

The Lived Experience of Serious Stroke Survival: A Hermeneutic Phenomenological Case Study

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Abstract

Purpose: The aim of this study was to describe the lived experiences of a serious stroke survivor.

Design: This is a hermeneutic phenomenological case study.

Methods: Data were collected via observations and conversations during 75 visits, 14 brief audiotaped interviews, field notes, and conversations with family members, close friends, and care providers.

Findings: Seven themes emerged that form the general structure of the lived experience of surviving a serious stroke. These themes were organized around four fundamental existential themes including space, time, body, and relationships.

Clinical Relevance to the Practice of Rehabilitation Nursing: Spend intentional time with patients beyond the initial stroke rehabilitation period to better understand the experience, individualize care, identify meaningful activities previously engaged in, and identify people who may be willing to partner with them to continue participation in the meaningful activities.

Conclusion: Hermeneutic phenomenology allows the essence of the stroke survival experience to be revealed and contributes to better understanding of the phenomenon.

Keywords: Lived experience; phenomenology; rehabilitation nursing; stroke survival.

According to the Centers for Disease Control and Prevention (CDC), approximately every 40 seconds someone in the United States has a stroke (CDC, 2022). Most strokes are ischemic strokes in which blood flow to the brain is blocked. Brief temporary blood loss results in a minor stroke, whereas blood loss of longer duration results in a more serious stroke. The time of lost blood flow to the brain is critical as it impacts the chance of survival as well as the possibility that the stroke will leave a person with serious long-term consequences. Long-term complications may impact some or all of the following functions: movement, speech, eating, vision, cognition, orientation, bowel and bladder control, emotional control, and the ability to perform activities of daily living (Johns Hopkins Medicine, 2022). The CDC states that “Stroke reduces mobility in more than half of stroke survivors” (CDC,

2022, para. 1, bullet point 7). According to the Mayo Clinic (2022), most people who experience a stroke will need some level of long-term rehabilitation that focuses on the areas of function that were affected by the stroke. The overall aim of rehabilitation is to improve the quality of life of the person who has had a stroke. The recovery trajectory for people who have survived a serious stroke is long and challenging, with some never regaining lost functions.

Unsurprisingly, the rehabilitation guidelines focus on the physical impairments resulting from a stroke, but what about the patients who are at the center of the rehabilitation efforts? How are they feeling about the medical event that has dramatically changed their life? What is their experience in the rehabilitation process and how can the people caring for them better understand their lived experience over time? When the ability to think and speak clearly is compromised, how can people communicate their lived experience to caregivers? Hermeneutic phenomenology offers an opportunity to invite those who have had a serious stroke to share their story regardless of the areas of function they may have lost. Paying close attention to fundamental themes such as body, space, time, and relational qualities offers a lens to explore the experience. Lived body refers to the physical body but also includes feelings as they are felt in the body. Lived space is defined as felt space and refers to the

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physical space of a room or rooms. Lived time is subjective time rather than objective time. Relationality is defined as the interpersonal interactions that occur with others in an environment. According to van Manen (1997), these four existential themes may be “helpful as guides for reflection in the research process” (p. 101), in essence allowing complex lifeworld experiences to be described and better understood.

Background

It started with a phone call in early May of 2020. Barbara’s good friend, teaching colleague, mentor, and writing buddy had survived a serious stroke and was in the hospital. Barbara’s first visit was brief and took place on a patio at a transitional care facility. As she waited for Roberta to arrive, she wondered what her first impression would be when she saw her. Barbara was not prepared for the changed person who was wheeled out in a wheelchair. Roberta recognized Barbara; she spent the visit crying, sobbing, and reaching out to her. She attempted to talk, but Barbara was unable to understand what she was saying. The visit lasted about 15 minutes. Barbara returned to her car feeling stunned and overwhelmed. It took weeks for her to realize the magnitude of Roberta’s stroke, which left her with multiple complications including hemiplegia, hemiparesis, dysphagia, aphasia, cognitive deficits, mood lability, and, occasionally, hallucinations. In addition, Roberta experienced ongoing intense pain, anxiety, depression, and, at times, suicidal thoughts. Early on, Barbara decided to visit Roberta weekly.

Currently, Barbara has visited Roberta at three different care facilities approximately 75 times. Each visit lasts between 45 minutes and 1 hour. On occasion, Barbara brings a friend, but most often she visits alone. The ongoing visits over time allow Barbara to clearly see that Roberta is seriously compromised physically and psychologically. Roberta is entirely dependent on others to tend to her medical and safety needs. Roberta’s life changed in an instant from a vibrant, active, autonomous, social being to a person confined to a wheelchair with total dependence on others. Restoration to her previous level of function is not a possibility in her recovery trajectory. Roberta will never live independently again.

It was during a visit in May of 2021 that Roberta joked about doing a writing “project.” Roberta and Barbara had collaborated on professional projects in the past, but would it be possible now? Could adjustments be made to the communication process that would allow Roberta to communicate her ideas? In the moment, neither Barbara nor Roberta believed it was a realistic

possibility because Roberta was unable to read or write, had memory gaps, and struggled to speak. In addition, she experienced chronic pain and low energy. Barbara and Roberta laughed together and concluded that working on a project together would not be a possibility. However, on the drive home, Barbara reflected on the ways in which she and Roberta had known each other and on their shared interests, professional orientation, and values.

Both Barbara and Roberta had conducted phenomenological studies in graduate school, so it was part of their way of being and thinking. Both had long careers as nurses, specializing in community health (Roberta) and psychiatric nursing (Barbara). They value care of the whole person, care that is centered on the person, and care that is strength based. Lastly, they knew each other well as friends and professionally as nursing professors. On subsequent visits, Barbara and Roberta began to discuss the idea of a project more seriously. They decided to focus on Roberta’s lived experience of surviving a serious stroke. Roberta believed her story might help others who had survived a stroke as well as their caregivers. Barbara thought that telling Roberta’s story would be helpful to healthcare professionals working in stroke rehabilitation. According to Cameron, “Being there for someone in deep distress, assisting to relieve that distress, while trying to preserve the dignity of that human being, call for the nurse to be wholly present” (Cameron as cited in van Manen, 2002, p. 24). Barbara agreed with these words about nurses but also believed they applied to her as a friend. Barbara felt called to be fully present in this unexpected circumstance, and she made a commitment to be there for Roberta.

Did Roberta also feel called to participate? Barbara was not sure, but she did know that when they discussed their plan, Roberta’s affect brightened, and she sat taller in her wheelchair. When they experimented with audiotaped short interviews, Roberta spoke louder and more clearly. The prospect of conducting a project about her experience seemed to engage Roberta more than the usual chats between her and Barbara. The writing project seemed to create meaning for Roberta; Barbara found it powerful to witness. Barbara believed the following, “The impact of our being, both bodily within a shared living space and relationally sharing another’s discomfort and despair calls us to transcend the concrete boundaries and prescribed behaviors” (Cameron as cited in van Manen, 2002, p. 24). Barbara and Roberta chose to enter the exploration with openness and to share their findings. The intent was to build on the existing phenomenological studies focused on the lived experience of people who had survived a stroke.

Methods

Design and Setting

This phenomenological case study asks the question: What is the lived experience of a person who has survived a serious stroke? The inquiry took place in three different residential care facilities over 2.5 years.

Data Collection

This phenomenological inquiry is focused on one participant who survived a serious ischemic stroke. Data were collected via observations and conversations during 75 visits, 14 brief audiotaped interviews, field notes, and conversations with family members, close friends, and care providers. Because of COVID-19 visiting restrictions, Barbara was only able to complete four visits in 2020. Roberta's speech was significantly impacted for these visits so no meaningful dialogue ensued. Thirty-nine visits were completed in 2021. Thirty-two visits have been made thus far in 2022. Fourteen short (10–12 minutes in length) audiotaped interviews were conducted from May 2021 to April 2022. There were significant challenges to conducting the audiotaped interviews because there were times when Roberta's speech could not be understood. On other occasions, Roberta's mental status was impacted in a way that did not allow her to speak about her experience in a coherent manner. For example, there were times when Roberta was emotionally labile, actively grieving, or experiencing severe pain. Altogether it took approximately 12 months to collect the interview data.

Data Analysis

Hermeneutic phenomenological methods were selected to review the transcribed interview text because they allow the person reviewing the text “to be reflective, insightful, sensitive to language, and constantly open to the experience” (van Manen, 1997, p. xi). Furthermore, according to van Manen (1997), “every interpretation can be called into question; every inquiry can begin anew; every hermeneutic phenomenological conversation is unending” (p. xv). Barbara and Roberta agreed they were not seeking “truth”; they were interested in better understanding the phenomenon of interest. In addition, despite the limits of language, Barbara and Roberta believed “in the power of language to make intelligible and understandable what always seems to lie beyond language” (van Manen, 1997, p. xviii).

Findings

To capture as much as possible of what Roberta communicated, Barbara transcribed the audiotaped interviews

herself. This was an arduous process because it involved listening to the tapes multiple times to discern the spoken words that were often garbled or whispered. At times, Roberta was sobbing so hard that she was unable to get the words out. The interview text was read and reread, first as a whole and then interview by interview, looking for meaningful phrases, themes, and patterns.

Four fundamental existential themes—spatiality, temporality, corporeality, and relationality (van Manen, 1997)—were selected to guide the analysis of the interviews. According to van Manen (1997), the four existential themes “are productive categories for the process of phenomenological question posing, reflecting and writing” (p. 102). To help ensure that the process of analysis was sound, Barbara collaborated with a retired university professor who is an expert in phenomenological methods. This person served as a sounding board for ideas as the study unfolded, reviewed the manuscript, and served as a point of contact for emotional check-ins. It was recognized and accepted that the experience under exploration would be sensitive for both Barbara and Roberta. In addition, one of Roberta's family members read the entire manuscript for clarity and accuracy prior to submission. Seven themes emerged that form the general structure of Roberta's lived experience of a serious stroke. These themes are organized according to the four fundamental existential themes.

Lived Body

Two themes capture the experience of Roberta's lived body.

Feeling Ugly and Disabled

“Lived body (corporeality) refers to the phenomenological fact that we are always bodily in the world” (van Manen, 1997, p. 103). Prior to her stroke, Roberta was a strong, able-bodied, active person. Now she was confined to a wheelchair and unable to care for herself. This shift was sudden, and the changes were dramatic. It was a frequent focus in the interviews. As nurses, Barbara and Roberta brought to this experience the belief that the lived body must be viewed as a whole, consisting of mind, body, and spirit. Roberta's physical changes were visible, whereas her emotional and spiritual shifts were less visible and fluctuated over time. The change that Roberta commented on consistently was her physical appearance.

My body is goofy. Like an old woman. I look more like an old lady. It (the stroke) aged me.... My eyes look scary. I look old...like someone who has been through a lot. (Interview #3, June 2021)

In a later interview, Roberta returned to the topic of what she sees when she looks at herself in the mirror.

I see myself as very different since I had my stroke... very disabled. And, I have lost most of my strength. I can't do many of the things I used to be able to do.... I feel very ugly. (Interview #5, July 2, 2021)

Physical appearance is the one thing that Roberta would like to change if it were possible to do so. Together, Barbara and Roberta discussed ways to change things she did not like about her appearance, for example, getting a haircut once a month and shaving the whiskers on her chin. In her current residence, the staff paint her fingernails.

Experiencing Intense Loss

Roberta faced many losses poststroke, including the loss of physical control of her body, the loss of her beloved home and neighborhood, the loss of her spouse, the loss of her independent lifestyle, the loss of some relationships, and the loss of memories. Also, she said that at times she felt like she was “losing her mind.” Sadly, the loss of her spouse was even more difficult because of the COVID-19 pandemic and because of his placement in memory care prior to her stroke. Because of these things, Roberta never saw her spouse after her stroke, and he has since died. The text excerpts below capture statements made during interviews that illustrate the impact of the losses:

I don't remember anything (about the stroke and early weeks). Not one single thing. Nothing. It is all gone. It's scary and I feel it's worse to try to remember and not be able to. (Interview #1, May 11, 2021)

I feel afraid of the future for me. Will I be happy again? Will I ever be normal? Will I be able to work to support myself? (Interview #1, May 11, 2021)

It (loss of spouse) was devastating, devastating because I needed help, and he wasn't available. [Roberta was crying so hard that it was not possible to understand what was being verbalized. The taping was stopped.]

Often times, the conversations about loss were difficult and emotional for Roberta. Some of the most challenging conversations centered on her feelings of despair, fear, and anxiety. These conversations were not audiotaped because of the highly sensitive nature of the dialogue. However, it is important to note that at times Roberta expressed suicidal thoughts to Barbara, including describing a specific plan to end her life. Barbara believed Roberta felt safe sharing this with her because she is a psychiatric nurse, and Roberta knew Barbara would follow up. Immediately after these conversations, Barbara spoke to Roberta's daughter, who in turn spoke to Roberta's care providers.

Lived Space

Roberta's experience of lived space focused on two themes.

Space Matters

Since her stroke, Roberta has lived in several new spaces, including a hospital, a rehabilitation unit, and three residential care settings. She does not recall the early experiences in the hospital or rehabilitation unit, and she recalls very little of her first residential care setting. In the interviews, we discussed her experiences of space in her home prior to the stroke and in the two residential care settings that she remembers.

Roberta lived in her own home for 21 years before her stroke; she felt a positive attachment to the space. According to van Manen (1997), “The home reserves a very special space experience which has something to do with the fundamental sense of our being” (p. 102). The space we experience impacts how we feel and engage in the lifeworld. In fact, “we become the space we are in” (van Manen, 1997, p. 102). Discussing her lived experience of space in her own home was a sensitive topic for Roberta.

Barbara: “I want to talk to you about this space. How do you feel about it?”

Roberta: [Roberta immediately begins to cry and is difficult to understand].

Barbara: “Is this a hard topic?”

Roberta: “I lived in the same place for 10 years” [actually it was 21 years].

Barbara: “That place was sold after your stroke.”

Roberta: “I don't know.”

Barbara: “You don't have a memory of that?”

Roberta: [Roberta shakes her head to indicate she does not].

The strong connection to her previous home complicated Roberta's adjustment to her new living spaces. Barbara wondered if it would be possible to become connected to the new spaces. According to van Manen (1997), “it is helpful to inquire into the nature of the lived space that renders that particular experience its quality of meaning” (p. 103).

Barbara and Roberta also talked about her confinement to a wheelchair and its impact on the use of space in her care settings. Roberta described initial negative feelings about the confinement but seemed to accept the confinement as inevitable because of her physical limitations. She is dependent on others to move her about in the space she lives in. In reference to her second care setting, Roberta stated,

I spend most of the time in my room or outside on a nice day. I like it (bedroom). It is nice. I am used to it. It feels comfortable. (Interview #7, July 2021)

Roberta appreciates the efforts her daughters made to create a comfortable space with photos, furniture,

and artifacts from her previous home. Roberta said she likes these touches. They create a level of comfort. Along with feeling comfort in her bedroom, Roberta finds comfort on the outside patio surrounding the care center where she currently lives.

Nature Heals

In an instant, Roberta lost her mobility; she could no longer freely go in and out of her home whenever she wanted to. Prior to her stroke, Roberta had been an avid walker and a lover of the natural world. She lived in a beautiful home with lots of windows and ready access to nature. Every day she took advantage of the setting and her ability to get out in the world. Poststroke, she lived in three care settings. Barbara never saw the inside of Roberta's first residence because of the COVID-19 pandemic. It was a large care facility, housing about 76 residents. Roberta is unable to recall much about her experience living at this facility. Barbara's understanding is that Roberta spent very little time outside the building because of her condition at the time and the pandemic.

The next two care settings are more "homey" and less institutional looking. The homes are set in neighborhoods among houses. There is more open space, lots of trees and gardens, and ready access to the natural world. Both places have patios for residents to use as they are able. In Roberta's case, someone must wheel her out to the patios. Roberta likes to spend as much time as possible outside on the patios. Many times she mentioned the positive impact that sunshine has on her mood. The space in Roberta's current care setting seems to provide healing access to nature both inside and outside. The following excerpts illustrate Roberta's reactions to the space.

Oh, it (the physical space) is beautiful. The view (common areas have a wall of windows overlooking a wooded area). The trees. There are birds everywhere. (Interview #14, April 2022)

This residence also has a beautiful patio and outdoor area where Roberta can visit with friends and family. Barbara and Roberta visit on the patio whenever the weather allows.

Lived Time

One theme describes Roberta's lived experience of time.

Tracking Time Passing Seems Pointless

"Lived time (temporality) is subjective time as opposed to clock time or objective time" (van Manen, 1997, p. 104). Barbara often wondered how Roberta experienced time passing. Was time passing slowly or quickly? Did the days seem endless? Barbara knew Roberta had periods of time when she was sitting in a wheelchair, sometimes alone and at times with others present, but perhaps not

interacting with her. What did these times feel like for her? Barbara mistakenly assumed that time was dragging for her. When Barbara and Roberta initially discussed time, Barbara learned that this was not the case. In the first audiotaped interview, the following interchange occurred when Barbara asked for Roberta's perception of time passing.

Barbara: "Do you feel like you are progressing?"

Roberta: "Yes, I do. It gives me hope."

Barbara: "I do see you changing. It is slow."

Roberta: "It feels fast."

Barbara: "In this situation progress is slow. It is a little bit each day."

Roberta: "It seems to go fast. I am happy about this." (Interview #1, May 2021)

In a later interview, Roberta continued to support her perception regarding the passage of time. When directly asked about her experience of time passing, Roberta responded that time passes "quickly" and that mornings are the time of day that she enjoys the most. However, as Barbara and Roberta discussed this further, Roberta stated that time is passing more slowly now compared to prior to her stroke. Over time, Barbara came to accept that Roberta's experience of time passing did not seem to matter much to her in her day-to-day life. On a recent visit, Roberta stated that time is now passing very slowly, adding, "It's a marathon not a sprint."

Roberta can describe her daily schedule, that is, when staff get her up and put her to bed, when she has meals, and what she does in between these touch points. But there does not seem to be much of an emotional connection to what she describes. The exception to this is when she has visits from family members and close friends. She looks forward to these visits and brightens when she talks about them. Visitors are a welcome distraction and a connection to the outside world. For Roberta, they decrease feelings of isolation and loneliness.

There are times when Roberta's level of despair regarding her situation prevents her from looking to the future as bright and promising. This corresponds with the following words of van Manen (1997), "Through hopes and expectations we have a perspective on life to come, or through desperation and lack of will to live we may have lost such perspective" (p.104). When Roberta expressed suicidal thoughts and plans, her outlook on the future was very bleak. At these times, she was focused on the present and had difficulty seeing beyond it.

Lived Human Relationship

Two themes capture Roberta's experience of lived human relationships.

Cocreating Meaning

For approximately 1 year during her weekly visits, Barbara carried a small bag filled with articles, books, and audiotaping equipment in case Barbara and Roberta could work on the project during the visit. Barbara never knew until she arrived and assessed Roberta's current mental status whether they would be able to do any audiotaping. If things seemed favorable to taping a short piece of conversation, Barbara would set up, ensure privacy, and begin. Barbara noted that, during audiotaping, Roberta sat up taller and spoke more loudly and clearly. Over time, it became clear to Barbara that the project was meaningful to Roberta and that Roberta looked forward to working on it. Barbara and Roberta became colleagues collaborating on a project rather than friends chatting. In the first audiotaped interview, Roberta mentioned the importance of working on the project together, "I think this project helps me...by far...it is the most helpful." In the second interview, in response to a discussion of her feelings of loneliness, Roberta describes feeling lonely much of the time. However, she adds, "There is one exception...when I am with you." In the context of this discussion, Roberta is referring to Barbara and Roberta's collaboration on the project.

In another interview, Roberta again mentions the significance of the project to her. She states,

Barbara: "What does keep you going?"

Roberta: "First and foremost meetings with you."

Barbara: "That's meaningful?"

Roberta: "Oh yeah. Oh, my yes."

Barbara: "Me too. I find it to be meaningful, too."
(Interview #3, June 2021)

At the beginning of a much later interview, Roberta spontaneously says,

I have been thinking about you. I enjoy your visits so much. This project makes me realize who you are as a person. (Interview #12, December 2021)

Barbara believes that being there for Roberta, encouraging her to talk openly, and then accepting her emotions as expressed help Roberta recognize and begin to accept her changed self.

Wanting to Keep Human Connections Without Feeling Like a Burden

According to van Manen (1997), "Lived other (relationality) is the lived relation we maintain with others in the interpersonal space that we share with them" (p. 104). Roberta's social calendar was full prior to her stroke. Relationships with others brought purpose and meaning to her. She valued these human connections. van Manen (1997) states, "In a larger existential sense human beings have searched in their experience of the

other, the communal, the social for a sense of purpose in life, meaningfulness, grounds for living..." (p. 105). Maintaining relationships with family and close friends was a priority for Roberta. How would she be able to do this now that her life had changed so dramatically? Roberta wanted to engage with others but did not want to feel like a burden to them. This sentiment was a frequent topic during our visits and appeared in several of the interviews. Roberta especially wanted to maintain relationships with her two daughters and her grandchildren. When Barbara asked Roberta what would help her to feel less alone, she stated, *I want more conversation with my daughters. I am saying it would be better to focus on me (Roberta's feelings about the stroke)...mostly we talk about the kids (Roberta's grandchildren).*

Regarding the impact of the stroke on her daughters, she adds,

I feel sad because it is early...they are kind of young. Their mother's support has been lost.

When asked what holds her back from talking about her feelings of sadness with her daughters, Roberta elaborates,

I am afraid that they would love me less. They would love me less. (Interview #2, May 2021)

Barbara wondered if, rather than loving her less, would having authentic conversations with her daughters about her feelings after such a life-changing event build an even deeper love?

This desire to maintain strong connections was a common thread in a series of interviews focused on some of Roberta's grandchildren. Barbara and Roberta talked about what Roberta wants the relationships to be like now and what she wants moving forward. Roberta expressed wanting to be more intentional in her relationships with her grandchildren. The following text excerpts are examples of what Roberta expressed in interviews that focused on her grandchildren.

I want to speak to her about school and what she likes best. I want to tell her that what you learn about yourself (in college) is invaluable.... I want to ask "do you have any question for me about how I am doing after my stroke?"...I wish I could have more time alone with her. There are often others in the room. (Interview #9, September 2021)

It (her relationship) was closer than it is now because he was over with XX (her spouse) quite a lot.... I have not seen him as much this year unfortunately. I would like to see him more alone...to have more time alone with him.

When asked if she thinks he might be nervous about visiting Roberta now, she stated,

No, I don't. I would be very surprised if he said that. (Interview #10, October 2021)

As a result of these interviews that focused on Roberta's relationships with her grandchildren, Barbara and Roberta cocreated letters to some of her grandchildren expressing her desire to maintain connections with them, to invite them to speak to her about her stroke and her feelings associated with it, and to tell them her hopes and dreams for what their relationships might look like moving forward.

Discussion

The findings of this study provide a description of the lived experience of one person following a serious stroke. They add to the extant body of phenomenological studies focused on the lived experience of a stroke. An initial search was conducted with the assistance of a reference librarian at a university. The search included the Ovid MEDLINE and the Epub Ahead of Print databases. It revealed an abundance of publications focused on stroke survival. However, when narrowed to focus on the experience of stroke and phenomenology, the literature was less robust. When the search was further targeted to phenomenological literature focused on four fundamental existential themes, (1) corporality, (2) spatiality, (3) temporality, and (4) relationality (van Manen, 1997), as well as stroke survival and phenomenology, the literature was sparse. In the end, 11 phenomenological studies were identified as germane to this inquiry. Five of the phenomenological studies included an emphasis on corporeality, two on spatiality, one on temporality (combined a case study approach with phenomenology), and two on relationality. An additional study conducted by Simeone et al. (2015) described the experience of stroke survivors 3 months after they returned home. Simeone and colleagues explored the stroke survival experience more broadly than the others, which targeted a very specific physical aspect of the stroke experience, for example, apraxia, hemiplegia, or upper limb dysfunction.

Five of the selected studies focused on the lived experience of a variety of bodily responses to a stroke, including apraxia (Arntzen & Elstad, 2013), somatosensory impairment (Connell et al., 2014), upper limb dysfunction (Purton et al., 2021), altered body perceptions (Stott et al., 2021), and hemiplegia (Takashima et al., 2016). Arntzen and Elstad (2013), Connell et al. (2014), and Stott et al. (2021) described themes focused on the dramatic changes to the physical bodies of their participants. This study identified one theme (feeling ugly and disabled) that is consistent with these findings. In addition, this study describes a second theme (experiencing intense loss), which is associated with the body, but is more focused on the

psychological aspects of the recovery process. Barbara and Roberta intentionally wanted to focus on the whole person in trying to understand the lived experience of surviving a serious stroke rather than to isolate one physical aspect of the bodily responses to a serious stroke. Perhaps beginning with a broader lived experience allowed this second theme to emerge. Interestingly, although focused on a physical response (upper limb dysfunction) to a stroke, Purton et al. (2021) identified a subtheme (meaningful and valued activities) that has a psychological focus. These authors reported that participants in their study spoke about the detrimental impact on their ability to fully participate in activities that had been meaningful to them prior to their stroke. Purton et al. interfaces nicely with the theme (cocreating meaning) that was found in the study reported here.

The Barbara and Roberta project became deeply meaningful to Roberta as she worked to reconstitute herself after her stroke. In a study conducted by Takashima et al. (2016), seven themes emerged, four focused on physical experiences of the body and three focused on coping with the changed body. Again, themes related to the physical body as well as themes related to psychological aspects of the stroke experience emerged and relate to the findings of the Barbara and Roberta study. One of the psychologically focused themes, "License for *amae*," is significant to the current study findings. Takashima et al. describe *amae* as "a tendency to count on other people's kindness" (Takashima et al., 2016, Results section, para. 2). According to them, "if clients have important people who permit the clients' *amae*, it will become [*sic*] a strengthening factor to make the client's view present lives and selves in a positive light" (Takashima et al., 2016, Implications section, para. 4). Perhaps *amae* was at play, although not identified as such at the time when Barbara agreed to participate.

Two studies explored space on an acute stroke unit. Both support Barbara and Roberta's finding of the importance of creating meaningful space for people who are recovering from a serious stroke. One of these two studies focused on the lived experience of healthcare practitioners (Suddick et al., 2019). A major finding of the study was that the acute stroke unit was viewed as a meaningful space for the practitioners. Their work with patients and others in the space held deep meaning that resulted in feeling a sense of belonging. The participants voiced "a concern, commitment, and felt responsibility to practice through their relationships with patients, relatives, but also their colleagues; and to sustain hope in what was perceived as the most tenuous of situations" (p. 18). The other study focused on stroke survivors (Suddick et al., 2021). Analysis of the transcripts revealed two interconnected forms: (1) holding space and (2)

transitional space. The holding space offered protection and safety, whereas the transitional space, including the practices of the nurses, gave the survivor time to transition into acceptance of their new self. Clearly, attending to space regardless of the location is important and impacts the responses of the patient and their caregivers.

Only one phenomenological study related to time perception was found in the literature. It focused on a very specific type of stroke, that is, thalamic stroke. In the study, Mole et al. (2017) used a case study approach to explore time perception impairment following a thalamic stroke. The case study participant was tested with the results compared to two control groups. The participant reported time perception problems, disorientation, sleep problems, fatigue, and low mood. Combined, these factors impacted her role performance. Barbara and Roberta's study confirmed that time perception difficulties are present following a serious stroke, although Barbara and Roberta concluded that time perception did not seem to have a significant impact on Roberta's day-to-day activities.

The finding Barbara and Roberta found most noteworthy and surprising was the deep meaning and value that participation in the project held for Roberta. It was valued by Barbara as well, but without a doubt the magnitude of the impact was greater for Roberta. The authors of two prior phenomenological studies found themes centered around relations with others that support Barbara and Roberta's findings (Bergstrom et al., 2015; Fallahpour et al., 2013). In the first study, Bergstrom et al. (2015) explored the lived experience of enacting agency during the first-year poststroke. Agency was defined as "making things happen by their own actions in the everyday lives, after a stroke" (p. 43). One characteristic (dealing with the outside world) described the stroke survivor enacting agency by activating another person in the outside world to engage with them. In the current study, Roberta enacted agency by bringing up the idea of a "project," lightheartedly at first, but later for more serious consideration. The project evolved to be something that created deep meaning for Roberta as writing was something that she was passionate about prior to her stroke. In the second study, Fallahpour et al. (2013) shared their findings regarding the importance of discussing the significant losses associated with the stroke, offering choices, and encouraging autonomy with the aim of preserving important roles from the person's previous life. Barbara and Roberta's study offers support to the works of Bergstrom et al. and Fallahpour et al.

Perhaps the most interesting aspect of this project has been the response of family members and friends when they hear about it. People are interested in how the process

evolved. They want to learn about Roberta's lived experience, but they also wonder about Barbara's decision to participate and spearhead the project. At times, they asked about accommodations that were made to allow the project to be conducted. An example of this was when philosophical ideas were discussed as they related to the findings of the project. Based on fluctuations in Roberta's cognitive abilities, adjustments were made during these discussions to capture basic ideas of a philosopher rather than their more complicated ideas. The ideas of Emmanuel Levinas are relevant to our project and influenced this phenomenological inquiry. Levinas emphasizes the importance of drawing together ethics and justice when exploring human behavior in social interactions. Moran (2000) describes Levinas's ideas regarding ethics as "ethics is never an egocentric mode of behaving, nor the construction of theories, but involves the effort to constrain one's freedom and spontaneity in order to be open to the other person, or more precisely to allow oneself to be constrained by the other" (p. 321). Phenomenology offers an opportunity to turn to the experience itself and to maintain an open attitude to the experience of the other person. In doing so, the essence of the experience may be revealed.

Barbara and Roberta believe that Barbara's decision to participate was ethical and just. Levinas believed that ethical experiences "have a *prescriptive* element, to incorporate a demand about how humans should behave, rather than merely describing how they *do* behave" (p. 321). Barbara recognized Roberta's physical and psychological vulnerability. This recognition triggered the "undeniable presence of loving responsibility" (van Manen, 1997, p. 6). Barbara felt compelled to participate as it felt like she should, and it felt like a loving responsibility or perhaps it was *amae* as described by Takashima et al. (2016) that influenced Barbara's decision to participate. Did Barbara help to create a milieu where Roberta was able to talk about the possible project? Perhaps because Barbara and Roberta had a longstanding relationship, Roberta was able to count on Barbara's kindness. Did Barbara's kindness encourage and strengthen Roberta's resolve to participate in and complete this project? Lastly, perhaps the decision Barbara and Roberta made to complete this phenomenological inquiry is purely what Bergstrom et al. (2015) described as enacting agency. Most likely, Barbara was motivated by all these things: ethics, responsibility, kindness, and agency.

Limitations

There were challenges to this project. Barbara and Roberta agreed that interviews would be a way to capture

Key Practice Points

- Gain a better understanding of poststroke survivors' responses to bodily changes, changes in time perception, reactions to lived spaces, and changes in interpersonal relationships to individualize care that extends far beyond the stroke and the initial rehabilitation period.
- Create care environments that ensure privacy and are homelike versus institutional as they encourage intimate conversations about intense feelings of despair, anger, and anxiety.
- Designate intentional time on a regular basis to meet individually with patients to discuss their feelings and concerns. During these times, be "fully present" and not distracted by the provision of other cares.
- Assist patients to identify meaningful activities previously engaged in that are no longer possible because of limitations and identify people who may be willing to partner with them to continue participation in the meaningful activities.

Roberta's experience in real time. However, the reality was that often Roberta lacked the stamina and even the ability to project her voice and speak clearly. In addition, there were times when Roberta's level of pain and fluctuations in mood did not allow for conversations beyond what she was dealing with in the moment. Having the luxury of hour-long interviews and many pages of transcribed text was not possible. Along with the challenges, there were limitations. Words are limiting as they often cannot capture the precise meaning the speaker is trying to convey. There are limitations when a case study approach is used as the findings are not generalizable. Following a stroke, a person's ability to reflect may be limited. Lastly, the outcome of this phenomenological inquiry is not the discovery of an absolute truth, rather it is a description of a lived experience.

Conclusion

Strokes are common and, when serious, carry devastating long-term consequences for survivors. Roberta's rehabilitation experience has been challenging, and improvement has been painstakingly slow. Currently, she resides in a care facility that provides round-the-clock care. She will not live independently again. Over the course of many visits Barbara and Roberta explored Roberta's lived experience of surviving a serious stroke. Phenomenology allowed Barbara and Roberta to turn to the experience itself with an open attitude, which allowed the essence of the experience to be revealed. Seven themes emerged that were organized around the existential lifeworld's of body, space, time, and relationships. Specifically, the dramatic bodily

changes following a serious stroke result in significant losses for the stroke survivor. The subsequent intense feelings associated with the losses need to be attended to. In addition, space matters. Creating spaces that are homelike and foster connections to the natural world will impact recovery and improve quality of life for the stroke survivor. Time perception problems appear to matter less than space and, in this case, did not impact day-to-day existence in a significant way. Perhaps the most important finding of this study was that cocreating meaning and a sense of agency played a critical role. The findings of this study add to the extant body of knowledge in the areas of phenomenology and stroke survival experiences.

Conflict of Interest

The authors declare no conflict of interest.

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