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Life in a Crossroad: Lived Experiences of Spouses Caring with Cerebrovascular Accident Survivor

Kevin Roy D. Sargadilos, Madelene A. Barcial, Cyrille Y. Panimdim and Jessica S. Simporios
Cebu Institute of Technology-University, the Philippines

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ABSTRACT

Cerebrovascular accident (CVA) may leave permanent and long-term disability placing a burden on the family. Disability following the CVA often required family, especially spouse to provide care. Spouses may struggle to adapt to a long-term caregiving role and relationships with CVA survivors. The study aims to describe the lived experiences of spouses of CVA survivors in order to gain a deep and thorough understanding of the phenomenon. The Husserlian descriptive phenomenology design was used to purposively identify the eight informants. The data were gathered through an interview, after which transcription was done and analyzed using Colaizzi's method. After the thematic analysis, four themes emerged: (1) Increased Domestic Workload (2) Exhaustion: (a) Physically Demanding (b) Psycho-emotional Distress (c) Financial Burden, (3) Bound for a Mission and Responsibility: (a) Being Obligated (b) Strength of Relationship (c) Spouse Welfare, (4) Sense of Loss: (a) Loss of Understanding (b) Loss of Hope (c) Loss of Control. Taking care of CVA survivor had contributed to the changes in the lives of these spouses. The physical, emotional, psychological and financial matters had to be considered that could affect the wellbeing of both the spouses and the CVA survivor. The support of spouses of CVA survivors and their families in achieving optimum long-term adjustment was essential.

Keywords: *Spouses, Stroke Survivor, Live Experiences, Husserlian, Descriptive Phenomenology*

INTRODUCTION

Approximately 15 million people worldwide experience stroke annually, of which five million experienced permanent disability, including loss or impairment of speech, sight, and mobility placing a burden on family and community. The incidence of stroke is increasing in developed and developing countries, including the Philippines (World Health Organization, 2005; World Heart Federation, 2013). It is the number five cause of death in the United States, a major health problem in developed countries, and one of the most common causes of death in many industrialized countries (American Stroke Association, 2017). The Philippines is one of the Asian countries whose aging population is high, and stroke is common in countries with this kind of population in which the average incidence of stroke is 116 and 483/100,000 per year (Suwanwela and Poungvarin, 2016). Stroke survivor often requires assistance in performing activities of daily living from the other people and commonly direct family members to provide unpaid support. This can lead to worker vulnerability. This is produced in complex webs of policy conditions, societal attitudes, structural inequalities, organizational practices, individual life-stories, and personal experiences. Being produced and shaped by interrelated social realities, however, they may be actively addressed through efforts towards changing these realities (Sardadvar, K, 2012).

Becoming and living with stroke survivor in the family often occurs without deliberation. Family members share the common experience, but this is lived within the context of individual member's daily lives. These individual nuances impact the experiences, roles, and contribution of members within the stroke family (Green and King, 2009). The study aimed to describe the lived experiences of spouses with stroke survivor and to gain an in-depth and thorough understanding of the phenomenon.

METHODOLOGY

Research Design

This study utilized Husserlian descriptive phenomenology design to explore the lived experiences of the study informants. The narrative coming from those who have experienced the phenomenon gives an in-depth and rich description of the phenomenon being studied.

Settings and Informants

The study was conducted at Barangay Labangon, Cebu City the adopted barangay of Cebu Institute of technology-University. They were interviewed in their respective home based on the informant's convenience. The purposive sampling was utilized within the selection of study informants with the following inclusion criteria: (1) had a partner diagnosed of stroke and must have physical restrictions that required total assistance with one or more activities of daily living, such as, bathing or eating; (2) Age must be 18 and above; (3) Must be the primary caregiver; (4) the caregiving situation must be one-year duration or longer. Ten informants were gathered but then 2informants backed out from the study. Hence, there were only 8 informants interviewed in this study. Data saturation was obtained through repeated information and experiences that were shared, and no new information and redundancy of the answer were present (Polit and Beck, 2012).

Research Procedure

To explore the lived experiences of spouses caring for a cerebrovascular accident survivor, the researcher conceptualized the topic and deliberated it with the faculty and the Dean of the College of Nursing. The researchers asked for approval from the Cebu City Health Department to conduct the study in Barangay Labangon. The list of cerebrovascular accident survivor was secured from the Barangay Health Workers. The processed consent was secured then preliminary meetings were conducted prior to the actual interview. The preliminary meeting was done to establish trust and to agree on the venue and the time that was convenient to the informants.

The researchers conducted an in-depth individual interview with the informants where the environment was quiet and free from distractions. The informants were also informed that a voice recorder would be utilized to ensure that data will be collected thoroughly. Data saturation was obtained after the seventh informants.

Ethical Consideration

The approval letter was secured from the Cebu City Health Department to conduct the study, and process consent was secured before the interview was conducted. During the interview, the informants were told that the interview would be voice recorded to ensure that all data will be thoroughly captured. After the transcription and analysis of the narrative data, all transcripts were kept in a locked cabinet where only the research has access. The transcripts were destroyed using a shredder after data were analyzed.

Data Analysis

To discover the real experiences of the phenomenon under investigation the Colaizzi's method was used. The audio-recorded interviews were played many times, and significant statements and feelings were extracted and transcribed. Each written transcript was read several times to ensure the accuracy of the transcribed audiotapes interview and to come up with a better overall understanding of each informant's experience. This method consists of seven steps. First, the researchers read and re-read the transcript in order to obtain a general sense about the whole content. For each transcript, significant statements that pertained to the phenomenon under study were extracted. Meanings were formulated from these significant statements. The formulated meanings were sorted into categories, clusters of themes, and themes. The findings of the study were integrated into a comprehensive description of the phenomenon under study. The fundamental structures of the phenomenon were described. Finally, validation of the findings was from the research participants to compare the researcher's descriptive results with their experiences.

RESULTS AND DISCUSSION

From the data gathered and analyzed, with the use of Husserlian descriptive phenomenology and Collaizi's Method, four main themes, ten subthemes had emerged namely:

Main theme 1: Increased domestic workload

In the care of stroke survivor, spouses faced an additional burden in promoting and maintaining their optimum well-being. All stroke survivors in this study were cared at home by their spouses. The conditions cost too much on the part of the spouses. The spouses act as a personal aid to the stroke survivor who lose almost all the physical functions. This is physically demanding on the part of the spouses as the source of physical and emotional support from the stroke survivor. As the following informants verbalized:

I1: (SS 1) I am taking care of him for one year already, he is bedridden and cannot stand up. I feed him, I clean his bowel and give his bath.
I4: (SS 4) To "move" when he is wearing a diaper. To keep to get up, would not get up. He cannot eat because his mouth is distorted. We find hard to feel him. To walk, and for him to learn to walk
I8: (SS 3) Always changing diaper.

Caregivers experience an increased workload, taking on tasks previously done by or shared with the stroke survivor. There are new caring tasks and role reversals. Spouses describe additional strain as they attempt to juggle competing demands. Caring for a stroke survivor is often multi-faceted and caregivers undertake nursing and physical therapy duties provide personal care, act as protectors, interpreters, intermediaries, and filter communication to shield, encourage and emotionally support the stroke survivor and advocates (Cecil et al., 2011; Lee and Mok, 2011; Kitzmüller and Häggström, 2012).

Main theme 2: Exhaustion

Subtheme 1: Physically Demanding

It is the state of being drained, consumed, or used up due to necessary care task for stroke survivors. Caring for their partner is physically demanding especially for those spouses who are the only one caring for them. Therefore, the physically demanding care that is required by the stroke survivors that causes for spouses altered their comfort and personal needs in order to attend the needs of their patient that could lead them experienced exhaustion during performing and assisting activities of daily living. As the following informants verbalized:

I1: (SS 6) I am the only one taking care; wake up at dawn, feed him or give him early breakfast, at daylight I bathe him and wipe him dry because he cannot stand as he is bedridden.
I2: (SS 1, 2 and 3) It causes stress, tiring. All tasks are yours. I wake up early to open the store and sleeps late because I need to clean the sala then let him sleep, because I need to wash the dishes…to bathe him I could hardly carry him…to clean his bowel in the diaper…very hard because I am alone.

Stroke survivor experiences physical impairment or functional disability, and they need the assistance of others to meet his or her basic needs. Stroke survivors require assistance from family members with activities of daily living. This can involve long hours providing care, leading to fatigue and burnout (Anderson et al., 1995) confirms the claims of a person's activities of daily living (ADL) dependency can create stress for family caregivers.

Subtheme 2: Psycho-emotional Distress

Mentally and emotionally distress from doing intense or prolonged work that requires thinking, figuring things out such as the cost of living, medication expenses, and situational outcome that can lead them to experience constant stress. Spouses get emotionally affected when stroke survivors are irritable and easily get distressed. Emotional tension arises in the way between partners due to a misunderstanding during the provision of the needs and the attitude of the patient towards the spouses. Stroke affects the behavior and mood of the survivor that can put the spouse into a stressful situation on a daily basis. Furthermore, due to the psychological and physical disability of the stroke survivor, spouses encountered that they are the sole decision maker of the family. Moreover, spouses felt being alone and abandoned with total responsibility that put them into a difficult situation. As the following informants verbalized:

> *I3: (SS 1) Very difficult, you need to understand them. They are irritable, sometimes it's stressful, it's really difficult.*
>
> *(SS4 and 6) Your cleaning then he suddenly harms you, like he is not in his self. It is difficult now because whenever we he wants something, it should be granted instantly.*

A population-based assessment of the impact and burden of caregiving for a long-term stroke survivor, over half of stroke caregivers experience emotional distress, especially if the stroke has resulted in dementia and/or abnormal behavior (Anderson et al., 1995).

In the study about physical and mental health, caregiving role is stressful and burdensome. Caregivers may experience psychological distress due to stressors such as the type and duration of care provided, cognitive disabilities, and behavior. Greater degrees stress and low ratings of subjective well-being in caregivers are consistently associated with cognitive and functional disabilities (Pinquart & Sorensen, 2007)

Subtheme 3: Financial Burden

Stroke can cause financial burden especially if the one affected is the breadwinner of the family. This causes a great handicap within the family because of the loss of a great productive income gainer within the family. The spouses who take care of the stroke survivor assume the responsibility of looking of means to generate funds for the family to survive. As the following informants verbalized:

> *I3: (SS 7) it's hard, no one helps you..ife is difficult, all my earnings goes to him…before it helped a lot…but now it's hard to be the bread winner.*
>
> *(SS 12) All of my earnings before were all spent for his condition*
>
> *I8: (SS 1) It's hard to live, he no longer can help us…our hospital bill is very big.*

Financial consequences are more prominent in Families where the stroke survivor was the breadwinner that results in dependency on the family for accommodation and financial support (Anderson et al., 1995; Thomas & Greenop, 2008). Some caregivers giving up their job to care for the stroke survivor despite resultant financial limitations while others continued working and required to find a job to sustain the needs of the stroke survivor (Buschenfeld et al., 2009)

Main theme 3: Bound for a Mission and Responsibility

Subtheme 1: Being Obligated

As a spouse, commitment and dedication are the string that binds the marriage to last longer. Being married to someone, the sanctity of marriage serves an important role in caring and commitment, and they are bound together which was largely regarded as lifelong. Spouses act being morally or legally bound to take good care of one another. Spouses felt the strong commitment and sense of duty and responsibility to deliver care and to stay close to the person who had suffered a stroke.

I1: (SS10) He is my partner. I will take care, feed and clean.
I2: (SS6) He is my husband…and that is my role…I serve.

Spouse or family member was often assumed to be the career. Being a close relative meant a feeling that they always had to be accessible, attentive, ready to act, and that through their actions they held the life of the sick person in their hands. They were forced to shoulder the responsibilities they have never had before. Caregivers described multiple reasons for taking up the role. The predominant appeared to be a societal and moral expectation that spouses and relatives would automatically or contractually (through marriage) (Backstrom and Sundin, 2009).

Subtheme 2: Strength of Relationship

Showing affection and compassion is innate in a relationship and becomes more evident in a grievous situation. This serves as a basis for holding on and strives to continue to stay together. Moreover, commitment involves the willingness of spouses to work for the continuation of their relationship. Spouses whose partners are affectionate tend to give back the generosity and love that they have received. It is a feeling of indebtedness and an emotional responsibility of the spouses to stroke survivors. The compassion shown by the spouses to their partners serves as a moral obligation due to their love for one another. They cannot afford to abandon their loved one in a difficult situation because of the deeper connection that is established between them.

I1: (SS 11) They are pitiful, our love is until death
I3: (SS 17) He is very good so he deserves goodness.
I6: (SS 4) I felt pity of him.

Compassionate love seemed in spouses and stroke survivors that to be most easily supported and maintained when it was experienced as a process of mutual give and take between partners. They described that caregivers opened patients to new levels of gratitude, love, and compassion, and similarly the patient's ability to act out of compassion opened the caregiver to continuing self-sacrifice, patience, and tending. (Roberts and DuBenske, 2009).

Subtheme 3: Patient Welfare

As the one caring of a stroke survivor, it is inherited a trait that welfare is the utmost concern. The spouses become sensitive to the actual and anticipated needs of the stroke survivor. While they render the needs, the spouses' needs (physical, emotional, social, and spiritual) is neglected. There were feelings of a demand to be present and available, requiring concentration and strength, a full-time responsibility. Spouses focused on the care and provided comfort and safety on a daily basis. As the following informants verbalized:

I2: (SS 4) My thoughts, that to take care does not change. I only thought of the house and to care.
I3: (SS15) Now, I only think to take care for him, give him what he needs.)
I8: (SS9) If he moves he might fall.)

There is a feeling of unable to leave the stroke survivor at home unattended, fearing they might fall, suffer a recurrent stroke and feeling guilty. In an online journal of the Disability and Rehabilitation caregivers feel trapped and imprisoned in their homes and have their usual routines disrupted by the survivor's increased presence. Some older caregivers do not find the stroke to be socially restraining as chronic health conditions had already restricted their lives prior to the stroke (Greenwood et al., 2010).

Main theme 4: Sense of Loss

Sub-theme 1: Loss of Mutual Understanding

The relationship decreases due to impairment of speech and behavior of the stroke survivor. This may be difficult on the part of the spouse and is often misunderstood. The lack of knowledge regarding the condition of the stroke survivor leads the spouse to break free from the attachment and becomes unconsciously insensitive to the needs of their partners.

> *I1: (SS 7) Sometimes I understand, sometimes I would say do not talk anymore because I cannot understand.*
>
> *I3: (SS 2 and 3) Their mood is difficult…sometimes good and suddenly they change and becomes violent and hurts.)*

Cognitive impairment is a common consequence of stroke. The degree of a cognitive deficit is related to career outcomes such as psychological wellbeing, and perceived stress and burden. In addition, the overall burden of care is high for family members of stroke survivors with aphasia because they may be required to take on a wide range of roles and responsibilities as the person with stroke cannot communicate easily and difficulty to understand the needs of the stroke survivor. (Anderson et al., 1995; Greenwood et al., 2010).

Subtheme 2: Loss of Hope

The uncertainties of what would happen to the stroke survivor that leads to a feeling of discouragement from the spouse. With a little knowledge regarding the condition leads to loss of hope and hurtfully accepts the possible detrimental outcome of the condition. The condition leads them to greater despair especially when they cannot do something to alleviate the suffering that the stroke survivor has to endure.

> *I1: (SS 12) Until when he will last. Patience is needed.*
>
> *I3: (SS 13and 14) it's good if he will be well but just no hope…at first you want him to get well but now its worst…no more hope that he will be well.*
>
> *I5: (SS 2 and 7) He can't see clearly anymore. I am in a dire situation. But God is there, but I already recovered and accepted that it is what it is. I already accepted the fact that this is how he is.*

Individuals lose their sense of hope caused by their overall well-being to have a negative impact. Lack of resources for care, struggles with relationships, long-lasting caregiving situation, and a number of other barriers can cause a feeling of discouragement to continue. When well-being is affected negatively, feelings of hopelessness can develop. Feelings of hopelessness in individuals or families have the potential to hinder any form of resilience they may have.

Subtheme 3: Loss of Control

Lack of ability to provide conscious limitation of impulses and behavior as a result of overwhelming emotion can happen in any stressful event such as taking care of long-term caregiving situation. This type of behavior is not intentionally inflicted by the spouses instead it is a result of emotional breakdown due to severe bombardment of sudden hardships, uncertainties and trials in life that they need to overcome. In addition, loss of control of the spouses that are provoked by the actions of the stroke survivors that is undesirable that lead the spouses to cursed their partners and even hitting them out of anger.

> *I1: (SS 4) I can only sigh and say…"When will God take him"...and then my sacrifices.*
>
> *I3: (SS 5) of course, I get frustrated, I spank him…. You pity, but there are times you get "pissed" because it's hard to take care…he is very good so he deserves goodness.*
>
> *I4: (SS5 and 7) Sometimes I shout at him because he is hard-headed, there are times he acts very childish, very hard-headed.)*

According to the Family Caregiving Alliance (2014), anger and frustration are a normal part of being around someone who needs help on an ongoing basis and who might not be accepting of help. Caregiving can be even harder, as the care receiver can be irrational and combative. It is not always possible to be in perfect control of your emotions. Anger "just comes out" sometimes. In a population-based study by Anderson et al., (1995) of 84 families in Australia, 35% of careers reported adverse effects on family relationships for a range of reasons, including misunderstanding and displacement of anger about the stroke to others.

Central Theme

Dealing with partners who survived from a stroke with physical disabilities is the same as being trapped in a crossroad. They created lots of sacrifices and efforts along the way hoping to overcome those obstacles. Exhaustion came in so many ways; physically, emotionally, mentally and financially. Taking care of a loved one suffering from a condition that they did not even know whether the stroke survivor would return back to normal in the future or not, took a lot of effort on the spouses' part. Uncertainties came in the way and affected the relationship between the survivor and the spouse. CVA survivors were cared for at home by their spouses who acted as a personal aid and physical support. Spouses tend to forget their personal needs and comfort due to the physical demands of their partner. They acted as the sole decision maker and breadwinner of the family knowing that their partner was disabled. Some spouses doubled their effort to sustain the needs of the family. Everyday life became uncertain and full of contradictory thoughts and feelings. The spouses also lost their will to continue because they felt that they had also been handicapped due to the disability their partner was suffering. Spouses were trapped in an inevitable crossroad in which suddenly became unfamiliar and changes that forced them to make important decisions in life.

Despite the disability, spouses still lived together; they assumed the responsibility of a caregiver and gave credit to the goodness of the stroke survivor. It was difficult on the part of the spouses to leave their partners because they knew that they were the only one that their partners relied on. It was just a way of giving back to the things that the breadwinner had done to the family before being struck with the condition. Moreover, this study had drawn attention to the fact that the feeling that they had no choice but to provide care for CVA survivor-led to a great deal of pressure and a great amount of strain to the relationships. Based on Social Exchange Theory, relationships should be given and take. Commitment involved the willingness to work for the continuum of relationships. It builds stability of relationships by increasing partners' dependence. In other words, the level of involvement, dependence, and resources contributed to the different interaction observed within the relationship. Spouses lost their mutual understanding and became insensitive to the needs of their partner and causing them to lose their control. Their actions were not intentionally inflicted, but instead, it is a result of severe bombardment. The overwhelming emotions led them to curse their partner, and even hitting them out of anger. They only continue moving forward in taking care of their loved ones and losing the hope that someday their lives would go back to the way it normally was. In the study about Philippine Values, spouses placed a high regard on their family and prioritized them before anything else. They had placed the utmost priority in meeting the family needs. They assumed the sense of duty and responsibility to deliver care and repaid the favors done to them with gratitude (Henig 1983).

Nursing Implications

The lived experiences of spouses with stroke survivor were never simple and easy. Their daily lives suddenly became unfamiliar and changed that reflected the reality of caregiving because they were disrupted by a stroke. The physical, emotional, psychological and financial matters had to be considered that affects the well-being of both the spouses and the stroke survivor.

The result of the study suggested that healthcare professionals must enhance the quality of life of these spouses when rendering care and support that would become meaningful to the care recipients. First, to create programs they would support the physical, emotional, psychological, and financial needs of spouses and stroke survivor like seminars that will enhance their knowledge and skills. Second, health care providers should consider how support was offered over the course of caregiving and taught spouses or any family members on how to take care of the stroke survivor during hospitalization to ensure the quality of care they rendered. Third, there should be an ongoing psychological evaluation of the spouses and families to determine the capability to provide long term care. Moreover, appropriate timed support should be provided to enable spouses to adapt; improve their psychological well-being and help them to feel supported and heard.

With a better understanding of the challenges that spouses face and health professionals would be equipped to support individuals through the caregiving process, in return for the benefits of the stroke survivor. Supporting the spouse of stroke survivors and their families in achieving optimum long-term adjustment should be fundamental in order to optimize the quality of life of the entire family members. Spiritual strength enhances a relationship if God is in the center of their lives.

RECOMMENDATIONS

On the basis of the findings, the following recommendations arrived:

1. To the spouses and other family members to look for support groups that would help and guide them in dealing more about their partners.
2. To the national and local government unit will support them financially and implement free caregiving seminars to enhance the well-being of these spouses of stroke survivors and the quality of care they provide to them.
3. Further study is recommended to explore other perspectives of the phenomenon similar to this study to be conducted different setting, and repeated observations must be done among the research subjects over a long period of time can solidify what has been found out from previous studies or can produce new ideas and result.

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