions following acute rehabilitation. This seems particularly important since clients may not fully understand and/or experience the comprehensive impact of the ramifications of a stroke on their life until well after

discharge, and perhaps, after the completion of rehabilitation services. Thus, occupational therapists should consider their role in the development and reformation of policies and consider their role in advocating for additional occupational therapy services for stroke survivors after discharge from inpatient rehabilitation. Likewise, occupational therapists should not only consider their important role in serving individuals, but also their vital role in addressing the needs at the group and population levels (Reitz & Scaffa, 2020). Similarly, occupational therapists need to ensure that they are actively involved in health promotion and enhancing well-being (Reitz & Scaffa, 2020).

Lastly, since this was an exploratory pilot study, it would be beneficial to continue research on the client's perspective of how their psychosocial needs are being addressed, as there currently is a lack of evidence on this topic.

Limitations

Even though this study is a good start to examining the client's perspective regarding the extent to which health care professionals addressed their psychosocial needs after a stroke, there is a lot more room to explore this important topic. Future studies with larger sample sizes and perhaps the development of a more structured survey combined with the use of a mixed methods design (collecting both quantitative and qualitative data) would enhance the rigor and might offer further support for the current evidence related to this area of practice. In addition, a study that simultaneously investigates the therapists' and clients' perspectives might offer more accurate and comprehensive information.

Conclusion

Stroke is the leading cause of disability in the United States and is one of the most common conditions treated by occupational therapists. This exploratory pilot study examined the perspectives of stroke survivors on how occupational therapists and other health care professionals addressed their psychosocial needs post stroke. Findings from this study indicated that occupational therapists are focused primarily on the physical ramifications of stroke and are not fully addressing the psychosocial needs of individuals after a stroke. Further research on this topic is highly recommended. Occupational therapists should examine their own practice to ensure that they are treating these individuals holistically and promoting wellness through interventions that address the stroke survivor's physical and mental health. A holistic approach to intervention will allow these individuals to receive the finest possible care and promote the best occupational and health outcomes. Occupational therapists should also consider their vital role in addressing the needs of groups and populations.

References

- Annoni, J., Staub, F., Bruggimann, L., Gramigna, S., & Bogousslavsky, J. (2006). Emotional disturbances after stroke. *Clinical and Experimental Hypertension*, 28(3–4), 243–249. <https://doi.org/10.1080/10641960600549173>
- Benjamin, E. J., Blaha, M. J., Chiuve, S. E., Cushman, M., Das, S. R., Deo, R., de Ferranti, S. D., Floyd, J., Fornage, M., Gillespie, C., Isasi, C. R., Jimenez, M. C., Jordan, L. C., Judd, S. E., Lackland, D., Lichtman, J. H., Lisabeth, L., Liu, S., Longenecker, C. T., . . . Muntner, P. (2017). Heart disease and stroke statistics—2017 update: A report from the American Heart Association. *Circulation*, 146–603. <https://doi.org/10.1161/cir.0000000000000485>
- Blömer, A. V., van Mierlo, M. L., Visser-Meily, J. M., van Heugten, C. M., & Post, M. W. (2015). Does the frequency of participation change after stroke and is this change associated with the subjective experience of participation? *Archives of Physical Medicine & Rehabilitation*, 96(3), 456–463. <https://doi.org/10.1016/j.apmr.2014.09.003>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp0630a>
- Christiansen, C., & Haertl, K. (2014). History of occupational therapy. In B. Schell, G., Gillen, & M. Scaffa (Eds.). *Willard and Spackman's occupational therapy* (12th ed.). Lippincott Williams & Wilkins.
- Creswell, J., & Creswell, J. (2018). *Research design: Qualitative, quantitative, and mixed methods approaches* (5th ed.). Sage.
- Cronin-Davis, J., Butler, A., & Mayers, C. A. (2009). Occupational therapy and interpretative phenomenological analysis: Comparable

- research companions? *British Journal of Occupational Therapy*, 72(8), 332–338.
<https://doi.org/10.1177/030802260907200802>
- Dar, S., Venigalla, H., Khan, A., Ahmed, R., Mekala, H., Zain, H., Shagufta, S. (2017). Poststroke depression frequently overlooked, undiagnosed, untreated. *Neuropsychiatry*, 7(6), 906–919.
<https://doi.org/10.4172/neuropsychiatry.1000296>
- DeSantis, L., & Ugarriza, D. (2000). The concept of theme as used in qualitative nursing research. *Western Journal of Nursing Research*, 22(3), 351–372.
<https://doi.org/10.1177/019394590002200308>
- Fallahpour, M., Tham, K., Joghataei, M. T., Eriksson, G., & Jonsson, H. (2011). Occupational gaps in everyday life after stroke and the relation to functioning and perceived life satisfaction. *OTJR: Occupation, Participation and Health*, 31(4), 200–208.
<https://doi.org/10.3928/15394492-20110513-01>
- Gibson, R., D'Amico, M., Jaffe, L., & Arbesman, M. (2011). Occupational therapy interventions for recovery in the areas of community integration and normative life roles for adults with serious mental illness: A systematic review. *The American Journal of Occupational Therapy*, 65(3), 247–256.
<https://doi.org/10.5014/ajot.2011.001297>
- Graven, C., Brock, K., Hill, K., Ames, D., Cotton, S., & Joubert, L. (2011). From rehabilitation to recovery: Protocol for a randomised controlled trial evaluating a goal-based intervention to reduce depression and facilitate participation post-stroke. *BMC Neurology*, 11(73).
<https://doi.org/10.1186/1471-2377-11-73>
- Hackett, M., & Anderson, C. (2005). Predictors of depression after stroke: A systematic review of observational studies. *Stroke*, 36(10), 2296–2301.
<https://doi.org/10.1161/01.str.0000183622.75135.a4>
- Hildebrand, M. W. (2015). Effectiveness of interventions for adults with psychological or emotional impairment after stroke: An evidence-based review. *American Journal of Occupational Therapy*, 69(1), 6901180050p1–6901180050p9.
<https://doi.org/10.5014/ajot.2015.012054>
- Hoover, E. L., & Carney, A. (2014). Integrating the iPad into an intensive, comprehensive aphasia program. *Seminars in Speech and Language*, 35(1), 25–37. <https://doi.org/10.1055/s-0033-1362990>
- Kneebone, I., Baker, J., & O'Malley, H. (2010). Screening for depression after stroke: Developing protocols for the occupational therapist. *British Journal of Occupational Therapy*, 73(2), 71–76.
<https://doi.org/10.4276/030802210X12658062793843>
- Legg, L. A., Lewis, S. R., Schofield-Robinson, O. J., Drummond, A., & Langhorne, P. (2017). Occupational therapy for adults with problems in activities of daily living after stroke. *The Cochrane Database of Systematic Reviews*, 7(7), CD003585.
<https://doi.org/10.1002/14651858.cd003585.pub3>
- Linder, S. M., Rosenfeldt, A. B., Bay, R. C., Sahu, K., Wolf, S. L., & Alberts, J. L. (2015). Improving quality of life and depression after stroke through telerehabilitation. *American Journal of Occupational Therapy*, 69(2), 6902290020p1–6902290020p10.
<https://doi.org/10.5014/ajot.2015.014498>
- Lucaci, P., Neculaes, M., & Haba, D. (2018). Contribution of physical therapy to the rehabilitation of patients with an ischemic stroke. *Sport & Society / Sport Si Societate*, 18(1), 29–38.
- Mavaddat, N., Sadler, E., Lim, L., Williams, K., Warburton, E., Kinmonth, A. L., Mant, J., Burt, J., & McKeivitt, C. (2018). Perceptions of self-rated health among stroke survivors: A qualitative study in the United Kingdom. *BMC Geriatrics*, 18(1), 81.
<https://doi.org/10.1186/s12877-018-0765-8>
- Miller, E. L., Murray, L., Richards, L., Zorowitz, R. D., Bakas, T., Clark, P., & Billinger, S. A. (2010). Comprehensive overview of nursing and interdisciplinary rehabilitation care of the stroke patient: A scientific statement from the American heart association. *Stroke*, 41(10), 2402–2448.
<https://doi.org/10.1161/str.0b013e3181e7512b>
- Munce, S. E. P., Graham, I. D., Salbach, N. M., Jaglal, S. B., Richards, C. L., Eng, J. J., Desrosiers, J., MacKay-Lyons, M., Wood-Dauphinee, S., Korner-Bitensky, N., Mayo, N. E., Teasell, R. W., Zwarenstein, M., Mokry, J., Black, S., & Bayley, M. T. (2017). Perspectives of healthcare professionals on the facilitators and barriers to the implementation of a stroke rehabilitation guidelines cluster randomized controlled trial. *BMC Health Services Research*, 17(1).
<https://doi.org/10.1186/s12913-017-2389-7>
- National Board for Certification in Occupational Therapy. (2012). *Practice analysis of the occupational therapist registered*. NBCOT.
- Quinn, T. J. (2016). In people with aphasia following stroke, how does the use of speech and language therapy affect outcomes? *Cochrane Clinical Answers*. <https://doi.org/10.1002/cca.1384>
- Reitz, S., & Scaffa, C. M. (2020). Occupational therapy in the promotion of health and well-being. *The American Journal of Occupational Therapy*, 74(3), 7403420010p1–7403420010p14.
<https://doi.org/10.5014/ajot.2020.743003>
- Rowland, T. J., Cooke, D. M., & Gustafsson, L. A. (2008). Role of occupational therapy after stroke. *Annals Of Indian Academy Of Neurology*, 11, S99–S107.
- Schwarz, M., Coccetti, A., Cardell, E., Murdoch, A., & Davis, J. (2017). Management of swallowing in thrombolysed stroke patients: Implementation of a new protocol. *International Journal of Speech-Language Pathology*, 19(6), 551–561.
<https://doi.org/10.1080/17549507.2016.1221457>
- Simpson, E. K., Ramirez, N. M., Branstetter, B., Reed, A., & Lines, E. (2018). Occupational therapists' perspectives of mental health practices with clients in stroke rehabilitation. *OTJR: Occupation, Participation and Health*, 38(3), 181–189.
<https://doi.org/10.1177/1539449218759627>
- Towfighi, A., Ovbiagele, B., El Hussein, N., Hackett, M., Jorge, R., Kissela, B., Mitchell, P., Skolarus,

- L., Whooley, M., & Williams, L. (2017). Poststroke depression: A scientific statement for healthcare professionals from the American Heart Association/American Stroke Association. *Stroke*, *48*, 30–43.
<https://doi.org/10.1161/STR.000000000000113>
- Wimpenny, K., & Lewis, L. (2015). Preparation for an uncertain world: Professional artistry and durability in mental health occupational therapy practice preparation. *South African Journal of Occupational Therapy*, *45*(2), 22–28.
- <https://doi.org/10.17159/2310-3833/2015/v45n2a5>
- Wimpenny, K., Savin-Baden, M., & Cook, C. (2014). A qualitative research syntheses examining the effectiveness of interventions used by occupational therapists in mental health. *British Journal of Occupational Therapy*, *77*(6), 276–288.
<https://doi.org/10.4276/030802214x14018723137959>

Appendix

Examples of Focus Group and Interview Questions

Did you experience any kinds of emotions during your rehabilitation?

- Did you have any fears and/or concerns?
- Were you sad and/or anxious?

How do you think your health care providers prioritized your rehabilitation needs?

- Did they let you know it was okay to focus on your fears and concerns?

Which members of your health care team addressed your feelings of sadness, fear, or any other emotions?

- How did they address your fears, concerns, and/or emotions?
- Did they encourage you to talk about what was bothering you?
- Did they inform you about emotional reactions that people may have after a stroke?

Before your stroke, were you aware that occupational therapists treat both the psychosocial and physical symptoms post stroke?

- Can you give some examples of how an occupational therapist responded to your fears and concerns?
- What kinds of things did occupational therapists do to address your emotional needs?

What are the main ways that you get support when you experience emotions about your stroke and recovery?

- Support groups? Family? Professional mental health counselors?

What are your recommendations for how occupational therapists can better address the emotional needs of individuals who have had a stroke?

- How should they bring things up?
- What kinds of information should they provide?

What are your recommendations for how other health care professionals can better address the emotional needs of individuals who have had a stroke?

- How should they bring things up?
- What kinds of information should they provide?