

# Journeying the life of a Post-Stroke Person

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## Abstract

Stroke brings about challenges that include psychosocial or cognition that may result in non-compliance as well as learning difficulties which interfere with the individual's speed of recovery thereby placing a burden on care or family. Additionally, it could also increase the financial burden to meet medical costs, increased dependence on caregivers, and decrease their capacity to participate fully in social activities. The qualitative study specifically the case study design utilized the phenomenological approach to explore the experiences of a post-stroke person. The unit that is being studied is the family and the post-stroke person who was clinically diagnosed with stroke with comorbidities. Getting to know ME, being hopeful, and being helpless are the three aspects of the life of a stroke person. On the other hand, being helpless where there was a feeling of maltreatment, financial burden, and self-pity greatly affects the relationship between the post-stroke person and the family. As a result of the study, health training institutions emphasize how best the psychosocial needs of post-stroke can be addressed by health personnel. Professional nurses as well as those in the academe should come up with a teaching-learning strategy for handling post-stroke persons. Counseling services should be mandatory and made available to post-stroke persons and their families hence, health institutions like the hospital to craft and implement a policy to address such activity. Another study is to find out how caregivers manage and how looking after a post-stroke person affects their quality of life.

**Keywords:** Stroke person • Post-stroke • Life

## Introduction

Stroke is one of the leading causes of morbidity, mortality, and disability worldwide. It occurs when an artery supplying blood to a part of the brain suddenly becomes blocked (ischemic stroke) or bleeds (hemorrhagic stroke). This causes loss of functions including the movement of body parts, vision, swallowing, and communication, and may lead to death. Nursing as a caring profession deals with unique patients with different diagnoses such as stroke [1-5].

According to the WHO, 15 million people suffer stroke worldwide each year: 5 million die, 5 million survive, and; 5 million are permanently disabled. Stroke is the second leading cause of death in the western world, Stroke is one of the leading causes of mortality in the United States with a rate of 5.28 per 100,000 population. In Australia, the median age is about 79 years. NINDS (2004) reported that the risk for stroke occurs at age 55 and the age of 65 is a greater risk for dying from stroke than the general population ranking after heart disease. In 2003 Australia, almost 7% of all deaths were caused by stroke. In CAR, one of the leading causes of mortality in stroke having a total of 93 with a rate of 5.28 per 100,000 populations while

hypertension is one of the leading causes of morbidity having a total of 27,523 with a rate of 1561.59 per 100,000 populations [6].

The results of this study provide further knowledge and skills in dealing with a post-stroke person and serve as a guide for professional nurses in developing a teaching-learning plan for both registered nurses and student nurses in caring for a post-stroke person [7]. Further, it will be used by health practitioners and policymakers in planning appropriate programs for people living with a post-stroke person to review their management approaches and promote appropriate interventions depending on the needs of the individual [8,9].

## Objectives of the study

The objective of this study was to understand the life of a post-stroke person. The question asked was "tell me your experiences as a post-stroke person". An ancillary question was asked to the participants to expand on the experiences of those who had suffered a stroke. Through these questions, participants were encouraged to describe both the positive and negative aspects of stroke experiences.

## Philosophical underpinning

As we learn and understand the life of a post-stroke person, positive changes in the approach to caring may be developed. It can also provide further knowledge, skills, and experience in dealing with this kind of patient suffering from a disability as a result of a stroke. This study was anchored on the theory of constructivism which posits that people form or construct much of what they learn through experience.

## Methodology

### Research design

The study utilized qualitative techniques specifically, case studies to explore the experiences of a post-stroke person.

### Setting and participants

The study was conducted in Bontoc, Mountain Province, Philippines from October 2021 to October 2022. The participant was interviewed at their home where home visits were done. The unit that is being studied is the family and the post-stroke person who was clinically diagnosed with stroke with comorbidities.

### Data gathering tool

Interviewees were asked questions that were translated into Bontoc language by two independent translators and in the local dialect. The main question asked was, "tell me your experiences as a post-stroke person". An ancillary question was used to encourage the participant to expand on their experience. An interview with her niece/nephew and members of the family was conducted to obtain data regarding the client's situation and condition. An audio recorder and video camera were used to capture the conversation and observations. The patient was interviewed at the hospital and at home 6 times and had a home visit 6 times.

### Data gathering procedure

Ethical approval was obtained from the College Institutional Ethics Review Committee (IERC) The standard operating procedure of research was followed. Communication letter was given to the Hospital to be able to review the patient's records. Most of the interviews and home visits were done early morning and evening so as not to be a burden for the participant and her family.

### Data analysis

The researcher organized the data into categories and sorted it into sub-

categories to compare, contrast, and identify patterns. Outliers are outliers that do not fit with the others and are corroborated with approaches to make sense of the rich and complex data collected.

## Results and Discussions

This study was done to explore and understand the life of a stroke patient. Through data analysis, the researcher was able to formulate three themes:

- (1) Getting to know ME
- (2) being hopeful:
  - (a) compliant with medication
  - (b) doing exercise,
  - (d) diet modification, and;
- (3) being helplessness:
  - (a) maltreatment,
  - (b) self-pity and
  - (c) financial burden.

Figure 1 presents themes that emerged in the data.

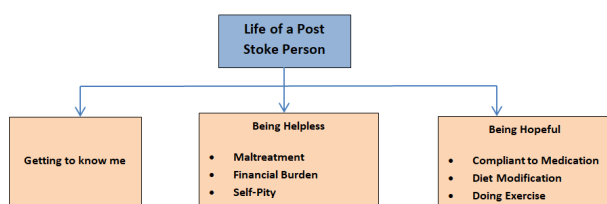


Figure 1. Life of a post stroke person

### Getting to know ME

Ellen (not her real name) female 50 years old, single was clinically diagnosed with a stroke with comorbidities 5 years before the conduct of the study. Before her stroke she had been at the market having coffee, Ellen experienced sudden onset slurring of speech, and had facial droop on her left hand with weakness in the left side upper and lower limbs. This was the second time she experienced these symptoms of stroke in the same year.

Upon arrival at the hospital, she was immediately intubated and admitted to the intensive care unit. After a week of medical and nursing management, her condition improve and finally extubated. While in the hospital traditional healing activities such as butchering pigs and chicken were done by the family. The family seeks consultation with faith healers outside of Bontoc like Cagayan and Baguio City and Ellen's condition was attributed to witchcraft. While she was confined her relatives took turns to watch over her and noticed an improvement in her condition. She was confined in the hospital for two weeks and was subsequently discharged. She was diagnosed with a stroke with comorbidities. During discharge, she was brought home by her nieces and nephews in her house. The family of her niece lived with her until the conduct of this study. She was often visited by her sister during her first month as a post-stroke person. Later, the sister seldom visits her when she got all her savings.

Upon review of her past medical history, she had been diagnosed with asthmatic bronchitis in 2010 and was also diagnosed with diabetes mellitus in 2016, was brought to BGHMC where medical management was done hence, she recovered. She was discharged and brought home with home medications that are unrecalled by the family members. However, she had not been compliant with her therapeutic regimen after she recovered instead she had been taking food supplements. Further review of her medical records shows that she had been admitted to the hospital many times after her discharge before her recent incident of stroke.

### Being hopeful

Being hopeful significantly influence mental and physical well-being through the promotion of a healthy lifestyle as well as through adaptive behaviors and cognitive responses. It is associated with greater flexibility, problem-solving capacity, and a more efficient elaboration of negative information. Holding onto the aspect of hopefulness would also help in achieving something we think we can't. This goes with the quote "the power of Mind" wherein if we believe we can, like the participant of this study being hopeful could lead to success. As it was evident in the following statement, "Kunkunak ah idi first nga datiak met nga makapag na. Isunga tata ket pracpractisek met nga mangikuti daytoy imak" (I was thinking that before I

can walk so now I have to practice moving my hands) as the participants tries to move her hand. The study participant added that "ti first nga inaramid ko, nu bumabaak dituy agdan, first daytuy ubet ko nu ngumato ak manen, ubet ko metlaeng" (what I first did was to get down from the stairs with my buttocks and when I go up I still use my buttocks) as she tries to demonstrate. The study participant helps herself and finds a solution to bring back her physical abilities to normal hence, even if she cannot do it she still tries to find ways to be able to do things for her.

Furthermore, many studies have found that being hopeful is correlated with better physical well-being compared to pessimism (Martinez-Correa A, et.al, 2006) which was observed in the participant as verbalized, "Ket dayta ngay sampayan idta gaw-atek ibitin ko daytuy showing her right arm ta isulaeng met ti makakuti, Sakton igaman daytuy, agkaskasjay ak nga magmagna enggana mabannugak. Enggana idi kaya kun nga lumwar." (I try to use the clothesline to walk and go out). The study participant utilizes things that would be helpful to her in attaining independence. She tries to show that she is also willing to recover.

Moreover, the participant further stated that "di first and second stroke ko, makaluto ak". (in my first and second stroke I can cook). She further explained that, "idi first ket talaga nga kelangan a ti assistance ngem di sumaruno kayang kaya na et, kaysa dagijay da dadduma nga maistroke ya mabaybayag" (in my first stroke I really need assistance but later she can manage unlike others that it will take a longer time). The post-stroke person makes a comparison to her previous life when she had a previous stroke that it is not easy and that determination is very important on her road to recovery. Her feeling of optimism is supported by the study of Ciro, et. al., that optimists were 55% less likely to die from cardiovascular disease than pessimists, even after traditional cardiovascular risk factors and depression were considered.

### Compliant to medication

A hopeful stroke person complies with the prescribed medications. It serves as therapeutic management to the factors that may contribute to or trigger stroke. This is noted when the participant stated that "apan kami agala ti agas ko ijay clinic. Tatta ampay nga ikathird nga stroke ko ket puro branded nganangingina ngem anya ngay anusan min a nga gatangen"(we get my medicines at the clinic but for my third stroke my medicines are all branded and it is expensive but we cannot do anything but to buy). The post-stroke person added that "haan kun nga araramiden jay inaramid ko id inga insardeng to tapos insukat ko si food supplement ta madi gayam dyay"(I don't want to do what I have done before that I stop taking my medicines but I substituted it with food supplement since that is not good). She then realizes the lapses in her previous strokes, and that she has to be compliant with her therapeutic regimen. She makes sure that she has to take all the medicines that were prescribed even if it is expensive since these medicines are branded. During home visits, it had been observed that she labeled all her medications placing the time when to take the medicines. This is so she does not miss one medication. For the post-stroke person to be compliant she has to be knowledgeable about her medications. This is evident when the participant verbalized, "daytoykua para highblood, losartan, ket every morning kongainumen. Adda ngay dagita dadduma ngem haanku met nga ammo. Dingay inreset ni doctora kaneak, di nadischarge ak pati jay pangdiabetic, adapay jay pangmemory kanu" (losartan is for high blood, I drink it every morning. I have some but I do not know the name. I have medicines for diabetes and memory enhancer which was prescribed by my Doctor) as she showed that container of her medications. The container is also labeled with the name of the medicine, its dose, its action, and the time when to take them. Good compliance with medication results in the prevention of complications and the occurrence of other diseases. A hopeful person always thinks about what's good for them to include compliance with medication. Further, it implies patient compliance signifying collaboration of the patient and the physician to improve the patient's health. It was strengthened in other statement "Ada ngay jay time nga inmay ni manang ket nagpagatang ak kanyana ti agas ko ta awan kwartak nga igatang ko" (there was a time when my sister visited me and I ask her to buy me medicines since I do not have money to buy). This show that is trying to find ways to be able to comply with her medication despite financial constraint. Taking prescribed medication when a person is sick is not just curing but also curtailing the long stay in the hospital. Another is helping lessen family disturbances since when somebody is sick members of the family will stay and even get absent from work just to accompany the sick person. In another context, a person tends to stay ill for a long time

which would also result in financial constraints. Her tears begin to fall as she verbalized "haan ko kayat nga maaramid manen jay naikasta kanyak idi sunga talaga nga inumek agas ko, narigat talaga" (I don't want to experience what I had experience before that is why I have to take my medicines, it is really difficult).

## Doing exercises

Not doing exercise is not just for physical enhancement but also the psychological aspect of living. Doing exercise is good for maintaining good brain circulation and when there is good blood circulation there is an adequate supply of blood in the brain which affects thinking. On the other hand, not doing exercise makes a person become incapacitated physically leading to being an irrational person. For this study participant, boredom became one of the motivational strategies to practice independency where exercise is evident as stated that "Kuna da apy nga apay gamin kano nga rumrumawarak...kunak ah nga: "eih nauma ak met nga agi-idda," Bassit lang ti pagnaek, dituy lang ket ag subli ak manen" (they ask me why I always go out but I tell them that I am bored, I walk a little and go back just the same). The participant further added that, "Kasla nu maborboringak nga agtutugaw ket alak ti sagad ket agsagadak, uray marigatanak di first ket inananusak ta kayat ku nga tumulong ken kasla metlang nga exercise kun" (if I get bored sitting down I get the soft broom, this would at the same time serve as my exercise).

Additionally, doing exercise enhances or maintains physical fitness and overall health and wellness. It is performed for various reasons such as it may help prevent stress and depression, help promote positive self-esteem and improve mental health. Frequent and regular physical exercise boosts the immune system and helps prevent "diseases of affluence" such as cardiovascular disease, type 2 diabetes, and obesity. It may also increase the quality of sleep and act as a non-pharmaceutical sleep aid to treat insomnia. This was evident in the statement that, "tadta nga makapagna aka ket lti aldaw ah ket magmagnaak. nu mamingsan dita sidewalk ti college ijay sanguna, agsstretch ak ijay, ket bumabaak ijay high school, mamindua ak nga aground ijay, sak tu agawid" (now that I can walk, I walk during day time and stretch through the college compound then to the high school compound then I go home). The participant further narrates "Nu mamingsan met apanak ijay steps ijay capitol, magna ak ijay igid ti left/right ta atleast ngay ya ada pagkappetak. Mamingsan ak ngumato, and then bumaba, dijay en agawid nak manen nga magmagna metlaeng." (At times I go to the steps of the capitol. I walk left and right, where I have something to hold. I walk up and down then walk home). She further continued that "ngem idi ket usarek a talaga dyay wire ti balaybayan mi, isu ti agbitbitinak" (I use the clothes like to walk). The post-stroke person believes that physical exercise is important in maintaining physical fitness and can contribute to building and maintaining healthy bone density, muscle strength, joint mobility, reducing surgical risks, and strengthening the immune system. This belief will help regain the body to function well and lead to a better quality of life.

## Diet modification

A modified therapeutic diet is designed to be part of an overall treatment regimen to combat a potentially serious condition like stroke. Diets low in fat and cholesterol may help avoid clogged arteries that can lead to heart attack or stroke. Modification of diet is very important to avoid further complications thereby preventing re-stroke. After an incident stroke, a person may notice a change in their food and drinks including consistency. As verbalized 'nu id a ket kaykayat ko ti taba, madik ti lasag ngem tadta medyo iwasak en tit aba" (I like to eat fats before but now I try not to eat fats). Changes in the type of food and lessen salt to reduce the chance of re-stroke as supported by the statement "haanak met nagkapkape, tano kitan metlang dagitoy kabalay ko umunget da ah ta kua garud amodan tisakit ko" (I do not drink coffee because if my children will see it they will scold me because they know my disease). The participant of the study further added that "maysa pay ket bawbawasakon ah mangan kadagijay maeparit nga makan." (another is I try to trim down eating those that I should not eat). The post stroke person showed sincerity as she further narrated "idi first a nga talaga ket permi kasla haan ko kaya ngem panpanunutek metlang nga para iti umimbagak talaga" (it is really very difficult for the first days but I believe it is for my own good). This data showed that the post-stroke person tries to do diet modification and understands that it can help in maintaining health. The study participant shows health concerns and

hence is determined to do diet modification and believes that diet modification is vital in life.

## Being helpless

Many people who survive from stroke feel helpless hence, they experience fear, anxiety, frustration, anger, sadness, and a sense of grief for their physical and mental losses. These are the normal phenomenological response of a post-stroke person. Some emotional disturbances and personality changes are caused by the physical effects of brain damage. This emotional disturbance was being experienced by the study participant as stated, "Ngem idi nu haan nga bumaba jay kaanakak nga mangipatumar kaneak ket awanen ah. Baka siguro nauma dan kaneak" (but before when my nieces and nephews do not come and let me drink my medicine I feel bad, what I know is they are already fed up on me). Additional response made was, "Kitak met ket nauma dan ngay dagita kaanakak nga mangar aramid ti ipaar aramid ko, mangibelleng ti bedpan ko, mangsukat pampers ko." (I can see that my nephews and my nieces are all fed up with all the things I am asking them to do). Another statement was "*Di bale kunak ta pumanawak tun metlang.*" (*anyway I will be leaving*). Sometimes the participant even blames self, "*kunkunak iti bagik nga, "apay ka man gamin", pakpakek jay imak.*" (I ask myself why and whip my hand). This clinical depression, which is a sense of helplessness that disrupts an individual's ability to function appears to be the emotional disorder most commonly experienced by stroke survivors. Signs of clinical depression include social withdrawal, irritability, fatigue, and suicidal thoughts. A post-stroke person can be treated with antidepressant medications and psychological counseling when needed. Further, the environment that a post-stroke person is living in is a contributory factor to this feeling of helplessness. Hence, to prevent the feeling of helplessness a healthy environment is needed so as not to let them feel being a burden to the family. As verbalized "nu naragsak da ti tattao ditoy puminpintas ti riknak ngem nu ag ungunget da ket feeling ko cyak ti ungungetan da sunga madepdepressed ak ngay"(I feel good if the people here are happy but I am depressed when they are angry) as the post-stroke person showed the pail that was destroyed when one of her nieces throw this to the dog.

## Maltreatment

Stroke produces personality changes that may be harmful to relationships or abusive after stroke. Physical and emotional maltreatment is evident in this study where the participant is being hurt by her nephews and her nieces. This was evident as the participant stated, "namingsan kettampaken da siak" (at times they whip me). The participant further added, "Jjay babae ya agkiting ket nasakit" (the girl even pinch, it is painful). Probably, this abusive attitude of the nieces and nephews is a result of being stressed out in rendering care for this post-stroke person. When this incident happens the post-stroke participant is at risk to have a variety of physical, emotional, psychological, and/or cognitive issues that has an impact on functioning and ability to properly care for her. This is shown when the participant stated "agsangit ak nga mangpanupanunut nu apay nga ikaskasta da dyay kanyak" (I cry and reflect on why they hurt me). The participant continued to verbalized that "anya ngay ti maaramid ko sunga ipapatin ti panunot ko nga aramiden ti haan ko nga kaya ta baka talaga nauma dan kanyak" (I cannot do anything I just do all means to help myself thinking that they are fed up with me). Verbal abuse is also evident in this study as verbalized "maminadu pay nga pagsasawan da syak si nasasakit nga sao, haan talaga nga matilmon" (there are many instances when they say bad and painful words to me). Even with maltreatment experienced by the post-stroke person she still tries to understand them and tries to convince herself that it might be because they are tired of their work. She also tries to believe that there are reasons why they are stressed may be due to some personal matters. The post-stroke person tries to believe that the demands and vigilance required for adequate care at home are often overwhelming and exhausting. This is evident when the study participant tries to restate one statement made by her nephew "kakauma ka chadlu, ad ikat matey" (I am fed up on you, why you just do not die).

## Financial burden

A stroke can have a crippling effect not only on the human body but also on a survivor's financial stability. As the participant narrated "Kelangak ah ngatulungantibagik ta awan en ti trabahok. Awanen pangalaan mi ti pangospitalya ken dagijay ag-agas" (I need to help myself since I do not have any

job and I have nothing). Another statement made "adi kami et ume y enpacheck up nu y rikriknaek tay maid siping" (there are times that I do not go for a follow-up checkup since there is no money). There are instances that the participant has to seek financial support from siblings and relatives as evident in the statement "san namingsan et tinawagak san esang ay friend ko ta enpatulong ak ken cya tay mid et ilakok si agas ko" (there was a time that I called for my friend to ask help since I don't have any money to buy my medicines). According to Cardiovascular Business, a recent market survey found that of all the adults in the U.S. with Cardiovascular Disease (CVD), which includes both stroke and heart problems, 56% report difficulties paying their medical expenses, while 29% say those medical costs wiped out "most" of their savings. Of the 56% who reported trouble paying their medical bills, nearly half (48 percent) are having difficulty maintaining monthly expenditures, 30% have amassed thousands of dollars in healthcare-related debt, 25% can't afford necessities such as food or rent, and 9% declared bankruptcy (National Stroke Association, 2016).

## Self-pity

Self-pity is common among stroke people as the participant claimed that "masegseg ang ak ay san awak ko tay aped ak et kagtuna" (I pity myself for my situation). The participant further added that "nu mamingsan ket agsangsangit ak ti rabii nga mangpanpanunut nu apay ngata nga cyak paylang ti kastoy" (there are times that I cry and ask myself why me). As the participant continued "nan riknak et kag ak lang pabigat san pamilyak" (I feel I am already a burden to my family). Studies showed that one of the most common psychological impairments caused by stroke is depression. The prevalence of depression after stroke, also referred to as Post Stroke Depression (PSD), ranges from 5–61% with a pooled average of 33%, and is associated with poor rehabilitation outcomes, which impedes the recovery process of stroke patients [10,11]. Depression after stroke is explained by some as a reaction to physical impairments caused by the stroke and by others as a biological cause due to the location of the lesion in the brain.. Still, others consider it to be a combination of both. Important consequences of PSD are lower functional status, slower functional recovery, higher morbidity, less participation in social activities, lower quality of life, longer stay in the hospital, and higher mortality [12,13].

## Conclusion and Recommendations

Getting to know ME, being hopeful, and being helpless are the three aspects of the life of a stroke person. Being hopeful makes the person comply with her medication, diet modification, and exercise. Being helpless where there was a feeling of maltreatment, financial burden, and self-pity greatly affects the relationship between the post-stroke person and the family. Further, the life of a stroke patient is not easy.

Post-stroke psychosocial needs can be best addressed by health personnel,

according to a study. Counseling services should be mandatory and made stroke persons and their families. Health institutions like hospital craft and implement a policy to address such activity. Another study is to find out how caregivers manage and how looking after a patient with stroke affects their quality of life.

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