

# Caregivers' Lived Experiences in Providing Care for Vegetative Patients: A Phenomenological Inquiry

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## RESEARCH ARTICLE

### Abstract

The challenges faced by caregivers, encompassing mental, emotional, physical, social, and spiritual dimensions, represent a critical area of study for healthcare professionals aiming to offer comprehensive support. This study, conducted at a Manila tertiary hospital over two weeks in April 2023, utilized an in-depth interview guide to explore the experiences of four diverse caregivers tending to individuals in a vegetative state. Findings revealed four prominent themes: the willingness to assume the caregiver role, lifestyle and social alterations, fear of the unknown, and personal struggles along with coping mechanisms and support systems. The intimate, personal interviews provided a deep understanding of the caregivers' multifaceted challenges. Caring for a loved one in a vegetative state demands substantial emotional and physical tolls, leading to daily anxiety and concern. Recognizing the complexities of their situation and providing the necessary support can significantly alleviate the burdens they face. Moreover, for these caregivers, it becomes a way to reciprocate the love and care previously bestowed upon their loved ones enduring such a condition. This exploration underscores the demanding nature of caring for those in a vegetative state within a familial setting, highlighting the imperative need for holistic support systems and interventions. Understanding the intricacies of caregivers' experiences is pivotal in designing effective strategies to mitigate their challenges and offer the necessary assistance and care.

**Keywords:** Vegetative State, Caregiver, Challenges, Experience

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## 1 INTRODUCTION

The hypothalamus and brain stem, which are primarily what keep a person alive, are the vital organs in charge of breathing, controlling body temperature, sleep cycle, blood pressure, heart rate, and consciousness. When the part of the brain that regulates mindfulness and behavior isn't functioning properly, the condition known as a vegetative state results. Despite being able to breathe and open their eyes, which gives the appearance that they are awake, they do not react meaningfully to any environmental cues. This is typically caused by severe brain damage from a head injury or any disorder that prevents the brain from receiving oxygen due to respiratory or cardiac arrest (Maiese, 2023).

While recovery from a vegetative state can sometimes occur spontaneously, it's typically just partial. The likelihood of recovery is influenced by the kind, severity, and age of the brain injury.

It is improbable that patients who have been in a vegetative state for a month will make a full recovery. This illness is estimated to affect 25,000 adults and 10,000 children in the US, according to Appel (2020). Nevertheless, there is currently no raw data available on patients who are in the vegetative stage.

Patients' lives can be extended as a result of improvements in medical, diagnostic, and technological methods over time, as well as family support. This necessitates a thorough level of family care. The recovery of the vegetative state is currently not treatable; instead, treatment is focused on the patient's needs and the patient's presenting symptoms. The essential duties of the primary caregiver for VS patients include monitoring them constantly and helping with eating, hydration, hygiene, aided movement, physical therapy (to help prevent ulcers and blood clots in the legs), and waste removal. The care given to the patient is greatly influenced by the family caregiver's support.

For the family as a caregiver, the difficulties of providing long-term care for people who are in a vegetative state can have grave negative repercussions. In order to give the patients the necessary care, some members of the family must make sacrifices. The pressures that are being encountered by the family caregiver—who is typically also an unpaid caregiver—include an abrupt change in their way of life, a consistent reduction in their workload, or quitting their job, interests, hobbies, and social engagement.

In the Philippines, a third-world country where assistance and support from the government are lacking, family caregivers are primarily referred to as "hidden patients" because they bear extraordinary care burdens that are ignored. As a result, in addition to the psychological toll that they are bearing, they are responsible for all of their patients' financial needs. Also, it is well recognized that those who care for people who are in a vegetative state bear heavy financial, social, emotional, and physical burdens and typically have poorer health than the general population.

This study aimed to have a better understanding of the experiences of the family as a caregiver of their patient who is in a vegetative state specifically the impact on their mental, emotional, physical, social, and spiritual state and their coping mechanism during this undeniable struggle of their loved ones.

The quality of life of family caregivers has a significant impact by providing long-term care for patients, according to Chinner et al. (2022) scoping review on the impact of prolonged disorders of consciousness. The review found that most outcomes related to quality of life were negative feelings, thinking, learning, memory and concentration, and personal relationships.

Family members who were compelled by circumstances to deal with protracted sorrow are susceptible to major psychological effects, such as melancholy, guilt, and crippling anxiety, without knowledge and without guidance in any of these areas of family grief (Smith, 2023). To better comprehend the family members who were grieving the loss of a loved one, the Five Stages of Family Grief have been highlighted in this study. Like the current study, this study sought to gain a thorough understanding of what it was like to care for a loved one when they are at their most vulnerable; acceptance, challenges, life changes, and hope were all interwoven in this experience.

The lengthy and rigorous caregiving responsibilities for HD patients place an exceptional care burden on primary family caregivers. According to this study's findings, the main challenges experienced by primary family caregivers were emotional instability and responses, care exhaustion, health-related health distortions, and numerous economic and social harms (Abebe et al., 2022). Similar to the current study, the participants' carers would like to know the whole impact on their lives.

The health and quality of life of both the patient and the caregiver can be promoted and improved with a better understanding of how changes in the caregiver's role and relationships in their lives may support targeted interventions aiming to empower their capabilities and new personal abilities and to support better integration between the past and the present (Covelli et al., 2014). One will have a better grasp of how to support the family caregivers and be given a specific intervention that will promote better care for their patients if they are aware of the roles and

challenges of the caregiver.

The primary goal of this study was to gain a deeper understanding of the challenges faced by caregivers in terms of their mental, emotional, physical, social, and spiritual states, and coping mechanisms in order to help health professionals become more aware of these challenges and ultimately develop interventions to support these caregivers.

## **2 METHODS**

This study was made by means of a qualitative interview design that captures the lived experiences of individuals who have experience in caring for patients in a vegetative state and describes these experiences from an insider's perspective.

### **2.1 Participants**

The researchers used purposive sampling to recruit volunteers using the following inclusion criteria: people who have been caring for patients in a vegetative state and are able to give informed consent. The researchers also selected participants on the basis of age (adults aged 18 years old and older), sex, marital status, income, relationship to the patient, and months or years of experience caring for a patient in a vegetative state to ensure variation and a range of experiences. Four participants were selected for this study which was conducted in a tertiary hospital in Manila, Philippines.

### **2.2 Data Gathering**

The primary data collection tool used in this research was an individual face-to-face semi-structured guided interview. The interview guide was formulated by the researchers in open-ended questions with a sequence of broad to narrow topics. A personal interview and observation of non-verbal forms of communication such as tearing, weeping, sighing, and hand gestures were also recorded and reported. Each interview lasted from 30 minutes to 55 minutes and was audio recorded with the participant's consent.

### **2.3 Data Analysis**

The data collected were transcribed verbatim by the researchers, and the transcription of interviews and field notes were read repeatedly to get the whole sense. The research data was approached with openness to whatever meaning emerged. Meanings and interpretations were according to the interviewed views rather than the researcher's perspective and expectations.

From this, developed a consistent statement regarding the structure of the participant's experience in caring for vegetative state patients. Next, meaning units were summarized and labeled to suitable themes. Finally, the researchers synthesized all of the statements regarding each participant's experience into one consistent statement that describes and captures the essence of the experience (Giorgi & Giorgi, 2003)

### **2.4 Ethical consideration**

The research was conducted with ethical considerations in mind. This includes voluntary participation; no coercion or manipulation was practiced. Informed consent was collected prior to facilitating the interview and confidentiality was assured throughout this study. The participants were also informed that they could withdraw their responses at any time in the study. There were no manipulations of the results that may favor the researchers' study.

### 3 RESULTS AND DISCUSSION

Four themes emerged in the analysis of the data collected: Willingness to assume the caregiver role, Change in lifestyle and social relations, fear of the unknown, and personal struggles and coping mechanisms and support system.

#### 3.1 Willingness to assume the caregiver role and self-discovery

The first theme describes the willingness of the relative to assume the caregiver role despite ceasing their day-to-day lives. It is their way to retribute the love, care and support they received from their loved one before they declined into their vegetative state. A son (CG02) replied when asked his readiness to take on the caregiver role, ***“Very willing po kasi yung po tulad ng sinabi ko kanina, kaya, pwede na mag-alaga bilang maging isang caregiver ko kay mama kasi tawag dito yung ginagampanan ko lang po yung panahon na parang hindi pala parang yung ginagampanan ko po yung panahon na malakas pa siya inaalagaan niya kame ng sobra sobra ngayon parang willing ako alagaan siya sa kalagayan ngayon kasi Syempre bilang anak po niya at nanay ko din po. Yun po ang responsibility ko ngayon kasi sa state ni mama ngayon eh talagang kailangan ko syang alagaan. (hitting table midly).”***

Same goes for participant CG01, ***“lima kameng magkakapatid, inalagaan at pinakain nila tatay hanggang ngayon may pamilya na kame nakasuporta pa din ni-minsan hindi sila nagreklamo kaya very willing ako alagaan si nanay masuklian lang ung pag aaruga niya sa amen.”***

Through the challenges faced by the caregivers they have discovered that they could be selfless, ***“un po kaya ko po pala talaga mag sakripisyo para sa taon mahal ko, parang na discover ko na ay kaya ko pa lang gawin to (clenched fist and hit the table) sa mahalaga sayo.”*** ***“Sa pag aalaga po? wala po (shaking his head) wala po, ung pag sasakripisyo ko po kay mama po, wala po, ung pag sstop ko po, ung sa social life ko po wala po akong pagsisi sa sakripisyo ko po.”*** proudly stated by CG02 and learned new skills ***“eto po, parang halos alam ko na lahat ng trabaho, ito di ko pa nagagawa sa tanan ng buhay ko ang nagawa ko ngayon, simula sa pagkabinata ko di ko nagagawa yun, ngayon ko lang nagawa to.(smiling)”*** CG03

According to the sociocultural adaptation of the stress and coping model, ethnicity has a significant impact on the outcome experiences of caregivers. Caregiving experiences vary by race and/or ethnicity, and research reveals that African Americans frequently have different role expectations, views about providing care, and coping techniques than European Americans. African Americans have more positive opinions toward older persons and see cognitive and/or physical loss in health as a normal part of the aging process (Burton et al., 2004). In relation to the caregivers, this study shows the parallel result of the above model the positive Asian Culture of willingness to assume the role out of love and sacrifices to their loved ones resulting in an experience of lower levels of stress and burden as well as higher levels of satisfaction.

#### 3.2 Change in lifestyle and social relation.

Undertaking the role of a caregiver for a vegetative state patient (VSP) is not easy and is surely time consuming. Since they are unable to move therefore requiring a great amount of care and also have special needs, as stated by CG02, ***“pinapaliguan ko po si nanay, naglilinis ng trache niya, dahil may sugat na siya sa likod tinatagilid tagilid ko po siya.”*** Another caregiver (CG03) confirmed this by saying, ***“kailangan lagi palitan ng diaper at banatayan ng suction kasi bumababa hangin niya.”*** With the constant care that needs to be provided the caregiver's daily living has altered leading to resignation from work and taking a leave at school, as participant CG01 explained, ***“dati po teacher ako pero nag stop ako ngayon dahil kailangan ko alagaan si nanay.”*** as well as for CG03, ***“wala akong trabaho ngayon, dati sa construction...”*** as for CG02 ***“Ayun po, nag stop po ako sa pag aaral dapat po magtatapos na po ako sa pag aaral. So ayun po ang pinaka nagbago imbis na matuloy ko nag stop po ako ngayon kasi kailangan ako ni mama ngayon, kailangan ko siya alagaan.”***

Certain lifestyle adjustments was made even in their social lives, to the point that its non existent

expressed by CG01, *“wala po talaga, iniinsip ko pag nakauwi na kame hindi din ako makakalabas if ever, pag need lang talaga tapos saglit lang.”* In CG02’s case, *“Syempre di naman po ako nakakalabas. Wala naman po ako nakakausap mashado bukod sa mga kasama ko dito sa ward kaya medyo nabawasan po talaga un social life ko.”* But with the help of social media, they get to communicate with their friends and loved ones outside the hospital, *“buti nalang may facebook at messenger, nakakausap ko ung mga dati kong ka-work at naka-kamusta ko ung anak ko.”* expressed by CG01.

Pearlin and colleagues created stress process theory to understand how stress was perceived as a process by informal family caregivers (Matzek 2011). Multiple conceptual components of stress theory are included in this theme when the primary stressors increase in relation to the vegetative state patient who requires highly specialized care, resulting in changes in the life of the caregivers such as giving up work to ensure care is given to their loved ones and compromising their own social relationship with others is the result to directly related to secondary role strains and indirectly related to secondary role strains.

### 3.3 Fear of the unknown and personal struggles

Family caregivers stated their fears of the unknown, they’re anxious of what could happen to their patient in the days ahead. *“kinakatakot ko ngayon (sobbed)mawala siya sa buhay ko (voice cracking)ang mawala siya sa buhay ko ang kinakatakutan ko.”* cried CG03.*“(faint laugh) ang fear ko po ngayon ang pwedeng mangyari kay mama syempre hindi naman po natin masasabi kung ano po mangyayari kasi nga po sa state ni mama ngayon. Tinatanong ko nga po ung doctor kung kailan siya gigising, ayun po meron pa daw po stroke si mama sa left and right brain ni mama, na-experience ko din po ngayon na medyo fluctuating ung pulse rate niya ung bp niya medyo natatakot po talaga ako ngayon sa pwedeng mangyari na hindi naman po natin masasabi kung sa susunod na araw ok pa siya o sa susunod”* conveyed by CG02. CG01 also mentioned, *“syempre maam kung ano pwede mangyari sa kanya sa mga susunod na araw, kaya mas gusto ko rin na ako mag bantay kay nanay kasi di ako mapakali pag nasa bahay ako.”*

Apart from the challenges the caregivers face in providing care for their patients, they also have personal struggles. For caregivers who have their own family, they are torn in wanting to care for their patient and being able to take care of their own child, recounted by CG01, *“parang gusto ko lumipad, nung narinig ko ung iyak ng anak ko. 6 years old lang un maam, nabaldian siya ng mainit na tubig. Umiiyak ako dito gustong-gusto ko puntahan ung anak ako pero walang mag aalaga kay nanay...”* In respect to this CG04 stated, *“iniisip ko ung maliit ko, malikot pa naman un baka di mabantayan.”* Some worry about their financial needs as they were staying in the hospital, CG03 said *“walang malalabas na pera kasi wala akong pera e.”*

Caregivers as well as patients may experience anxiety and distress, particularly if they lack information or control over something. Children of the patients may develop a fear of the unknown if one or both parents are particularly anxious about the unknown and uncertainty of their condition. Seeing how parents cope with anxiety or stressful situations can affect how they react in that situation. Fear of the unknown refers to anxiety around unpredictable situations or events. It can also link to things that people find unfamiliar or strange. Individuals are likely to experience fear of the unknown when there is a lack of information. Another name for the condition is intolerance of uncertainty. In this situation where the caregivers are emotionally and psychologically affected, a mental health care specialist can recommend the most appropriate treatment for fear of the unknown and provide tips for coping.

### 3.4 Coping mechanism and support system

Being a sole caregiver of a VSP can be consuming not only physically but also emotionally and psychologically. The majority of them find tranquility in God’s grace, Three family caregivers commented on this respect: *“Ayun po nilalabas ko po sa dasal (hands in praying position)”, “dasal lang sa panginoon number one.(pointing up)”* and *“prayer po talaga, lagi po ako nagdadasal.”* Acquiring support from their loved ones such as siblings has significantly helped them overcome their challenges, *“number 1 talaga ung sibling ko maam. As much as possible hindi kame nag ask for*

*help from relatives kasi baka may masabi pa. Basta kameng magkakapatid solid kame for nanay.”, “nailalabas ko lang sa kapatid ko lahat ng ngayari tapos nagiging ok din ako”, “kay ate at papa lang po talaga, May iba pong kamag-anak pero hindi ko rin po sila ma-oblige. kasi may kanya-kanya nang pamilya tapos ung iba nagtatrabaho din.”* professed by the participants. Having a positive outlook in life also helped them cope with the difficulties they encounter, “*tapos po mindset na positive pa rin na kahit ganyan na ung ngayari. Kasi kapag naging negative ka wala, parang manghihina na rin po si mama. Always positive po ako tapos, dasal. Nilalakan ko nalang po ung loob ko para makapag cope ako sa mga ngayari ngayon.*” as told by CG02.

As part of the process stress theory, these last themes place a strong emphasis on the concept of mediators. Coping skills and social support, for example, can help to prevent or lessen stressors and bad effects (Figueiredo, 2017). Caregivers' coping methods include any activities they do to reduce stressors and increase their own well-being. Caregivers' coping tactics include controlling the circumstance (learning about the sickness), making sense of the situation (lowering expectations or making positive comparisons), and reducing stress connected with the situation (spending time alone, exercising, meditation, and prayer). Social support is defined as both instrumental and expressive. Having someone assist the caregiver with household duties or provide care to the care recipient is an example of instrumental social assistance. Friends and family provide caregivers with expressive social support in the form of trust, compassion, confidence, and happiness.

#### 4 CONCLUSION

The study concluded that the caregivers acknowledged their physical, emotional, and financial adversities and challenges. However, their willingness to reciprocate the love the patient once gave them overcame the difficulties. The caregivers' life has drastically altered by having a loved one in a vegetative state since attending to their patient's needs is time-consuming. As a result, they sacrificed their chances to pursue education or employment but discovered how selfless they could be for their loved ones. Their pronounced fear is losing their patient. Nevertheless, faith in miracles and a positive mindset keep them going. The vast majority also have a strong faith in God; they entrust their daily struggles to the Father Almighty, hoping that He will provide them with the courage and direction they need to persevere and do their best to care for their loved ones.

Caregivers for vegetative state patients also need support and financial assistance, psychologically and especially emotionally, as all respondents expressed their gratitude that they were relieved in expressing their thoughts, worries, and struggles. This study hopes to encourage the creation of programs to aid family caregivers' and build support groups to ease their stress.

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