Master's Thesis of Child Development and Family Studies

Family caregiving to patients in a persistent vegetative state in India: A multi family member perspective

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Graduate School of Human Ecology
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Abstract

The purpose of the present study is to investigate the family processes of adaptation and resilience in India among family members who care for patients in a persistent vegetative state at home. Previous research has shown that patients in a persistent vegetative state are difficult to care for at home because they require ongoing medical intervention and extensive care due to the severity of the condition. However, in India, patients diagnosed with PVS are often discharged from the hospital after their condition has stabilized due to the length of the caregiving period, and family members are required to provide care at home. Therefore, the lack of home care support from the government and the unavailability of an adequate healthcare system led to the complete reliance of the PVS patient on the family, and the family is responsible and obligated for the comprehensive care and cost associated with it. Hence, family caregivers must be able to respond effectively to the demanding needs that result in caregiver burden and financial distress. Earlier studies also indicated that witnessing a family member in a PVS may trigger feelings of ambiguous loss, despair, anxiety, poor appetite, sleeplessness, and other psychosomatic disorders. The crucial point is that taking care of these individuals is challenging, and the fact that they live longer and are more likely to survive for many decades further adds to that challenge.

This study was qualitative research using Multi-Family Member Interview Analysis (MFMIA; Van Parys et al., 2017). The participants were six family caregivers who were recruited through purposive sampling. Data were gathered through semi-structured interviews, and the narratives of two-family caregivers from each family were collected. Each participant had two in-depth interviews; in each family, one member was the patient's spouse, and the other was the patient's child. The analysis of the study was conducted using MFMIA (Van Parys et al.,

2017), and it contributed to a deeper understanding of how family caregivers' experiences are affected by a broader social context and, in turn, how their individual experiences contribute to a broader understanding of family dynamics and resilience in the context of caring for a patient in PVS.

The findings of the study is represented by five superordinate themes that run through all of the families. The themes that were prevalent among all families are clustered into five superordinate themes: 1) Struggles with adversity; 2) Family values 3) Belief systems 4) Family unity: strengthened family bond; and 5) Perceived social support. The results showed that families experienced struggles due to adversity, such as caregiving burden, feelings of ambiguous loss, the strain of family ties, a decrease in perceived social status, caregiving difficulties due to the COVID-19 pandemic, a lack of proper healthcare, and affordable home care services. In addition, the findings indicated that families facing this adversity drew the majority of their strength and motivation from their resources of family values, belief systems, and social support. They utilized and mobilized these resources into dynamic family processes to get the strength and motivation necessary for adaptation and resilience. These findings suggest that despite the struggles families face due to adversity, they still rely on their resources of strong family values, belief systems, and support from their extended social networks to gain strength and motivation for adaptation and resilience. These results showcased that family values, belief systems, and social support systems serve as crucial resources for families to adapt and maximize their resilience during adversity.

The findings also showed noticeable changes in family functioning regarding flexibility and cohesion. In addition, it was observed that the degree of change differed between families.

In addition, the study provided insight into how each family constructs unique adaptation processes and resilience pathways based on their resources, the values they support, their belief systems, and their aspirations. In this research, two families positively adapted, responded effectively to the adversity, and exhibited the characteristics of resilient families, but one family barely adapted to the adversity and had just enough resources to survive through this adversity. Considering the results that indicated that providing care for a loved one in PVS at home has a significant load, families need access to professional, cost-effective in-home care services to adapt and build resilience. The findings of this study suggest that families facing this adversity need services that focus on fostering resiliency, as such services will help families feel more in control by giving them a sense of shared optimism, giving them a chance to develop new and renewed skills required for caregiving, and making their family relationships stronger. Moreover, these services should be tailored to the particular needs of each family, based on their resources, values, and belief systems, so that they can maximize their capacity to adapt and manage adversities.

Keywords: family resilience, caregiving, multi family member perspective,
persistent vegetative state, family adaptation processes

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I. Introduction

Globally and in India, the number of patients in vegetative or minimally conscious state has risen dramatically (Pistarini et al., 2019) and a lack of effective palliative care is a major problem for India's healthcare system (Devakirubai & Gnanadurai, 2014; Sinha et al., 2012). Vegetative state or minimally conscious state, clinically referred to as disorders of consciousness, are potential outcomes following a severe brain injury (Monti et al., 2010). The advancement of critical care technologies has enhanced the survival rate, hence extending the life span of patients with serious brain injuries (Giovannetti et al., 2015**).** Patients in persistent vegetative state (PVS) have a life expectancy of between 2 and 10 years, and in some cases, it can be decades (Jennett, 2005; Monti et al., 2010). Due to the severity of the medical issues associated with PVS, it requires continual medical treatments and extensive care, such as maintaining airway, fluid balance, nutrition, dental care, skin health, perineal hygiene, body temperature, urinating, and enhancing bowel functions through physiotherapeutic activities (Goudarzi et al., 2018). Hence, family caregivers must be able to respond effectively to the demanding needs that result in caregiver burden and financial distress (Covelli et al., 2014; Leonardo et al., 2012). In addition, family caregivers experience complex feelings of ambiguous loss owing uncertainty for recovery and to the nature the condition (Leonardo et al., 2012; Giovannetti et al., 2015). There is no standard method for supporting the adaptation of vegetative patients and their family members (Lavrijsen et al., 2005). Hence, it is recommended that the majority of the care required for PVS be provided by trained professionals (Goudarzi et al., 2018); however, when family members are required to provide such care, it can cause problems for the patients, such as dislocation of the hips or shoulders, and is extremely challenging for the caregivers. The findings also indicate that witnessing a family member in a PVS may trigger feelings of despair, anxiety, poor appetite, sleeplessness, and other psychosomatic disorders (Chiambretto et al., 2010; Giovannetti et al., 2015). The crucial point is that taking care of these individuals is really challenging, and the fact that they are living longer and are more likely to survive for many decades further adds to that challenge.

However, in India and several other developing countries, patients diagnosed with PVS are often discharged from the hospital after their condition has stabilized due to the length of the caregiving period, and family members are required to provide care at home. In addition, readmission to a hospital is a challenge in many cases (Pistarini et al., 2019). Therefore, the lack of home care support from the government and the unavailability of an adequate healthcare system leads to the complete reliance of the PVS patient on the family, and the family is responsible and obliged for the comprehensive care and cost associated with it (Jagannathan, 2014b; Chadda, 2014; Gouzardi et al., 2018). In light of this, the majority of the medical professional respondents believed India lacked appropriate and competent caregiver support services, and the study also revealed that more than eighty percent of home care expenditures are paid by family members, with 10 to 20 percent covered by insurance in some cases (Pistarini et al., 2019). Most research evaluating the caregiver experience in PVS has been conducted in developed countries where advanced and efficient home care facilities are accessible (Goudarzi et al., 2018; Pistarini et al., 2019). Relatively little is known about the family caregiving experience in less developed countries, such as India, where formal support is not readily available and patient caregiving is entirely left to family members. Given the complex and challenging nature of the caregiving environment for families of patients in PVS in India, more research is needed to explore the family caregiving experience to understand how families adapt to this adversity.

Scholars have commented that resilience is an increasingly relevant notion for understanding how family caregivers manage and cope with providing care to those with terminal diseases (Rosa et al., 2017; Walsh, 2016). Numerous studies in the area of family stress have shown that despite adversity and difficulty, families often emerge stronger, more loving, more life-focused, and better prepared to face future obstacles (Walsh, 2016; cite a few more empirical studies that actually showed this result). The caregiving process for PVS and its associated factors in the sociocultural context of India are unexplored and mostly unknown, highlighting the need for qualitative investigations that might be extremely beneficial in comprehending how family operates in this under explored phenomenon. Furthermore, most studies have examined the narratives of only one family member who is often a primary caregiver in each of the participating families (Chiambretto et al., 2010; Giovannetti et al., 2015; Goudarzi, 2018). Very little is known about the family-level process of adaptation involved in caring for a spouse, an adult child or a parent. Given that in India, the family is the primary source of care provision amidst the insufficient home care services and limited government support, it is all the more relevant and worthwhile to examine voices from multiple family members involved in caregiving instead of just one member and to shed light in the family level understanding of the phenomenon.

In attempt to fill the gap, this qualitative study seeks to investigate and comprehend the experience of family caregivers and the family processes for adaptation and resilience in Indian families. Furthermore, this study aims to examine the phenomena of caregiving for family members in a permanent vegetative state in India from the perspective of multiple family members in order to gain a family-level understanding of the situation.

Research question

This study's research question is as follows: “What are the family processes of adaptation and resilience in families who are caregiving for patients in persistent vegetative state (PVS) in India?”.

II. Literature Review

Family Resilience Framework of Walsh

Family resilience is defined as the ability of a family to endure and recover from stressful life events or adversity, emerging stronger and more resourceful (Walsh, 1996; 2003). The concept of family resilience derives from the notion of relational resilience, which highlights family dynamics and how families uniquely mobilize their protective mechanisms and processes to withstand and recover from a range of adversities (Walsh, 1996; 2003; 2016a). As family resilience requires continuing transactional processes on multiple levels, ranging from dyadic and family levels to ecosystems such as community and culture (Boss, 2001; Walsh, 2016b), each family takes a different path to resilience depending on the crisis or stressor (Whitchurch & Constantine, 1993; Hawley, 2000). Hence, family processes mediate the adverse impact caused by a crisis or persistent stressor on all the family members, their relationships, and the family unit's functioning (Walsh, 2016). According to Walsh (1998), resilience is more than just coping or problem-solving because it involves positive adaptation and aids in transformation, recovery, and growth in the face of a persistent crisis event. It is a complex, multidimensional, and dynamic construct that requires context-specific comprehension, resulting in unique adaptation processes and trajectories (Hawley, 2000; Patterson, 2002; Walsh, 1998).

The family resilience framework is grounded in ecological and developmental perspectives to understand family functioning in a social-cultural context and its evolution through the multigenerational life cycle (Walsh, 2003). Family meaning systems emerge within families and regulate shared meaning at three interrelated levels: family worldviews, family identity, and perceptions of family stressors and resources (Walsh, 1998; 2016). Therefore, these family meaning systems are shaped by the context in which families live and the intersecting sociocultural, historical, and personal forces they encounter. By acknowledging the complexity of family systems, the family resilience framework encourages a strengths-based approach to understanding and examining family functioning. In addition, the framework does not support a single-family functioning model that could be labeled as healthy. Instead, it presumes that healthy functioning should be assessed in context with the family's values, structural, situational, and relational resources, constraints, and challenges (Walsh, 2016; 2018). In addition, it is a valuable framework that provides a research-informed conceptual map and a practically relevant guide to identify and target family processes that can support and strengthen families to deal with life challenges and persistent stressors.

According to Walsh's analysis of the research literature, research studies, and practice experience, three broad family functioning domains (i.e., belief systems, organizational processes, and communication processes) encompass the key family processes that determine a family's capacity to overcome a stressful event. Nine family processes fall under the three domains of family functioning. Belief systems include a) shared meaning-making efforts, b) a positive outlook and transcendence, and c) spirituality. The organizational processes dimension involves (d) strengthening of flexibility in interpersonal relationships, (e) connectedness and cohesion of social networks, and (f) economic resources. Lastly, the communication processes dimension involves (g) clarity, (h) emotional expression, and (i) collaborative problem-solving processes.

Life problems may vary from life-cycle changes, such as retirement, divorce, or remarriage, to more non-normative situations, like having a family member diagnosed with an untreatable disease, prolonged pressures of migration, or inner-city violence. Walsh (2016a) states that her research and practice in family resilience have deepened her conviction that highly vulnerable or troubled families have the potential to strengthen their resilience. Research on the resilience of a family caregiver's environment analyzes how the family's capital and resources influence the ability to adapt and thrive through adversity (Teahan et al., 2017). It is a concept that is becoming increasingly important in understanding how family caregivers manage and adapt to providing care to people with chronic conditions (Rosa et al., 2017). This research will evaluate, from a multi-member perspective, the family processes of adaptation and resilience in the context of caring for patients in a persistent vegetative state (PVS) in India.

Relevant literature

Caregiving

Caregiving burden. Caring for family members who are chronically ill is a stressful component that affects the entire family, often leading to a caregiving burden. Caregiver burden is the stress perceived by caregivers due to caregiving responsibilities and demand in a home care situation (Taylor et al., 2013). In a family where there is an individual who is chronically ill, the caregiver (e.g., the spouse, daughter, or family as a unit) undergoes considerable distress (Taylor et al., 2013). Moreover, in low and middle-income countries, family caregivers receive little support for their work and contribution to caring for persons with severe brain illnesses like dementia or Persistent vegetative state (PVS) patients (Chan, 2011; Goudarzi, 2018). Governmental policies in these countries also do not provide financial support for the tasks of care provided by the family caregivers. In addition, home and community care health services are scarce and insufficient (Chan, 2011). As a result, the role of family caregivers' plays a vital role in long-term home health care (Goudarzi et al., 2018; Levine, 1999) and their contributions to patients' recovery must be acknowledged and given proper credit (Janardhana, 2015). While these caregivers struggle to fulfill the demands of their work, family, and caregiving, they experience tremendous stress, and their physical and emotional health is often neglected (Chan, 2011).

The caregiving burden in a family is a multifaceted phenomenon affecting their physical and mental health, social life, financial status, and overall family functioning (Chan, 2011; McPeake et al, 2016). Moreover, improvements in emergency medicine and advancement in critical care technologies have increased patients' survival rate in severe brain injuries, leading to continuous and demanding caregiving workload from the family members as such patients are kept at home or long term care facilities (Monti et al., 2010; Giovannetti et al., 2015). High levels of anxiety, PTSD, depression, sleeplessness, and caregiver strain were seen among ICU survivors' caregivers. Moreover, during critical care recovery, caregivers endured financial pressure, workplace difficulties, and physical strain (McPeake et al, 2016; Howard et al., 2022). Unpredictable health and care transitions, unmet information and support requirements, and interruptions to the patient's lifestyle, career, and finances have been cited as causes for family distress and anxiety (Howard et al., 2022). In addition, family surrogate decision makers are susceptible to decisional conflict, difficulties coping and regret, as well as mental and physical tiredness in case of chronically critical patients like Intensive Care Unit survivors (Howard et al., 2022)

Burden of grief: Ambiguous loss in caregiving situation. Ambiguous loss is an individual as well as a family stressor (Boss, 1999, 2002). According to Boss and Greenberg

(1984), family conflict, anxiety, and depression experienced by the family facing ambiguous loss situations seem to be positively related to the amount of confusion the family is experiencing. So, the more significant the confusion and uncertainty, the greater it is to deal with the ambiguous loss predicting family stress for individual family members and the family as a unit (Boss, 1999, 2006). It has been emphasized that of all the losses that a person experiences in personal relationships, the ambiguous loss is the most devastating as it remains unclear, uncertain, unsettled, and indefinite without closure, adding to a lot of confusion, stress, and torment (Boss, 1999, 2010).

Ambiguous loss is qualitatively different from ordinary grief (clear-cut loss), for instance, that comes from a death of a loved one, it is different in a way that a part is still there and a part is gone, and the process of grief is said to be frozen as there is no possibility of resolution or closure (Boss, 1999, 2010). However, ambiguity can cause personal and family problems as people are immobilized from making sense of the situation, thereby blocking the coping processes. (Boss, 1999). Pauline Boss (1999) identifies ambiguous loss into two types. For this study, the second type is of relevance, which is the physical presence with psychological absence, which occurs when loved ones suffer from Alzheimer's disease, dementia, traumatic brain injury, coma, chronic mental illness, and autism. (Boss,1999, 2010).

Caregiving to a family member who is physically present but is gone mentally and psychologically is challenging. The caregiver feels alone as there is no feedback or response; therefore, many caregivers reported that it feels as if there is a stranger in the house (Boss & Family Caregiver Alliance, 2022). Although Boss's "goodbye without leaving" notion is relevant for discussion in this study as it is one of the stressors in caregiving situations to patients with severe illness like dementia or vegetative state patients (Yehene et al., 2021). However, it does not adequately address the mechanisms or the processes by which family members are challenged in the evolving realities of the caregiving situation. Therefore, exploring the caregiving experience to understand these processes can significantly contribute to the advancement in the field of non-death loss.

This study will focus on families caregiving for a family member in a persistent vegetative state (PVS), and ambiguous loss can be an added burden that is particularly challenging for family members and caregivers due to the uncertain and unpredictable nature of the situation (e.g., uncertainty with how long the patient will survive, awake but unconscious, no feedback from the patient).

Positive aspects of caregiving. It is well-acknowledged that caregivers experience positive gains, apart from the burdens and strain (Lawton et al., 1991; Kramer, 1997). As suggested by the two-factor model of caregiving, there are both positive (e.g., enhanced emotional closeness) and negative (e.g., stressors and burdens) subjective responses to caregiving (Lawton et al., 1991; Kramer, 1997; Lou et al., 2014). Such uplifts may be crucial to keep a caregiver going despite the day-to-day challenges and may even reduce feelings of burden (Cheng et al., 2013)

Several studies have highlighted that most theoretical perspectives have neglected to consider positive experiences of caregiving(Biegel et al., 1991; Kramer, 1997), and scholars remarked that the lack of attention to the positive dimension of caregiving limits the holistic understanding of the caregiving experience and adaptation (Kramer, 1997). The negative aspects of family caregiving have been well-explored and comprehended, but little is known about the determinants of positive gains in caregiving (Cheng et al., 2013). However, a growing interest in assessing and exploring the positive dimension of caregiving has been seen. Studies have found that beyond stress and burden, positive aspects of family caregiving contribute to the strength paradigm of the caregiving situation (Kramer, 1997; Cheng et al., 2013; Lou et al., 2014).

Recent studies have found that family resilience positively affects the caregiving burden (Palacio et al., 2018), and the caregiver's resilience serves as a protective factor against the caregiving burden in epilepsy and cancer patients (Li et al., 2019; Ma et al., 2021). A study by Palacio and scholars showed that encouraging the identification of positive aspects of caregiving facilitates the caregivers' adaptation by promoting a resilient coping style, leading to personal growth and minimizing emotional distress associated in case of advanced diseases (Palacio et al., 2018). Furthermore, positive aspects of family caregiving, for instance, caregiving resilience, are essential for advancing program design and policy and research on family care within the global aging context. Therefore, caregiving should not be seen only from a negative light, for it also involves many benefits and growth-enhancing aspects (Taylor et al., 2013). Hence, for future studies, scholars have expressed the need to focus on the protective factors to caregiving burden that promotes caregivers' resilience taking in account the socio-cultural context (Chan, 2011).

The role of culture in caregiving experience. Culture gives individuals a framework for interpreting and assigning meanings to personal experiences (Lindisfarne, 1998, as cited in Gilbert et al., 2007). Therefore, caregiving experiences can differ depending on the society or culture; for instance, different sociocultural factors in different countries may influence a family's obligation to care (Chan, 2011). Research has demonstrated the differences in caregiving experiences of dementia in terms of problem recognition, help-seeking behavior, and caregivers' perceived burden between Eastern and Western countries (Gilbert et al., 2007). For example, in many Asian countries, the family is the primary source of long-term caregivers. A study on

Indian Hindi-Punjabi families found that participants strongly believed families could and should have a central role in providing care (La Fontaine et al., 2007).

Also, with changes in the socio-economic and demographic scenario in developing countries, like nuclear families replacing the traditional extended family living in one house, have led to changes in the family caregiving experience (Chan, 2011). The needs of family caregivers also vary across cultures (Jagannathan, 2014) and moreover, caregivers in developing countries face challenges due to a lack of primary health care facilities providing support to the family caregivers with chronic conditions (Levine, 1999). Therefore, sociocultural context needs to be considered and assessed to understand caregivers' experiences and coping behaviors (Chan, 2011), which is essential to develop an intervention to support the caregivers (Jagannathan, 2014). In light of these issues, this study will focus on the families in India caregiving to a family member in Persistent Vegetative state (PVS).

Socio-cultural context of India. As families do not live in isolation, and family dynamics are typically best understood in the context of their social and cultural background (Chadda & Deb, 2013), it is important to understand the socio-cultural context of India.

India is a traditional, hierarchical and a collectivistic society (Chadda & Deb, 2013; Mullaiti, 1995). It is evident in caste groups, amongst individuals, and in family and kinship groups (Scroope, 2018). As a collectivistic society, the Indian culture encourages social cohesiveness and interdependence (Chadda & Deb, 2013). Moreover, family is an important institution that plays a central role in the lives of Indians. The family's interests usually take priority over those of the individual, and decisions affecting one's personal life – such as marriage and career paths (Scroope,2018). Family loyalty and unity is a deeply held belief system. In order to maintain family harmony, lines of hierarchy and authority are clearly outlined, and rules of conduct help fuel it (Scroope, 2018).

It is known that the caregiving burden is a universal phenomenon reported worldwide, including in Europe, Africa, America, the Middle East, and Asia (Chadda, 2014); however, the caregiving experience varies depending on the socio-cultural and economic context (Jagannathan, 2014). In most developing countries, families have been the primary source of caregiving for persons with brain illnesses such as PVS. For example, in India, more than 90% of patients with chronic brain illness live with their families (Chadda, 2014), and families are obligated to care for the patients at home. The role of family caregivers is crucial when there is an acute shortage of home care facilities, affordable professionals, rehabilitation services, and home-care facilities, and a lack of health insurance, in India (Janardhana, 2105).

The family caregiver plays numerous roles and responsibilities in caring for persons with DOCs, including daily caregiving routines and medications, identifying the signs of illness, taking patients to the hospital, managing financial demands, and planning for their future. (Chadda, 2014; Janardhana, 2015). Studies report that caregivers who are highly involved with caregiving to patients with brain illnesses face the highest stress and burden (Jagannathan, 2014a). However, according to Jagannathan (2014a), caregiving resilience in Indian caregivers could be higher than in Western societies due to the firmly held family value systems and beliefs about family loyalty and responsibility in Indian society. Nonetheless, the changing realities in increased survival rates of patients leading to long-term care, the socio-demographic scenario where nuclear families are rising, and the inadequate health infrastructure for home care services are creating a crisis for family caregivers in India (Chadda, 2014).

With urbanization, joint families in India have been replaced gradually by nuclear families, and there has been an increasing load on family caregivers, especially if both spouses are working (Chadda, 2014). Suppose the family is not financially capable of hiring a formal caregiver or has no satisfactory health care services available. In that case, the family caregiver needs to make considerable compromises on his or her career to providing continuous care to the patient and might have to leave the job, further increasing the financial problems (Chadda, 2014, Jagannathan, 2014b).

On this ground, more and more families are looking to professionals for help, highlighting the need for family-based programs. Therefore, there is a need for an in-depth evaluation to understand the caregiver's role and experience in Indian context.

Caregiving to persistent vegetative state patients

The vegetative state (VS) and minimally conscious state (MCS) is a complex neurological condition that may occur after an acquired severe brain injury, where patients are in the wakeful stage but have no awareness of themselves or their surroundings (Monti et al., 2010). It is characterized by a significant loss of functioning at several levels (Giovannetti et al., 2015). The lack of the patient's psychological presence creates room for more worries, continuous supervision, and checks, increasing the burden on family and friends providing care (Giovannetti et al., 2015). It becomes even more of an unending torment in the case of VS as their eyes would open or blink but would never speak, and though the patients are not attentive or responsive to commands, there would be limited postural and reflexive movements of the limbs (Chiambretto et al., 2010).

The advancement in technologies in critical health care has increased the survival rate, prolonging the life of patients with severe brain injury (Giovanetti et al., 2015). Estimation for a chance of recovery for VS patients decreases significantly from 18% to 12% after three months of diagnosis and to 3% after six months (Monti et al., 2010), leading to a permanent/persistent vegetative state (PVS) with no capacity to regain consciousness even though they retain some autonomic physiological functions, such as breathing unaided (Holland et al., 2014). The life expectancy of PVS patients can be up to 10 years and even up to 20 years in some cases (Monti et al.,2010), implying long-term caregiving by family members (Covelli et al., 2014).

In addition, the severity of the clinical condition associated with PVS requires demanding and 24-7 continual caregiving leading to caregiving burden and distress (Covelli et al.,2014). Caring for people who are in a PVS condition requires continual medical treatments and extensive care, such as keeping a clear airway by suctioning, maintaining fluid balance, ensuring enough nutrition, proper dental care, maintaining healthy skin and, monitoring body temperature, measuring urinating amount, improving bowel function and perineal hygiene. The patient also needs to be engaged in physiotherapeutic activities and sensory stimulation (Goudarzi et al., 2018). Also, due to the limited scope of the current clinical diagnosis methods, PVS is often associated with a high rate of misdiagnosis (Monti et al., 2010; Jaul & Calderon Margalit, 2007). Though patients with severe or terminal dementia can progress towards the condition of PVS (Jaul & Calderon Margalit, 2007), PVS follows a significantly different onset from dementia, marking the difference in caregiving demands and caregivers' needs (Monti et al., 2010). Unfortunately, only a few studies have approached the issues related to PVS (Jaul & Calderon Margalit, 2007), and due to limited literature on the caregiving experience of patients with PVS, studies on dementia were used as a reference to relate with the studies and findings done on patients with PVS due to similarities in later stages of dementia.

As the patients can no longer make their own healthcare decisions, family members or the primary caregiver usually decide on their behalf without receiving any feedback or response. Family caregivers experience caregiving burden, ambiguous loss due to the absence of clear-cut loss, and economic burden (Leonardo et al., 2012; Giovannetti et al., 2015). Counterintuitively, studies on PVS did not show a direct relationship with diagnosis, disease duration, and place where the patient was taken care of with the overall burden of caregivers. Therefore, the relational factors for the burden on caregivers of VS patients remain undefined (Romaniello et al., 2015).

However, these recent years, there has been increased attention to the experience of informal caregivers of patients in PVS (Giovannetti et al., 2015). Studies have found that witnessing one's family member in PVS may evoke symptoms of depression, anxiety, poor appetite, insomnia, and other psychosomatic conditions, as the onset of the event, can happen suddenly and unexpectedly with no time to prepare practically, cognitively, or emotionally. (Chiambretto et al., 2010; Giovannetti et al., 2015). A quantitative study by Chiambretto et al. (2001) on first-degree relatives (husband and wives, parents, children, sons, daughters, brothers, sisters) of 41 Italian vegetative patients found that the caregivers and family members suffered from an emotional paradox arising from their partners' irreversible state, whether their loved one is alive or dead making them a difficult to mourn. The findings also show that caregivers cope with the situation by avoiding thinking about the future and focusing on the present. They mainly use a task-oriented coping style concentrating on practical issues such as micro-management of care (Giovannetti et al., 2015).

In developing countries like India, due to the long period of care required for patients in PVS, they are usually discharged from the hospital, and the family is obliged to give care at home (Goudarzi et., al 2018). Caregiving to PVS patients at home is challenging due to the high demand for continuous medical interventions and extensive care (Goudarzi et., al 2018). Moreover, caring for such patients also involves a complex experience of ambiguous loss (Chiambretto et al., 2010). However, limited studies have been conducted on the family caregivers taking care of vegetative patients at home in the Indian social-cultural context. As of date, knowledge of family members' caregiving experience, grieving processes, and coping styles comes mainly from studies of patients with chronic or degenerative diseases, particularly dementia (Romaniello et al., 2015).

In addition, caregiving to patients in PVS is a family phenomenon, and there is a need to gain a deep understanding of the phenomenon, especially when the family is the only resort for such patients in developing countries (Gouzardi et al., 2018). In developed countries, there are advanced and effective care facilities for critical and chronically ill patients like PVS and government support such as national long-term home care services in Korea. Unfortunately, in developing countries such as India, the lack of support from the government and the unavailability of an adequate healthcare system leads to the complete reliance of the PVS patient on the family, and the family is responsible and obliged for the comprehensive care required (Jagannathan, 2014b; Chadda, 2014; Gouzardi et al., 2018). Nonetheless, the existing studies have tried to evaluate the caregiving experience in PVS using the narration taken only from primary caregivers or one family member's perspective (Chiambretto et al., 2010; Giovannetti et al., 2015; Goudarzi, 2018), and very little is known about the family-level coping processes in taking care of a spouse, an adult daughter or son, or a parent. Therefore, to fill this gap, the study aims to explore family caregivers' experience and the family processes involved in coping and resilience in Indian families by interviewing two family members from each family. By doing so this study intends to identify a family level understanding of the phenomenon of caregiving for family members in a permanent vegetative state.

The importance of multi-family member perspectives in caregiving to patients in PVS

Earlier studies on family caregiving for patients in PVS expressed the limitation of using only one family member's narrative (Chiambretto et al., 2010; Giovannetti et al., 2015; Goudarz et al., 2018), and only a few studies have used a multi-member perspective to understand the experience of caregiving in persistent critical illness (Howard et al., 2022). This gap in the literature is a significant limitation that hinders our understanding of how multiple family members experience, manage and adapt to caring for individuals with chronic conditions such as PVS. Therefore, this research seeks to contribute to the literature by providing a multi-family member perspective on family adaptation and resilience in the caregiving context for PVS patients in India.

Based on research findings, a family-centered care approach to healthcare is especially essential in chronic critical disease as it meets the family's needs and values, and more research is required to design and assess treatments (Moss et al., 2019). Furthermore, consistent, open communication between patients, family members, and healthcare professionals is essential for delivering appropriate treatment for the chronically and critically ill (Moss et al., 2019). However, there are limited studies undertaking narratives from family caregivers in their natural context, such as their homes (Moss et al., 2019), and this is mainly due to the difficulty in recruiting participants in home-based care (Goudarzi et al., 2018). It has been proposed and speculated that conducting family caregiver narratives at home may result in more straightforward and honest responses describing their role as family caregivers and decision-making with less emphasis on healthcare professionals (Moss et al., 2019). Therefore, this research also aims to explore how a family-centered approach to healthcare supports families during caregiving for PVS patients in India.

In addition, to comprehend the family functioning and dynamics between the family members caring for patients in PVS, a multi-family perspective qualitative study will be able to give more insights, enabling the systematic investigation of family processes and the co-construction of shared family perspectives (Van Parys et al., 2017). Therefore, more research is needed to comprehensively understand the family dynamics, experiences, challenges, and significant needs associated with caring for patients with PVS. In order to fill this gap in the literature, this study aims to evaluate, from a multi-member perspective, the family processes of adaptation and resilience in the context of home-based caregiving for patients in a persistent vegetative state (PVS) in India.

III. Methodology

Interpretive phenomenology analysis (IPA) provides a useful framework for examining the phenomenon of families who are caregiving to a patient in PVS in India. IPA is a qualitative methodology first developed by psychologist Jonathan Smith (1996). IPA is a qualitative methodology that explores the participant's outlook on the world and encourages adopting an 'insider's perspective' of the phenomenon under study (Smith, 1996). At the same time, it emphasizes participants' lived experiences and how they interpret them (Smith & Osborn, 2007). It is a widely used qualitative approach, especially in health and clinical psychology, and is gaining importance in the research panorama of other disciplines (Van Parys et al., 2017). Furthermore, we believe that the interpretative phenomenology approach matches our intention as it is committed to obtaining the data about how the participants "think and feel in the most direct ways" (Bentz & Shapiro, 1998, p. 96) and is concerned with examining individuals' personal experience and their subjective meanings attached towards a particular experience (Smith & Osborn, 2007).

In addition, IPA is a blended approach as it involves a double interpretation, first when the participant is trying to make meaning of what is happening, then secondly, when the researcher performs an active role in the interpretive process (Smith et Osborn, 2007; Antoine et Smith, 2017; Neubauer et al., 2019). Therefore, one of the key aspects that distinguish IPA is the active role of the researcher in the inquiry and the recognition that researchers, like the research subject, cannot wholly be unbiased and conduct the interview with a clean slate mind (Neubauer et al.,2019). Instead, this approach values the experiences and past knowledge of the researcher that made him/her acknowledge the importance and the worth of investigating the phenomenon and consider bringing out the under-represented and unheard voices in the world. On the other hand, openly acknowledging the involvement of the researcher's preconceptions will keep in check how it has intervened in the analysis process and then reflect upon it (Neubauer et al., 2019). Therefore, as a researcher who has undergone a similar situation of caregiving to a family member in PVS in the same socio-cultural context, adopting IPA allows me to explore this phenomenon confidently by acknowledging the importance of my past knowledge and experience.

This research employs a qualitative design since it requires an in-depth exploration of the participant's life experiences and their meanings to the specific event. The condition of PVS is a unique phenomenon as it involves many uncertainties starting from the diagnosis, treatment, recovery, life expectancy, and intensive demands of caregiving. This qualitative study aims to examine family-level coping and resilience processes in Indian families caregiving for an ill family member in a persistent vegetative state (PVS). To gain a comprehensive understanding of the family unit's coping and resilience, narratives from two family caregivers from each family are collected, and Multi-Family Member Interview Analysis (MFMIA; Van Parys et al., 2017) is used as the methodological framework to analyze the individual interviews, with family serving as the unit of analysis. This study's principal objective is to collect in-depth information on the participants' views on family caregiving and the development of coping mechanisms within the family unit. Consequently, the interview questions focus on the participant's experiences, emotions, and beliefs, along with what does and does not work in sustaining family functioning throughout the process.

Sampling and Recruitment

This study applied snowball sampling method, which is a purposive network sampling strategy. It is a method used when it is difficult to access subjects with the target characteristics (Noy, 2008). As PVS patients in India are taken care at home, accessing the participants information from the hospitals was difficult. So, recruitment of the participants was done by contacting the health care home services providers and contacted providers could reach out to informal caregivers to see if they were interested in participating in the research study. In addition, the existing participants then recruited their acquaintances for the study. The criteria for selecting the research participants included:1) Family members of PVS patients at home with the duration of the condition for more than one year, and 2) A minimum of two family members from each family should be available to participate in this study where at least one member is a primary caregiver. Three families were recruited and two family members in each family agreed to participate in this study.

Data Collection

The data was collected from Manipur, India using semi-structured, separate one-on-one interviews with each of the 6 participants from three families caregiving to patients in PVS at home. Two family members from each family were interviewed individually. Each participant had two in-depth interview sessions except for one participant who couldn’t give the interview due to health conditions. Therefore, altogether 11 interviews were taken for this study. In all participating families, one member was the patient's spouse, and the other was the patient's child. The age of the spouses who participated in this study ranged from 51 to 79 years-old, while the age of the children ranged from 21to 37 years-old.

Depending on the participants' preferences, the interviews were taken either at their residence or virtually via the zoom platform due to the COVID-19 pandemic. Out of the eleven interviews, four face to face interviews at their residence and seven virtual interviews via zoom were conducted, with the interview duration ranging from 60 to110 minutes. An average length of the interview was approximately 70 minute. The interview duration and the number of questions varied from one participant to the other due to the caregiving circumstances and responsibilities of the participant. The data were collected over a period of seven months, starting from 20th May to 21st November in 2022. Though the participants were fluent in English, they preferred to speak in their native language and therefore, all the interviews were taken in their native language, Manipuri and later on translated to English. The interviews were recorded after the participant's consent and transcribed. The transcripts were de-identified by giving code names and imported to the MAXQDA2022 software. I read each transcript to identify codes and used MAXQDA for organizing the codes. After the interview, memos about the big impressions made during the interviews and an overall interpretation on what I thought the interviewee was saying were taken.

Ethical Considerations

Before the interviews, it was ensured that the participants were well-informed on the purpose of the study and provided with consent papers. After the data collection all personal information and participant names were changed to pseudonyms to ensure anonymity and protect the personal information. The study took appropriate ethical considerations of multiple perspectives research, such as network confidentiality. As the recognition of participants' accounts increased, anonymizing details were carefully balanced during the interviews and also made sure identifiable information was not used as a quote for their narratives in the study.

Researcher's reflection

My mother was in a persistent vegetative state for five years, receiving at-home care. Being a family caregiver for a person with PVS has provided me with much expertise on this issue, increasing my competency as a researcher. Because of this background of mine, the interviewees could trust me more and be more willing to open up, which made it easier for them to convey their stories. At the same time, I could easily relate to their stories because I have been in a similar situation. Although they could communicate in English, I interviewed our native tongue (Manipuri) to give them more freedom to express themselves. As a bilingual in Manipuri and English, I could comprehend the participants' experiences, opinions, and ideas and easily listen to them and translate the recordings efficiently. Before each interview, I thought about how I could keep my emotions and memories of the past to myself. Even though there were times when I could relate to the respondents' stories, I did my best not to interfere with my own opinions, ideas, or feelings while I was conducting the interviews. Instead, I attempted to listen to their narrative without bias. There were moments when I used personal examples to help the interviewees comprehend my inquiries, such as when I inquired if their family dynamics had changed due to the incident. A few interviewers sought clarification on what I meant, so I gave it to them by noting that my family spoke to one another more often and worked together to overcome obstacles. Sometimes I unintentionally interrupted by stating, "Yes, that also occurred to me." While conducting the interview transcription and analysis simultaneously, I had a peer-debriefing session and double-checked my work with my adviser. To avoid bias in my analysis or interpretation of the narrations, I gave myself a week after each interview to reflect on it. Nevertheless, despite my best efforts, it is still likely that I might have provided more feedback during the interview or misconstrued the narration.

My advisor repeatedly emphasized the need for me to write memos to analyze the data critically and that it was crucial to take some time after each interview to reflect. The suggestions were beneficial to me in improving the quality of my study. I compared my interpretation of the interview and the analysis with these memos to assess the credibility and trustworthiness of the findings.

Interview procedure and questions

The interviews began with a brief conversation to collect sociodemographic informationt on age, relationship with the patient, data of time from the event, what caused the event, the place where the patient lives, education level, occupation and source of income. Then, continued with a general question about changes in the participant's life after the event (i.e., Would you describe your experience since the event or what changed after the event?"). After building rapport and trust with the participant, the interview headed toward the main questions (See Appendix A for interview questions). The main questions were as follows:

1) Tell me about your experience after your family member got diagnosed with PVS?

2) What are the changes in roles and responsibilities in the family faced after the event?

3) Tell me about the dynamics of your family?

4) How did you cope with the difficulties and challenges?

5) How did your family cope as a unit, and what factors helped in the process?

6) What do you think your family's strengths are?

Data Analysis

The interviews were then analyzed using a methodological framework called Multi Family Member Interview Analysis (MFMIA; Van Parys et al., 2017), which was inspired by Interpretative Phenomenological Analysis (Smith & Osborn, 2007) and Dyadic Interview Analysis (Eisikovits & Koren, 2010). MFMIA has proved effective in analyzing the experiences shared by multiple family members in the context of adjustment to an illness (Eisikovits & Koren, 2010; Van Parys et al., 2017; Van Schoors et al., 2018). This framework allows us to analyze individual interviews while focusing on the family as the unit of analysis (Van Parys et al., 2017).

Unlike the traditional data collection models where only one family member is interviewed, such data, though valuable, fails to capture the complexities of family life (Carr & Springer, 2010). Instead, multi-family member interview studies (MFMIS) help us to understand overall family dynamics by bringing in and connecting the perspectives of multiple family members(Reczek, 2014) and delivering a more rounded picture of family life (Harden et al., 2010). Furthermore, it allows the researcher to compare and contrast the viewpoints of different family members and to build an understanding of family practices or culture (Harden et al., 2010).

According to the MFMIA framework, qualitative data analysis is conducted in two phases(Van Parys et al., 2017). For the first phase of the data analysis, the principles of

Interpretative Phenomenological analysis (IPA) (Smith, 1996) are applied as the principal methodology (Van Parys et al., 2017; Van Schoors et al., 2018).

The second phase of the analysis was based on Eisikovits and Koren's (2010) dyadic interview analysis approach. The dyad in this study is the parent-child relationship experiencing the phenomenon of caregiving to a family member in PVS. The preferred method of interviewing each dyad member is separate one-one interview while using the dyad as the unit of analysis (Eisikovits & Koren 2010). The dyadic analysis procedure outlined by Eisikovits and Koren (2010) is similar to that conducted in qualitative studies on the individual level, identifying essential statements, sentences, and quotes that explain how the participants experienced the phenomenon. The distinctive point of dyadic analysis is the study of the themes emerging from each dyad's (parent-child) individual narratives by evaluating similarities and dissimilarities between the individual versions, leading to various reconstructions of the existing themes and the emergence of unique subthemes.(Eisikovits & Koren, 2010). Scholars have pointed out that though dyadic analysis enhances understanding of the relationship dynamic, it also comes with complexities. An overlap in the narratives does not automatically represent cohesion, while contrast does not mean separateness on all occasions (Eisikovitis & Koren, 2010). Therefore, dyadic analysis using separate interviews can enrich and limit the perception of the phenomenon under study, unlike individual-level interpretation. Every narrative version needs to be considered and cannot be disregarded, thereby creating a structure for dyadic narratives and interpretation(Eisikovitis & Koren, 2010). Therefore, this method permits the thorough and systematic analysis of family practices and the co-construction of shared family realities.

The steps followed for the data analysis of the study are: First, each interview’s Interpretative Phenomenological Analysis (IPA) was done one by one. Second, each family unit was analyzed by identifying the themes specific to each family. Third, each family unit's themes and subthemes were integrated to bring out new cross-family thematic categories. Lastly, a peer debriefing session helped to confirm the credibility of the research findings and interpretations

The first step involved applying the Interpretative Phenomenological Analysis (IPA) principles to all interviews, each given a separate analysis (Van Schoors et al., 2018). In this step, a memo was written for each interview, and each transcript was read several times to familiarize myself with the participant's narrative. After that, a preliminary coding (i.e., feeling anxious, sleep disturbance, financial distress, feelings of uncertainties.) based on the research questions was done on MAXQDA2022 software. I applied open coding while examining the data line-by-line and word-by-word, finding and marking key words and concepts on each line or paragraph based on the event, scenario, subject, action, and response they reflected. Following an evaluation of the primary codes based on their similarities and differences as connected activities, events, occurrences, topics, actions, and interactions, the overlapping codes were reallocated, resulting in a final code system with 946 codes. The codes were then allocated to categories based on conceptual ideas.Next, the initial coding was converted to more general themes (i.e., Caregiving burden, feelings of ambiguous loss, social support, etc.), after which similarities were looked at to produce a grouping of themes for each case. The same procedure was followed in each case. Throughout the entire process of coding and defining categories, as a researcher I repeatedly asked, "What is occurring in the data? What is the participants' primary concern?”.

The implementation of IPA laid the groundwork for subsequent analyses at the family and group levels (Van Parys et al., 2017; Van Schoors et al., 2018). It also allows the participant to narrate as much of their experience as possible, allowing us to read their narratives at a micro level. After analysis of the individual interviews, the second step was conducting an integrated and comprehensive evaluation within each family unit as suggested by Van Schoors et al.(2018). After combining the narratives and clustered codes from the first step, themes relevant to each family were identified, and new thematic categories at the family level were developed. During the analysis, 'similarities' and 'dissimilarities' between the individual accounts of each family unit were identified, on a descriptive and interpretative level. As a result, the individual perspectives of each family member within a family unit constituted a 'dyadic' perspective which is an added perspective on the family dynamic and functioning. For instance, the father stated that he feels closer to his daughter during adversity, whereas the daughter feels more distant. Through this dyadic perspective, it is possible to comprehend the bigger picture of their family functioning.

In the third step, while paying thorough attention to how each family communicates, adapts, and builds resilience, an overall analysis of all families was also carried out to look for connections between earlier themes that had been developed in various cases (different families). The analysis at a family level was a repeated process between more abstract levels of analysis and meticulous investigation of each meaning unit. Finally, all themes were put into a written statement, explaining the analysis and illustrating it with direct quotes from the participants.

Trustworthiness and Credibility

To boost the data's trustworthiness and credibility, I interviewed each participant twice, with a two- to three-week interval between the first and second interview. To avoid the possibility of information bias, I ensured that the participants were in a comfortable environment and agreed to be interviewed using the method they preferred (either at their home or via a virtual platform), and while conducting virtual interviews via zoom, I ensured that they were alone and not in the presence of an outsider. If there was a health complication with the patient or the participant, I rescheduled the interview and conducted it at a different time.

Peer debriefing was used as a step to ensure the validity of the data and to provide a means of determining the overall reliability of the findings. Peer debriefing is a procedure that helps build the credibility of the research study and assures that the findings and the interpretations are valid and reliable. (Spall, 1998). As a student researcher, my thesis advisor debriefed me throughout my research study. During a debriefing session, in-depth conversations about the research outcomes and progress were made step by step, starting from the conception of the framework, the data collection, and the analysis. Due to the level of trust built and shared, I could discuss any issues and brainstorm alternative approaches concerning the study, which helped me confirm my ideas. Furthermore, consistent guidance kept me in check of my emotions throughout the study.

IV. Results

Key characteristics of the participating families

Demographic characteristics of each family, including the duration of the patient's illness, the cause of the disorder, gender, age, education level, and occupation of each family member, the source of household income, and a current caregiving arrangement in each family are presented in Tables 1, 2, and 3. The families who participated in the study were labeled by their pseudonyms as Naorem's family (Table 1), Nagamapal's family (Table 2), and Thokchom's family (Table 3). Of the three families taken under study, two family members from each family participated in the study. One of them was a primary caregiver at the time of the study while the other one took part in caregiving during the course of illness.

Table 1

Key characteristics of Naorem's family

	Patient	***Spouse***	***Child 1***	Child 2
Cause of the disorder	Brain injury	-	-	-
Duration of illness	3 years	-	-	-
Sex	Male	*Female*	*Male*	Male
Age	51	*51*	*22*	16
Occupation	Entrepreneur	*Government employee*	*Student*	Student
Education level	Master's degree	*Bachelor's degree*	*Secondary education*	Primary education
Current source of Income	-	*Monthly salary*	-	-
Current caregiving situation	Receiving home care	*Primary Caregiver*	Co-caregiver (currently away from home for studies)	-At home (does not take part in caregiving)

Note. Bold and Italics indicate the participants of the study

Naorem's family consists of four individuals (i.e., the patient, the spouse, and two children). I interviewed the patient's wife, the primary caregiver, and the eldest son, who assisted with caregiving for one year before leaving for college. Whenever he returns home from vacation, he currently provides care. After sustaining a severe brain injury, the patient has been in a persistent vegetative state (PVS) for three years and has received intermittent nursing care at home.

Table 2

Key characteristics of Rajkumari's family

	Patient	***Spouse***	***Child 1***
Cause of the disorder	Brain stroke	-	-
Duration of illness	4 years		
Sex	Female	*Male*	*Female (Married)*
Age	73	*79*	*37*
Occupation	Bank employee	*Electrical engineer*	*Social worker*
Education level	Secondary education	*Diploma*	*Master's degree*
Current source of Income	Pension	*Pension*	*Income earner*
Current caregiving situation	Receiving home care	*Co-Caregiver*	*Co-Caregiver*

Note. Bold and Italics indicate the participants of the study

Rajkumari's family consists of 3 members; the patient, spouse, and daughter. The patient has been in Persistent Vegetative State (PVS) for four years after a brain stroke. I interviewed the spouse and the daughter, who are co-caregiving at home with the support of a nurse. The spouse is a retired pensioner; the daughter is an income earner, married, and has two children. Despite her work and children, she looks after her mother every day in the evening. She has arranged that her children get off from school at her natal family's house as she goes there directly after work. By the time she arrives, the nurse takes off for the day and handles all the caregiving responsibilities until the last feeding for the day. When she is done with the feed, around 8 pm, her husband comes to pick them up, and the spouse takes over for the night.

Table 3

Key characteristics of f Paonam's family

	Patient	***Spouse***	***Child 1***	Child 2	Child 3
Cause of the disorder	Brain stroke	-	-	-	-
Duration of illness	3 years	-	-	-	-
Sex	Male	*Female*	*Female*	Female	Female
Age	62	*58*	*25*		
Occupation	Medical officer	*Lecturer*	*Unemployed*	Student	Student
Education level	MBBS	*PhD*	*Master's degree*	Bachelor's degree	Bachelor's degree
Current source of Income	Pension	*Monthly salary*	-	-	-
Current caregiving situation	Receiving home care	*Co-Caregiver*	*Co-Caregiver*	-Away from home for studies	- At home (does not take part in caregiving)

Note. Bold and Italics indicate the participants of the study

Paonam's family consists of 5 members, the patient, the spouse, and three daughters. The patient had a brain stroke and has been in PVS for the past three years. I interviewed the spouse and the family's eldest daughter, who are currently co-caregivers to the patient at home for the past two years. While the second daughter is studying away from home, the youngest daughter prepares for examinations and assists with household work. Currently, the patient is cared by the patient's spouse and daughter without the assistance of a nurse.

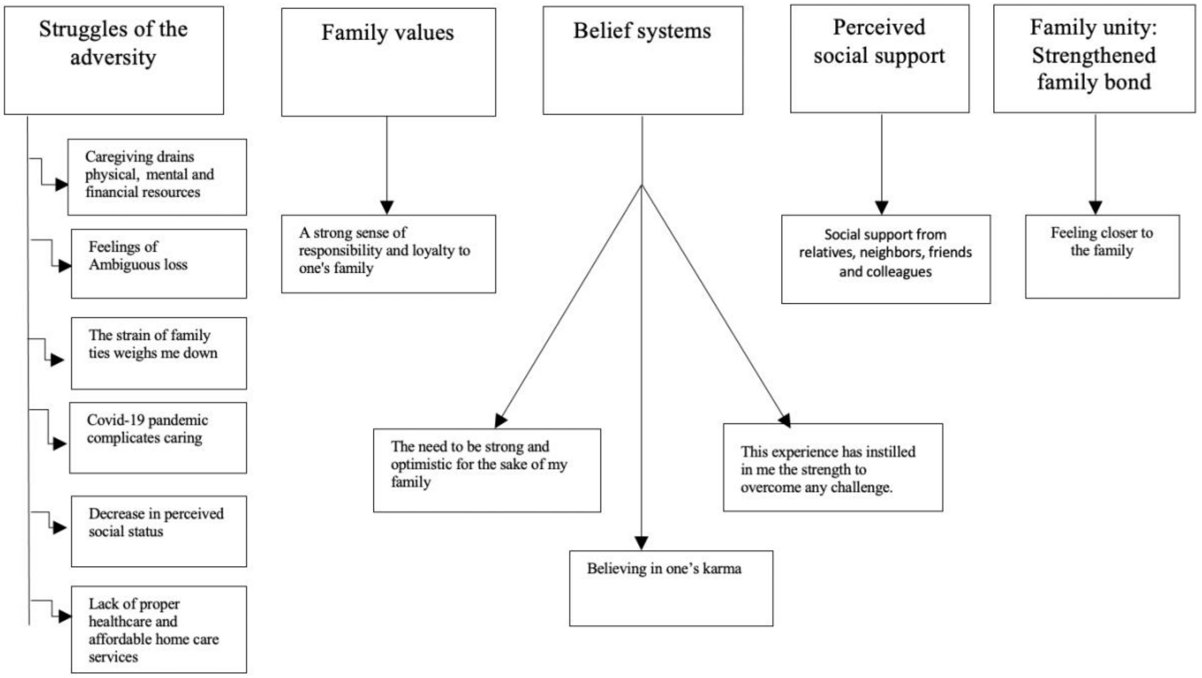
This section presents the findings and results of this study. First, similarities between families will be highlighted based on the superordinate and subordinate themes that have emerged, and second, differences in the formation of family hierarchy and family adaptation process will be discussed.

Similarities across all the families

In this part, the themes that emerged across all of the families will be discussed. These themes are the result of similarities across all families and will be examined based on the narratives of each family's experience providing care to a family member with PVS. The themes that were prevalent among all families are clustered into four superordinate themes: 1) Struggles of the adversity, 2) Family values, 3) Belief systems 4) Family unity: Strengthened family bond and 5) Perceived social support. As indicated in Figure 1, the superordinate themes were derived from the corresponding subordinate themes. The findings indicate that the process of family adaptation to the caregiving situation of PVS patients is complex and multifaceted, marked by contradictory dynamics within the emerging themes. For instance, in the second theme, even though family caregivers have a deeper connection with one another and see the family as a more unified whole, there is a noticeable separation within the structure of the family.

Figure 1

Superordinate and subordinate themes.



Struggles of the adversity

Caregiving drains physical, mental, and financial resources. Families encounter challenges in providing care to their family members in PVS due to the need for intensive care and regular monitoring. The majority of family carers reported that their lives had undergone profound transformations. They shared their financial difficulties, mental distress, emotional pain, and physical discomfort to explain how distressing the situation is. In addition to being in a condition of perpetual anxiety, caregivers also report feeling exhausted, frustrated, and irritable. Below is the narrative of a 25-year-old who remarks caregiving as emotionally distressing as she realizes that her father is incapable of performing normal things and states the high expenditure associated with the condition.

> Caregiving is very tiresome emotionally. I have accepted that my father is weak and he is in such a state. Sometimes, it hurts alot when I come to the realisation that he is no longer able to do all the things which he was able to before. Financially also, it is a struggle since the treatment for such ailments is very costly (Daughter of Paonam's family)

It was found that the carers experienced physical and mental distress like chest pain, body ache, sleep disturbance, constant worry, and anxiety-related problems. Some reported experiencing sleep difficulties owing to the urge to check throughout the night and stress-related anxiety problems. The 37-year-old daughter comments that she is not adapting well to the adversity and she needs anxiety medications to reduce her stress level.

> I think I am not very good with coping up with my stress or relieving myself from all the stress that I get. And maybe that's why I have anxiety problems due to all the buildup stress. I have been taking anxiety reducing, stress reducing medications for a while now. (Daughter of Rajkumari's family)

The family caregivers also indicated that they rarely have time for self-activities and social meetings and no longer have the opportunity to spend meaningful time with friends. There are often conflicts between work and caregiving roles and expressed the need for caregiving support and division for caregiving roles. The spouse of Paonam’s family expressed how it is challenging to manage the strict caregiving routine, her work and her role as the head of the family.

> We couldn’t give him any extra care like spending time next to him trying to manage work, household chores and his caregiving. As for my work, I need to prepare for my classes, make lesson plans and also take care of my children since I am the head of the family now. We make sure that we fulfill whatever is needed for him but anything extra is challenging to work around our schedule and his routine. It’s not like we can feed him whenever we get free or change his position as we get time but to follow his strict routine for the day….When I want to speak to him or talk to him, he would be sleeping and when I am just about to go to work, his eyes would be open, so it gets harder to get the right timing. It is very tiring to manage all of this.

Feelings of ambiguous loss. During these challenging times, the family members who provide care for their loved ones not only bore the stress of providing care for them but also endured emotions of ambiguous loss. They expressed the torment of the patient losing their identity, even though they are alive. While providing care for family members, they experienced uncertainty and expressed how difficult it is to accept the situation. Most of them voiced the desire for an alternative circumstance in which the patient could communicate with them.

Moreover, they remarked that they feel lost and helpless due to the condition's ambiguity, which exacerbates their despair. Even though they were desperate for the patient to recover initially, most still hoped that the patient would live longer, despite the challenges and difficulties of caring for them. Below is the narrative of the 22-year-old son of Naorem's family, who expressed the grief of indefinite loss and stated that they feel stagnant in this situation of uncertainty.

> Absolutely, I have gone through such feelings of uncertainty. When I call out his name sometimes, or try to talk to him, there are times when he nods but he is nodding out of natural instinct, he nodding naturally but he is not present psychologically or mentally.

> He does not understand what I am saying, it just feels like talking but he is not there. Mom talks to him also, and sometimes when he smiles, we are happy to see him happy but at the end we know that he is not psychologically active to understand what we are saying. We feel like sometimes he is understanding and sometimes he is not, it really uncertain, it feels like we are stuck in the middle. (Son of Naorem's family)

The strain of family ties weighs me down. As the caregiving scenario is financially draining, and the extended length of this condition takes a toll on the families' financial resources, it was eviden through the findings that the families faced financial distress. Due to this, financially supporting both the patient and their own family is a burden mentioned by family caregivers. The children felt a sense of indebtedness to their parents or the need to repay. On the other hand, for the spouse, there was an added stress and burden of filling the patient's void in the family; therefore, all the responsibility to emotionally and financially support their children fell on the surviving spouse. A spouse shared how she often finds herself in a conflict with her children over the things the children want to acquire but cannot because of the financial circumstances in which they find themselves. This responsibility is made much more difficult for her because she would want to make up for her husband's absence but is unable to, and this led to distress as she thought she had some of the blame for the current situation.

> Most of the arguments that I have with my children is around the things that they want to buy and since I cannot meet their demands due to financially difficulty, there is a slight tension. It makes me feel bad because I want to fulfill their wants, all the more to fill their father's absence but there are times that I cannot just afford it… It's harder for me to cope with this situation, all the more because of my children. (Spouse of Naorem's family)

Decrease in perceived social status. The findings revealed that families experiencing this difficulty undergo a decline in their perceived social status. They had voiced their perception that their social status has decreased as a result of changes in people's conduct and indicated that the illness of the patient has brought about a shift in their family's image and reputation in the community. In families where the patient was formerly the head of the household, this sense of diminished social status was pronounced. In a sociocultural setting where social ties are seen to be of significant value, a decline in perceived social status was an additional stress to adversity, as family members felt a sense of despair with the changing family reputation in society. For instance, Paonam's family expressed that their social standing had lowered due to their father's condition. The fall of the patient, who was once the head of the family and a physician, seemed to affect the attitude and behavior of the community's residents. Before the patient's illness, their home was a common destination for favor requests and casual conversation. Now, barely people inquired about their well-being or exchange greetings when they cross paths on the road. The wife stated that people had lost regard and respect for her family. To quote from the narrative, “Well, there has been a lot of changes happening in our lives. But if I were to point out, at the time when my husband was healthy and considering the fact that he used to be a doctor, people in our locality or neighborhood would come to our house every now and then, spend time with us, greet us when we pass by them, but now everything seemed to have stopped. The way how people regarded our family, seems like it is lost…”. (Spouse of Paonam’s family)

Covid-19 pandemic complicates caring. Due to the COVID-19 pandemic, the caregiving scenario faced additional obstacles. Caregivers experienced pandemic-related stress and difficulties due to travel restrictions during the lockdown, consulting a doctor, apprehension that the patient will be infected due to the fatality of the disease, obtaining medications and groceries due to the closure of stores, entry restrictions, and longer hospital procedures. As a result of being infected with COVID-19, a caregiver was unable to care for her spouse, which caused her to feel very sad and anxious.

> There was a time when I got infected with Covid and I couldn’t tend to him since I was in isolation and it made me feel very sad and was constantly worried. Times like that made me realized that I need to be all the more strong and healthy for my family. (Spouse of Naorem’s family)

Lack of proper healthcare facilities and affordable homecare services. Families had raised their concerns over inadequate healthcare facilities and services in Manipur for patients in PVS. Due to lack of medical equipment like MRI in government hospitals, critical brain related cases can face delay in diagnosis and lose out on the “golden hour” for treatment. As mentioned earlier, there are no proper rehabilitation centers for critical-state patients, which leaves no choice for the family members but to give home care to patients in PVS. There were many challenges and risk involved with caregiving at home especially with the lack of information and awareness on caregiving for families in such situations. In addition, there were minimal private sectors providing home care services and it is very costly to afford on regular basis. On this note, families shared their sentiment on how government should also provide such services on a reduced cost. Not only were the private healthcare facilities costly, there was also a shortage of such services if the families live outside of urban areas due to transportation problems.

> In the beginning, we thought about hiring a nurse but since we live away from the city, it was hard to get a nurse who would commute to our place every day. (Spouse of Paonam’s family)

Families who sought formal help for caregiving were dissatisfied with unprofessionalism and limited skill sets for dealing with patients requiring intensive care. As a result, they had emphasized their skepticism and the necessity to keep a careful check on and speculate about the quality of treatment offered.

> We used to have nurses from the start and there were nurses who were disgusted to touch the patient or clean his body. My mother also said that these guys were not handling him properly and not responsible as a nurse. He was very unprofessional in a manner that he

> used to treat the patient inhumanly like objects or he would just perform the small tasks that is needed to be done and not give much attention to my father. (Son of Naorem's family)

Family values

A strong sense of responsibility and loyalty to one's family is a tremendous resource for strength and motivation. In this study, value systems like family loyalty, obligation, duty, and responsibility were a tremendous source of strength and motivation to overcome the adversity, hence fostering family resilience in all three families. The findings showcased that family caregivers embody a strong value system and set of beliefs and help to unify the family during this hardship. The 58-year-old spouse of Paonam's family said that it is her responsibility to care for her husband, and that she and her family have no choice but to embrace this responsibility and confront the difficulties.

> There is a saying in our culture, "Even if you run away, you won't survive", so this is exactly what has happened to me and my family. You know, I cannot replace my role and responsibilities towards my sick husband with anyone else, and I cannot throw him away or not get medical treatments done… For us, it is our duty and responsibility, we cannot run away from it. We have to think about it every moment…(Spouse of Paonam's family)

The following extracts from the narratives also showcase the strong sense of family responsibility, obligation in Naorem's family. For instance, the 51-year-old wife of the patient in Naorem's family felt strongly about her responsibility and role as a spouse, which appears to be what kept her going.

> I have to do what I can do like to look after my husband to my best, I cannot escape it. It's been already 3 years and I am taking care of him very well and people are quite surprised and impressed with how well I have taken care of him… Even if I am tired, I have to do it, even if I don't feel like doing it, I have no choice but to do it because who will do it, he is my husband. (Spouse of Naorem's family)

The below narrative of the 22-year-old son echos his mother with his strong conviction for stepping up as responsible child and compromise for the well-being of his family.

> Not more of a thought but like a requirement that needs to be done. Someone is down in a family, you can't keep being individual at that point. Like naturally, even though you need to do something for yourself, you need to keep that aside and think for the whole family. Everyone has to come together no matter what. The situation demands it. No matter what, you have to work together even though there are differences in the family. I need to compromise and do whatever that needs to be done, that's the conclusion for me. Then you see the similarities when you try to work together and then make it work. (Son of Naorem's family)

The power and motivation that may come from a strong sense of duty and commitment to one's family can't be overstated even in Rajkumari's family. Though the family is barely getting by through this hardship, the sense of duty and responsibility is factor that keeps the family afloat.

> As a daughter, looking after my parents when they are old is my responsibility regardless of if I am married or not married, it doesn't matter. It's not like they have a son and as their only child I need to take care of them. Even if I am married and I have my own family, I take all the responsibility to provide physical, emotional support, financial support…. this is my responsibility and that's why I am doing it by any means. By hook or by crook I am handling it so far. (Daughter of Rajkumari's family).

Belief sytems

The need to be strong and optimistic for the sake of my family. Family caregivers voiced their desire to maintain a positive outlook in the face of this challenge. The majority of the participants said that they must be strong to survive, endure and continue facing this hardship, and not give up for the sake for their family (e.g., "Times like that made me realized that I need to be all the more strong and healthy for my family" Spouse of Naorem's family). It is one of the key family processes which shows positive outlook for overcoming the challenges with confidence and accepting what cannot be changed.

In addition, the circumstance requires a great deal of endurance and patience, and one of the participants said that they must be patient since they can only wait as time passes and continue to search for an effective strategy to deal with the situation (e.g., “We can only go along as time flows and find our own ways to cope up with the situation” Spouse of Rajkumari’s family) In light to this, being courageous and optimistic is also a necessary tool, which helped them to accept this adversity rather than trying to deny and escape. The need to be strong and optimistic for the sake of my family is a theme, which show how families are tolerating the uncertainty and building resilience to fight the challenges of this adversity. A caregiver expressed how she feels the need to be strong and courageous for the children and to face the hardship that has fallen in front of her family.

> As for me, I think that I need to survive, I need to work hard for the sake of my three children, I need to be strong, I need to be courageous. This is how I feel. I have to face it and I cannot escape from this, so whatever comes my way, I have to face it all, this is what comes to my mind. (Spouse of Paonam’s family)

Believing in one’s karma. Here, *karma* refers to the concept that one's actions will impact his or her present or future life. Every action a person makes will, at some point in the future, impact that person. This is the concept of karma, which refers to the cycle of cause and effect (Castor, 2013). Many Indians tend to accept how things are in their lives, believing that good or bad things happen to people because of what they did in their past lives. In this study, it was discovered that the caregivers attributed significance to the adversity they are enduring as their karma. However, karma is often used in contexts that are not entirely congruent with its original significance, like representing fate or explaining sudden hardships (Castor, 2013). In the study, it was noticed that the caregivers blamed past actions or sins they have committed in their present or past lives and questioned what they did to deserve such adversity. This finding demonstrated how the family caregivers developed a way to make sense of this adversity through karma. Here, the family caregivers meant to explain the adversity using the cycle of the cause-and-effect rule of karma and the sudden hardship that has fallen upon them. They reasoned by looking for the cause of events that had occurred in the past or past lives and used it as a resource that helped them to accept this adversity, as there is no way to undo the deeds of their past lives. This belief system is one of the processes of family adaption and resilience, which assisted the family members to normalize the adversity as something that is not escapable.

> I sometimes wonder if I have wronged or sins in my past life that I am facing just a horrid situation in this life. I ask myself, why has this happend to me? What have I done wrong? It is sad. What karma have I done in my past life that I am facing this kind of consequences in my life. (Spouse of Paonam's family)

The caregivers tried to embrace their fate by accepting this hardship as their karma. Though they wondered what they had done in the past, they no longer strived for or attempted to find meaning in this adversity, but instead accepted the reality and faced it.

This experience has instilled in me the strength to overcome any challenge. When asked how their attitudes on life had changed as a result of the hardship, the narratives revealed a shift in life perspective and positive transformational development. They believed that this experience had given them the ability and perseverance to withstand any future hardships or difficulties. In light of this, the son of Naoram's family said that after experiencing this difficulty, all other challenges in life appear little, and he is no longer hesitant to confront any difficulties.He said:

> Things have changed and increased to a certain level like responsibility, charity, empathy, compassion towards my family. All those things have contributed to development and how i see the differently now. Before i was scared of even the small problems but after what i have gone through and what i have become now makes me

> have a sense of growth within like I have come this far. There is no other problem that I think I can't handle because i have handled such a big thing in my family and the intensity of every other problem is minimized when we think from that perspective and i am able to handle much more that way. (Son of Naorem's family)

They had the notion that the hardship that they are going through right now came out of nowhere, and it had taught them that life can be unpredictable. Therefore, the only thing left for them to do is face it head on with bravery and courage. The sentiment was reaffirmed by the daughter of Paonam's family, who said that there are no challenges that they would not be able to surmount in the years to come (e.g., "We are now able to overcome whatever has come our way by facing each and every obstacle that have come our way. Also, whatever may come in future, we will be facing it and will overcome it" Daughter of Paonam's family).

Family unity: Strengthened family bond

Feeling closer to my family. Over the years of caregiving, family cohesion and connectedness had strengthened and is a family process that assist in family functioning for adaptation and resilience. During the years of adversity, there had been shifts in family relationships and dynamic. The results demonstrated that these families felt closer to one another and worked with a better degree of family unity and collaboration in response to this adversity. For instance, Paonam's family had a great sense of solidarity and cohesion. Both the wife and the daughter expressed that their familial relationship is stronger and that they feel closer than they ever have and they make decisions after seeking each other's opinions and discussing the matter collectively. Prior to their father's illness, their parents would make the most important family decisions, and they would only participate in matters pertaining to their studies; however, they now make all family-related decisions collectively, including construction of their house, household expenditures, and caregiving techniques.

> Me and my sisters have become much closer with our mother…Now, even for family issues, for example, our house is under construction right now, so even for this, my mother and our siblings discuss together about it. Even for my father, while making timetable for his caregiving, we discuss it among ourselves as what will be the best. We discuss it as a group since we cannot handle it individually. Our minds are clearer when we discuss together. (Daughter of Paonam's family)

Despite the fact that the family caregivers had a feeling of a greater connection and regarded the family as a more cohesive unit, there were noticeable separations within the family unit. To mention an instance, a different impact on the bond between the spouse and the daughter of Rajkumari's family was identified after the patient got diagnosed and fell into PVS. The daughter expressed that though there had always been an emotional gap with her father, she found herself growing distant from her father as she struggled to communicate with him. She felt that there is a lack of consideration and understanding despite her constant effort to physically, emotionally, and financially support her father. Instead of acknowledging her endless support, she experienced growing demand for financial support even when her salary was delayed for three months. According to her description, every phone call she received had a sense of urgency and demanding questions that wear down her patience. She struggled to keep up with how her father is overly dependent on her and thereby, it made her feel distant from her father.

According to the results, it is observed that the process of family adaptation to the circumstances of providing care for PVS patients is complicated and multidimensional, characterized by opposing dynamics within the family. Nevertheless, the overall findings showcased that these families felt closer to each other and operated with a higher level of family unity and teamwork to face this adversity. It was also observed that strengthened bond has a synergistic effect across family functioning domains. For example, strengthened family bonds facilitated increased communication, emotional sharing, and collective decision-making.

Perceived social support

Support from relatives, neighbors, friends and colleagues. All the family caregivers remarked that they get help from their relatives, friends, and neighbors. In this research, it was discovered that social support is a resource from which families get tremendous strength and motivation that assisted the families to adapt and build resilience to the adversity. The narratives demonstrated that they are highly interdependent on their relatives and through this interdependency they worked together to face this hardship. Though the support received by each family differs in terms of physical, emotional support and financial support, they commented that they would not have been able to face the challenges without the help of their relatives. This resource contributed to families' adaptation to the adversity and facilitated the development of the resilience required to address the challenge. As an example, the wife of Naorem's family remarked that she is able to manage her caregiving responsibilities due to the help she gets from her relative who offered to stay with her during this hardship.

> Everything I am managing and it has become possible with the help from the relative's family who is staying with me. I am able to go out even for an hour or two because they are at home. Even if they don't do anything for my husband in terms of caregiving, the mere presence of them at home makes me feel like I can go out with a light heart. Even though, I am the one who does everything for my husband, all the caregiving responsibilities I handle it but the fact that they are there, makes a huge difference and that's how I am able to go out even for a shortwhile (Spouse of Naorem's family).

Families also receive support from neighbors, colleagues from their workplace and their friends. Below is the narrative given by the wife of Paonam's family on how she manages work with caregiving responsibilities through the support she gets from her colleagues.

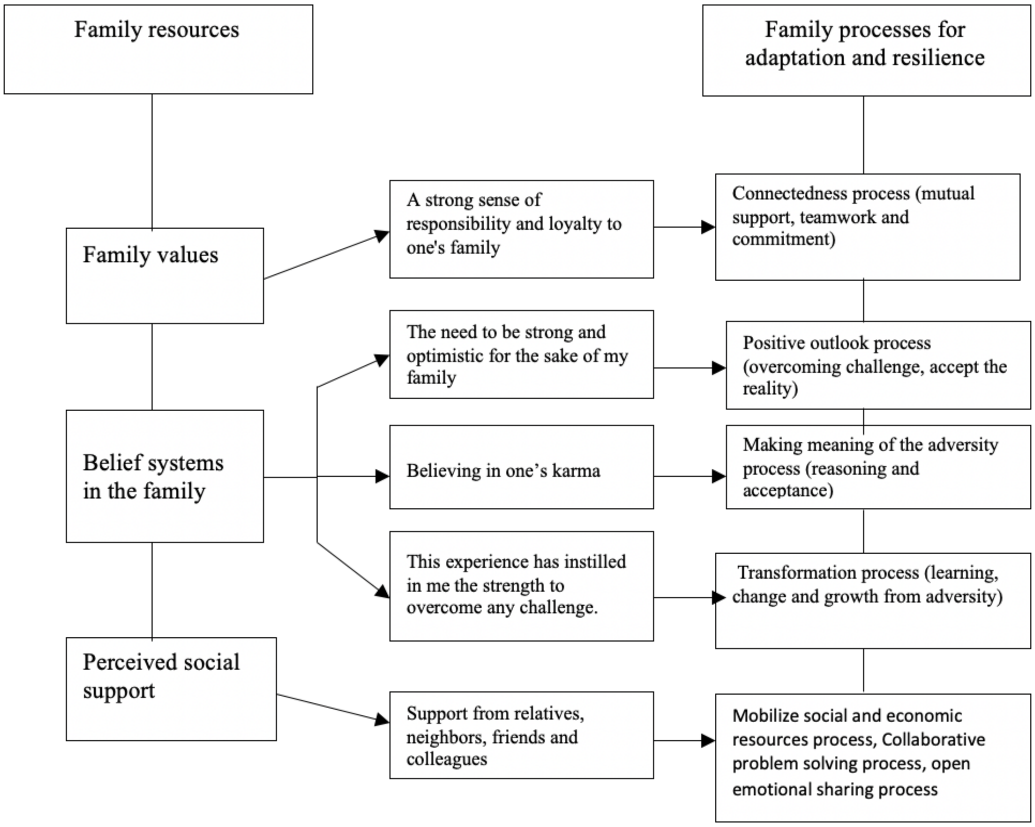
> They know that my husband is ill and whenever I need to take care of him or be at home for some emergency, they help me out by changing the time slots or filling in for me on some days. It was hard for me to leave all the caregiving responsibilities to my daughter

> and go to work. Since caregiving is very new to my daughters, my guidance is still required in a lot of things. (Spouse of Paonam's family).

In this section, the findings were organized and discussed according to the superordinate and subordinate themes that was prevalent across all the families. The results showed that families experienced struggles due to adversity, such as caregiving burden, feelings of ambiguous loss, the strain of family ties, a decrease in perceived social status, caregiving difficulties due to the COVID-19 pandemic, a lack of proper healthcare, and affordable home care services. In addition, the findings indicated that families facing this adversity drew the majority of their strength and motivation from the resources: family values, social support from their relatives, neighbors, friends and colleagues. They utilized and mobilized these resources into dynamic processes to derive strength and resources for adaptation and resilience. As indicated in Figure 2, these findings suggest that despite the struggles families faced due to the adversity, they relied on their strong family values, belief systems, and support from their extended social networks as their resources to gain strength and motivation for adaptation and resilience. These results provide evidence that family values, belief systems, and social support systems serve as a tremendous resource for adaptation and resilience during times of adversity. Through these resources the families performed key family processes for adaptation and to build resilience in the face of this adversity. The family processes for adaptation and resilience found in the study were organized according to the nine key transactional processes identified by Walsh (2003) that facilitate family resilience and optimal family functioning. Though there were various family processes found in each of the families, following are the key family processes identified in the families caregiving to patients in PVS in India: 1) Connectedness process (mutual support, teamwork, commitment), 2) Positive outlook process(to overcome the challenges with confidence, accepting the reality), 3) Making meaning of the adversity, 4) Transformation process (learning through experiences, change in perspective, and positive growth from the adversity), 5) Mobilize social and economic resource, 6) Collaborative problem solving, 7) Open emotional sharing of painful feelings and positive interaction.

Figure 2

Key family resources and family processes for adaption and resilience



Differences across the families

In this section of the results, differences across the families will be examined. Two differences were seen between the three families: a change in family functioning and a family adaptation process and resilience.

Change in family functioning: Family flexibility and cohesion

There was a noticeable change in the family functioning, and it was observed that the degree of change varied between families. To understand the change in family functioning, this study referred to Olson’s Circumplex model to interpret the findings. The Circumplex Model focuses on the three central dimensions of cohesion, flexibility and communication for understanding family functioning (Olson, 2000). Cohesion is described as the emotional connection between family members, while flexibility focuses on the changing of a family's leadership, roles, and rules. Communication is the constructive communication skills used within the family structure and is the facilitating feature that helps families adjust their degrees of cohesiveness and flexibility (Olson, 2000). Before the adversity, the parents and the children were on a distinct level of functioning in terms of family flexibility (or adaptability) and cohesion. As a result of one parent's illness, there is increased cohesiveness in the families. The findings show that emotional bonding between the family members is strengthened and collective decision making is observed. The parent-child boundaries seemed to be less prominent compared to the times before the illness of the family member as their interdependency on each other increased with the caregiving responsibilities. In terms of family flexibility, varying changes in leadership/ authority, roles and rules were found in each of the families. For example, the children had taken up some roles that was previously performed by their parents. This shift in family functioning dimensions brought about by this adversity has resulted in varying levels of family cohesion , family flexibility and communication among family members.

Regarding how families respond to the situation, the Rajkumari family's response to the circumstances and adversity substantially differs from that of the other two families. The family was operating at a low functional level prior to the adversity and responded differently from how the other families did. The narratives revealed that although there is increase in collective decision-making in the family, there is lack of emotional bonding, mutual understanding and trust in the parent-child relationship of Rajkumari’s family. At the same time, the father showed high dependency on the daughter and demanded loyalty in physical, emotional and financial support. The findings indicated that there was lack of personal separateness and little private space is permitted for the daughter. In terms of family flexibility, there are changes in leadership roles where the father's authority over the daughter appears to have lessened and rules are not as rigid like it used to be.

The results of the study found that poor communication, ineffective conflict management could have increased the emotional separateness and also decreased the family adaptability to the situation. The rigidity to change found in family adaptability in Rajkumari’s family could be due to the substantial intergenerational gap that the father and daughter have, or it could be the influence of patriarchy in Indian society. The daughter expressed that she struggles with her father's rules, and though she does not want to abide by them, she felt obliged to since he is the elder of the family. She commented that such rules bring separation from her father and make her feel angry and frustrated with him.

> My father has many rules. We can't touch him while he's eating. We cannot talk while having lunch or dinner, we cannot go out at night, and we cannot attend birthday parties, all as he feels attending such events will make us want to do the same. Because of all these rules, a distance developed between my father and me. He kept trying to apply all these rules, even now. Maybe he thought that I might obey him since my mother did too. But no, I will not until and unless it is applicable. (Daughter of Rajkumari's family)

Paonam's and Naorem's families were moderately functioning families before the onset of illness and became even more functional after the onset of illness. The findings showed a higher level of cohesion with deeper emotional connection, more collective decision-making, and decreased boundaries between the family members as they had become more interdependent on each other amidst the adversity. Both the families demonstrated changes in family flexibility by increased sharing of roles and responsibilities. However, it was apparent that the leadership role of the mother in Paonam's family still maintained with some negotiations given to the children, even though there is increased fluidity in roles and rules of the family. Despite the family's cohesion, the mother had apparent authority and power over her children. The firm leadership role was evident in how the mother and the children divided their tasks, such as caregiving, household chores, and financial responsibilities. For example, the mother and the children collectively decided on family issues, but she still wanted her daughter to obey and abide by her rules. This is an interesting situation because the family seems to be actively adapting to the changes in their environment while also trying to maintain their family values and belief systems. As a result, the family showed structured relationship with a leadership showing some degree of fluidity by allowing the children to participate in certain discussions. Some responsibilities are constant, while others are shared and there are few changes in rules. Nevertheless, the family shows flexibility to change while maintaining the balance of the family structure amidst this adversity. On the other hand, Naorem's family also showed increase in family cohesion with increase in emotional bonding, collective decision making, and in addition the intergenerational boundaries between the mother and her children seemed to have dissolved amidst the adversity. This family seemed to maintain a flexible relationship characterized by equitable leadership and shared decision-making except for monetary related issues. The children took active participating in the negotiations for roles, responsibilities and rules in the family. Such an arrangement indicates a greater level of equality within the family, as all family members are seen to have a balance of interdependency as well as clear individual boundaries. In addition, all the family members maintain open and effective communication with one another which facilitated a balance between family cohesiveness and flexibility in the face of this adversity.

Though Paonam and Naorem's families differed in their family functioning style, considering the structure of their families and the resources they had in their disposal, the findings of this study suggested that both the families showed optimal familily adaptibility and embraced the development of resilience in different forms (i.e., when initially struck with stress, families may experience a downfall, but subsequently, they pick up and move higher in their unique pathways). In addition, both families value close connection, positive communication, and shared decision-making, which allows the family to function with right degree of cohesiveness and flexibility called by the current crisis and adversity.

Family adaptation process and resilience

In all the families, differences were found in how they adapted and became more resilient in the face of adversity. While each family's adaptation process was unique, the findings showed that Paonam and Naorem's family were positively adapting to adversity and demonstrated traits of resilient families. Despite the struggles of adversity, both families functioned with the flexibility to change while maintaining balance without going to the extremes, as previously discussed in the change of family functioning. They had mutual trust and communicated effectively to handle caregiving tasks and faced the challenges ahead of them. There was a shared family value system of family loyalty and obligation, which allowed them to commit and compromise for the family's well-being. They also had a positive outlook on life; for example, building a house amid this adversity was a sign of hope for better days and regaining their perceived social status in society. They were highly interdependent on their relatives, and moreover they mobilized their social resources to meet the needs of the adversity. The findings also showed that their relationship with the relatives was strengthened through this hardship. Apart from the key processes of resilience mentioned above in the similarities section, in both Naorem’s and Paonam’s families, flexibility processes of Walsh (2016) family resilience could be identified in how these families are fluid to changes to meet new difficulties, they reorganize their roles and responsibilities and work as a cooperative caregiving team and at the same time, the caregivers showed mutual respect for each other and guided each other through the adversity.

Furthermore, both families shared a unique turning point that seemed to be a tremendous source of strength and drive for the family. For example, Naorem's family experienced the joyous event of the spouse's brother getting a breakthrough in his political career, which influenced the spouse's sense of importance in society, while Paonam's family embarked on their journey to construct a house, a chance to fulfill the patient's wish and to regain their social standing. On the other hand, Rajkumari's family were barely adapting to this hardship, hindering their capacity to develop resilience. Though they derived their strength and motivation from their values, belief systems, and support from relatives and neighbors, the financial and physical resources required for caregiving are insufficient, and not able to achieve financial stability. In addition, the findings showed little evidence for emotional bonding before and after the onset of the crisis and thereby, had a low sense of coherence within the family dynamic. The results also indicated that rigidity to flexibility of rules and leaderships roles on the father's part and negative communication pattern led to conflicts and disagreements in the family increasing mistrust between each other . Nevertheless, despite the rigidity to flexibility in the family functioning, structure, the findings shows that the strong sense of family obligation and family loyalty exhibited towards the patient's healthcare acted as a tremendous resource for the family to acquire the amount of adaptability just enough to survive and provided the strength to continue facing the hardship and did not give up.

The family's challenge, in this case, had highlighted the need for formal and informal support systems. This includes the professionalization of home-based care, effective and evidence-based interventions by health workers tailored to the needs of each family as there are varying degree of adaptability and pathways to resilience. Overall, the findings of the study indicated that Paonam's and Naorem's families are positively adapting with greater resiliency in the face of adversity, whereas Rajkumari's family is adapting barely enough to endure this difficulty.

V. Discussion

The number of patients who are in a vegetative or minimally conscious state (MCS) has increased drastically worldwide and in India (Pistarini et al., 2019), and the advancement of critical care technologies has enhanced the survival rate, thereby extending the life span of patients in PVS (Giovannetti et al., 2015**).** PVS patients have a life expectancy of two to ten years (Jennett, 2005; Monti et al., 2010). Effective palliative care is a major problem for India's healthcare system (Devakirubai & Gnanadurai, 2014; Sinha et al., 2012). The lack of home care support from the government and the unavailability of an adequate healthcare system lead to the complete reliance of the patients on their families (Jagannathan, 2014b; Chadda, 2014). Therefore, in India, the family is the main source of care and is responsible for the comprehensive care and costs associated with it. Given the socioeconomic backdrop of India and the complexity of the caregiving setting given to families caring for PVS patients, this study examines the coping and resilience experiences of family caregivers in Indian households.

The purpose of this qualitative research is to gain a comprehensive understanding of the family unit's processes for adaptation and resilience through an in-depth exploration of the participants' life experiences and the meanings attached to this specific phenomenon. The narratives of two family caregivers from each family are collected, and Multi-Family Member Interview Analysis (MFMIA; Van Parys et al., 2017) is utilized as the methodological framework to analyze the individual interviews, with the family acting as the unit of analysis. Using MFMIA (Van Parys et al., 2017) for analysis allows for a deeper understanding of how the family caregivers' experience is affected by a broader social context and, in turn, how their individual experiences contribute to a broader understanding of family dynamics and resilience in the context of caring for a patient in PVS. The key insight gained from the findings revealed that each family worked as a unit to overcome and deal with the adversity in their unique adaptation and resilience pathways, depending on the resources they had at their disposal to face the challenges associated with the caregiving circumstances. Through the analysis, it was found that family values, belief systems, and social support were the main resources that shaped their ability to adapt to the hardships of providing care to their loved ones in PVS.

In the first section, the themes that emerged across all of the families were presented. These themes are the result of similarities across all families and were examined based on the narratives of each family's experiences of providing care to a family member with PVS. The themes that were prevalent among all families are clustered into five superordinate themes: 1) Struggles of the adversity, 2) Family values, 3) Belief systems 4) Family unity: Strengthened family bond and 5) Perceived social support. The findings indicate that the process of family adaptation to the caregiving situation of PVS patients is complex and multifaceted, marked by contradictory dynamics within the emerging themes.

In the later section of the results, differences across the families were examined, and changes in family functioning and family adaptation processes and resilience were the two main differences found across the families.

Based on the findings of the study presented above, the research question of the study, "What are the family processes of adaptation and resilience in families caregiving for patients in PVS in India?", will be addressed by discussing the processes of adaptation and resilience.
In this context, "processes" refer to the strengths and resources that families have access to and utilize to adapt and maximize their capacity for resilience in the face of adversity (Walsh, 2003). The results of the study provide evidence that family values, belief systems, and social support systems serve as tremendous resources for adaptation and resilience despite the struggles of adversity. Through these resources, the families performed key family processes for adaptation and to build resilience in the face of this adversity. The family processes for adaptation and resilience found in the study were organized according to the nine key transactional processes identified by Walsh (2003) that facilitate family resilience and optimal family functioning. Though there were various family processes found in each of the families (i.e family flexibility processes), nevertheless following are the key family processes identified in the families caregiving to patients in PVS in India: 1) Connectedness process (mutual support, teamwork, commitment), 2) Positive outlook process(to overcome the challenges with confidence, accepting the reality), 3) Making meaning of the adversity, 4) Transformation process (learning through experiences, change in perspective, and positive growth from the adversity), 5) Mobilize social and economic resource, 6) Collaborative problem solving, 7) Open emotional sharing of painful feelings and positive interaction.

Previous studies on family resilience have shown that families with stronger and more positive family functioning encourage the expression of their emotions, are able to manage conflict, are able to make choices, and have high morals and values (Daniels & Bryans, 2021; Walsh, 2016). As cohesion is also a dimension of family functioning, it is seen in families with a commitment to the family system that provide mutual support and encouragement to each other (Olson, 2000). Strengthened family bond and cohesiveness create the atmosphere suitable for families to adjust positively and build resilience in the midst of adversity (Daniels & Bryans, 2021).

In Paonam's and Naorem's families, it was observed that family cohesion and connectedness were strengthened by the adversity, allowing the families to work as a unit through sacrifice, compromise, and support for each other. Connectedness is a valuable family resource in providing strength and support for family members to adapt to the stress of providing care, and it is one of the key processes of family resilience (Walsh, 2003). Previous qualitative and quantitative research has shown that family cohesiveness is increased in families confronting adversity, providing evidence for family resilience (Van Schoors et al., 2015). Furthermore, despite the lack of adequate home care facilities, this study found that social resources, such as support from relatives, neighbors, friends, and colleagues, have a significant impact on how families adapt to and build resilience in caregiving situations. It was also evident in all the families that they perceived social support from the relatives and that their interdependency on each other increased during this hardship, and families utilized these resources to gain strength and adaptability to facilitate resilience. The availability and utilization of resources such as family values of family obligation, loyalty, and high social interdependence by the families can be attributed to the cultural context of the collectivist nature of Indian society, which encourages social cohesion and interdependence (Chadda & Deb, 2013). Moreover, studies on family caregiving for individuals with schizophrenia in India have also shown that an increase in perceived social support has a significant impact on reducing caregiver burden among family caregivers (Jagannathan, 2014). Thus, it is undeniable that the support of relatives and other social resources plays a crucial role in helping these families during these times of crisis by providing physical, emotional, and financial support. Hence, these resources of family and social support can provide a greater sense of resilience and stability to families, even in the face of such challenging situations (Van Schoors et al., 2015).

In this study, all of the families drew a lot of strength through the resource of family values of family loyalty, duty, and a sense of responsibility to ride through the hard times and keep facing them. Such value systems allowed the families to find a sense of purpose, connectedness, and direction during times of difficulty, enabling them to make better decisions and focus on resolving their problems. Similar findings were noted in research conducted by Goudarzi and colleagues (2018) on the family caregivers of PVS patients in Iran, which revealed that some of the factors that compelled the participants to care for the vegetative patients were their family values and their family members' commitment. In addition, this finding can also be explained by the socio-cultural characteristics of Indian society, where people believe that no sacrifice made for the well-being and unity of the family is insignificant. As a result, there is a strong sense of obligation and duty toward their families prevailing in Indian society (Mullaiti, 1995).

Further, it was found that families tried to attach meaning to and make sense of the hardship by attributing it to their karma. According to Walsh (2003), families with an Eastern philosophical or religious orientation have a stronger propensity to accept things beyond their control or understanding. For example, this research showed that caregivers try to make sense of the adversity they are going through based on the concept of karma. This meaning-making process acts as a resource by enabling family caregivers to accept the circumstance once they stop ruminating on the past and by providing them with the strength to confront the adversity head-on. In line with this, earlier research on family resilience in the context of dementia (Teahan et al., 2018) found that the social and cultural aspects of the caregiving context affect the ability of caregivers to adapt to hardships.

Caregivers voiced the importance of maintaining a hopeful and optimistic attitude to survive, endure, and continue facing obstacles for the sake of their families and mentioned that they needed to be courageous and brave to overcome any challenges that lay ahead. This is also evident from research studies that show how a positive outlook helps people overcome challenges with confidence, build resilience, and get past obstacles to success (Walsh, 2003). Hence, family caregivers who are able to make meaning of their caregiving experience and view it in a positive light, no matter how difficult the circumstances may be, show more adaptability and adjust better to the adversities they are facing.

In conclusion, these findings provide significant evidence on how families adapt and develop resilience in times of adversity, implying that a supportive network of relatives, friends, and neighbors, as well as family values and belief systems, have a positive effect on families when dealing with adversity.

Future implications

Given the complex and costly nature of providing care and the deterioration of family finances brought on by the prolonged nature of such circumstances, it is increasingly clear that additional steps need to be taken in order to assist these families. The study has provided three important recommendations for future consideration.

Families need interventions that are personalized to their specific need

The findings indicated that families experiencing this hardship adapted and built resilience in varying pathways. According to these results, interventions and support programs for these families must be customized, considering the resources families have at their disposal and the unmet needs of each family undergoing this adversity. The findings of this study revealed that the major resources of these families are family values of obligation to family, belief systems, and social support. It can be deduced that obligation or a sense of responsibility is the essential source for these families to continue facing the challenges, and that the quality of family relationships and a healthy family environment for strengthened family cohesiveness are crucial intervention targets in order to develop more strength for these families and maximize their capability of resilience. Thus, professionals and counselors can use strength-based interventions to prevent negative family adaptability and a lack of family resilience in the future.

Families require government support for affordable home care services

It can be challenging to afford home care services, such as a caregiver or physiotherapist. The cost of hiring a private firm to provide services is very expensive and varies depending on the number of hours required for the service; for instance, a 6-hour shift costs roughly Rs 10,000, while a 9-hour shift costs approximately Rs 15,000. To assist home caregivers, the government should build a health system that provides these services at a low cost or implement a home care reimbursement system.

Need for awareness programs for family caregivers to patients in. PVS

Families caring for patients in PVS have a hard time adapting to their new routine because the procedure for caring for patients with PVS is so intricate. It takes at least a few months to gain the relevant skills and other criteria. As a result, these caregivers should have access to the necessary awareness initiatives to enhance and improve their caring abilities. It is crucial to offer these families information-seeking facilities.

Limitations

The limitation of this study is the small sample size caused by the challenge of locating patients in persistent vegetative states and their family caregivers. Moreover, finding families in which a minimum of two family caregivers are willing to participate in the study was an added challenge, which led to the small sample size. While the small sample size can be viewed as a disadvantage of the study as it may raise concerns regarding the generalizability of the results, it also allows for an in-depth examination of the data.

Conclusion

Despite the limitations noted above, this research has the strength of adopting a multi-family interview study and bringing together the perspectives of two family members from the same family. It also enables a greater grasp of the complexities and intricacies of the caregiving situation and gives a broad understanding of family-level processes to adaptation and resilience amidst the adversity. The current study adds to the literature of research focused on building family resilience amidst the hardship of caregiving to patients in PVS in Indian socio-cultural context.

The results showed that families undergo a heavy caregiving burden, feelings of ambiguous loss, depletion of financial resources and undergo challenges due to the lack of adequate home care facilities and minimal government support available for home caregivers in Manipur, India. Nonetheless, by finding strength and motivation in their family unit, sharing the responsibility of caregiving, and committing to the common purpose of providing ongoing quality care for their loved one, each of the three families displayed their own adapting mechanisms and family functioning leading to varying pathways to resilience. They derive their strengths and resources mainly from their family values, belief systems, and social support. The findings of this study demonstrated that it is important for counsellors to focus on the strength based interventions for families by focusing on the key processes of adaptation and resilience found in the study as well as tailor it according to the different adaptive processes each families utilizes. Overall, this study demonstrated how important it is for families to have access to the necessary resources and supports in order to adapt to the caregiving process more effectively.

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APPENDIX A

First interview questions

1)How did you feel when your family member first got diagnosed?

2) Could you talk about your experience after your family member got diagnosed? You could talk about some of the memories, both good and not so good.

3) What is your role in your family with regards to caregiving? What are your responsibilities?

4) What are the difficult aspects to caregiving?

5) Could you tell me about the barriers to caregiving you have faced? (Psychological barrier, financial barrier, asset barrier- insurance problem, health care system)

6) After explaining what Ambiguous loss is: Have you experienced something similar to that of ambiguous loss?

7)How do you feel about such an uncertain loss? Does it make the situation more difficult for you and your family? Please share your thoughts on how you and other family members thinks about it.

If it was a clear-cut loss like cancer, do you think it would have been better for you and your family?

8) How did you adjust with the difficulties and challenges?

9) What is it like for you now?

10) Has it changed your life? Can you tell me more on the areas of your life that have changed? (Change in relationships with friends, relatives, social network)

11) Who has supported you during these difficult times?

12) Can you share about your psychological well-being?

13) How has the financial status changed after the diagnosis?

14) What is your strength and how do you think has helped or supported your family?

15) What are the activities that would help you release stress due to the situation?

16) What is your relationship like with the patient? Is there any specific memory of the patient that you would like to share?

17) Have you attached any meanings to this situation?

18) What are the positive changes and negative changes that has occurred after the diagnosis? What have you learnt out of the experience?

19) What are the lessons you have learnt through this experience?

20) Is there any advice or thoughts that you would want to share with other family members who are going through a similar situation?

Second interview questions

1) How have your family adapted to the demands that have been placed after the event?

2) What are the changes in roles and responsibilities in the family faced after the event?

3) Could you tell me about the dynamics of your family before the diagnosis and how has it changed after the diagnosis?

4) Who takes part in making decisions for your family (before and after the event)? Did it change over time?

5)How did your family cope as a unit and what are the factors that helped in the process?

6)How do you know you are a family?

7)What are the things that you do for each other makes you feel like a part of the family? How does it help you?

8)Do you have a family chatroom? (*If yes then,) Do you think having a group chatroom helps in the communication?

9)If there is a conflict or a misunderstanding in your family, do you talk about it? Can you ask for clarification? How does your family work through it?

10)What are the rules in your family? Do you think the rules in your family change according to your family needs? ** Implicit and explicit rules

11)How did the different family members express their emotions and handled disagreements regarding the situation?

12)What do you think your family's strengths are?

13)How did your family use these strengths to cope with the difficulties?

14)Did your family realize any new strength or resource during this situation?

15)Were there any special activities that you and your family did together as a ritual?

16)Are you close to your extended family? After this event have you gotten closer or not?

17)Who are the people who have been giving support to your family?

18)Are members of your extended family aware of what your family have been experiencing? How have they been helpful and unhelpful?

19)Has there been any change in how your family mix with other extended families after the event?

20)Do you think the people in your community are willing to help in case of emergencies? On what occasions do you go to your neighbors or your extended family for help?

21)Do your family get support from any support group in the community or from the state?

22)If there were better facilities for healthcare with regards to your situation, would the difficulties that your family is facing become better?

23)How is your family holding up despite the lack in facilities?

24)Would you like if there are programs provided for caregivers in this state? If yes, how would it help? What type of programs?

25)Has there been any change in your perceived social status after your husband/wife/father/mother became ill?

26)Do you think there has been change in how the people in your community behave towards your family?

27)Has there been any family tension, or conflict around caregiving situation?

28)How do your family members feel about the situation? Is it the same or different?

29)How have these feelings changed over time?

30)How has your family defined this situation? What are the meanings that your family have attached to this situation?

31)Do you think your family can work through the difficulties together as one?

32)What are the positive changes and negative changes in your family?

33) Have you experienced any change in yourself (i.e., perspectives on life, meaning of life, etc., and as a person if they feel like they have grown and matured in certain ways) and if other family members also talk about it.

Instruction and Consent for a Research Participant

Title of the research: Family caregiving to patients in a persistent vegetative state in India: A multi family member perspective

Principal Investigator: Thoinu Karam (Master's Course, Department of Child and Family Studies, College of Human Ecology, Seoul National University)

This research is about the experiences of family members caring for patients with persistent vegetative state (PVS). Persistent vegetative state refers to a state in which some functions of the autonomic nervous system are maintained, but there is no ability to regain consciousness. A vegetative state is a complex neurological condition in which one is unable to recognize oneself or the surrounding environment lasting for more than six months. You are being asked to participate in the research because you meet the research participant criteria for this study (family of patients with persistent vegetative state in a long-term care for at least a year in a home or follow-up care rehabilitation center. A researcher at Seoul National University , Thoinu Karam (010-6591-6120) will explain the research to you. The research will be conducted only with the voluntary consent of the participants, so before your decision is made it is important to understand the content and purpose of the research. Please read the content below carefully and thoroughly, and please let us know if you consent to be involved. If necessary, ask your family members or friends. If you have any question, the investigator will explain in detail.

1. Why is this research being conducted?

The main purpose of this research is to understand the experiences of families living with patients in a vegetative state. We want to explore the process in the context of the ambiguous loss and burden of care caused by a family member (spouse/parent) in a persistent vegetative state to the primary family and the process that promotes family unit coping and the family's ability to overcome and recover from stressful situations or adversity, that is, resilience.

2. How many people will participate in the research?

12 families with patients in a persistent vegetative state in long-term care for more than one year living at home or in a rehabilitation center will participate.

3. How will the research proceed?

The research will be conducted as follows.

i. You will participate in two face-to-face interviews lasting from a minimum of 60 minutes to a maximum of 120 minutes. In the first interview, you will talk about your personal experience as a family member of a person with a persistent vegetative state, and in the second interview, you will talk about how you are coping with other family members. The interview will be recorded with your consent. The recorded file is destroyed immediately after transcription, and personally identifiable information is deleted from the transcription file. In some cases, if you have difficulties with face-to-face interviews (e.g., those who feel uncomfortable with face-to-face interviews due to COVID-19, those who have difficulty setting aside time for interviews due to nursing care, those who have difficulty moving due to transportation problems, etc.) may choose to have a non-face-to-face interview. The non-face-to-face interview will be conducted via zoom remote video platform.

ii. After all the interviews, you will be asked to answer a questionnaire asking for demographic information. The survey will take approximately 3 minutes. All courses will be held at a location that has been agreed with you in advance.

4. What is the duration of participation in the research?

Two interviews will be conducted, and each session will last from 60 to 120 minutes.

5. Once participation in the research has begun, is it possible to stop participating?

Yes. You can stop participating in the research whenever you want with no disadvantage. Any time you want to stop, please tell the investigator immediately. In case of withdrawal, previously collected data will be destroyed immediately if the research participant wishes to discard it. However, if you do not want to discard, data prior to the time the interview was discontinued will be used as an old material.

6. Are there any side effects or risks involved in participation in this research?

There are no special side effects or risk factors associated with participating in the study. However, when you talk retrospectively about a family member's illness or caregiving experience, unpleasant memories may come to mind. In this case, you may withdraw from the interview at any time. If you have any questions about the possible side effects or risk factors while participating in the study, please contact the researcher immediately.

7. Are there any advantages to participating in the research?

You will not receive any direct advantage. However, the information you provide will be helpful to promoting understanding of the experiences of families caring for patients with persistent vegetative state.

8. Are there any disadvantages to participating in the research?

You are free to agree or decline to participate in the research. There will be no disadvantage if you decide not to participate.

9. Is the information gathered during the participation secure?

The person in charge of managing the personal information collected for this research is Thoinu Karam (010-6591-6120) at Seoul National University. The personal information collected in this study includes name, contact information and account information. However, this personal information will be used only for simple contact and reward payment for research. This personal information is only allowed to be accessed by Thoinu Karam and Grace H. Chung, and will be stored in the manner described in a password-set file on the researcher's personal computer. The collected contact and account information will be disposed of after completion of reward payment. The consent form will be stored for three years in accordance with the relevant laws and then discarded. The research data will be kept as permanent as possible by the Seoul National University Research Ethics Guidelines. Interviews with research participants are transcribed after being recorded and made into transcripts, and in the process of writing the transcripts, the names of the research participants are written as code names. Recorded files are personally identifiable information, which is destroyed as soon as the purpose of collection is achieved. All possible measures will be taken to secure and protect all personal information gathered while proceeding with this research. When the research is reported in an academic journal or presented at a conference, your name and other personal information will not be presented. However, if required by law, your personal information may be provided. In addition, the Seoul National University Institutional Review Board may directly access the research results within the scope of the relevant regulations to inspect whether the research has been conducted without the participant's personal information security and verify the reliability of the research data. By signing this consent form, you acknowledge that you have been informed of all necessary information related to the research in advance and will be deemed to have consented to it.

10. How much will participants be paid for participation?

If you participate in the study, 1500 rupee will be provided to you for actual expenses such as transportation expenses after each interview, and a total of 3000 rupee will be paid if you participate in both interviews. However, even if you stop participating in the study while the interview is in progress, the reward for the interview that has already been conducted is paid.

11. If I have any questions about the research, whom can I contact?

If you have any questions related to the research, or if there are any problems or concerns related to the research, please contact the investigator below.

Name: Thoinu Karam Contact: 010-6591-6120

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Consent Form (for Participants)

Title of the research: Family caregiving to patients in a persistent vegetative state in India: A multi family member perspective

Principal Investigator: Thoinu Karam (Master’s Course, Department of Child and Family Studies, College of Human Ecology, Seoul National University)

1. I have read the instructions above thoroughly and discussed them with the investigator.
2. I have been made aware of the potential risks and benefits of participating in the research, and I have received satisfactory answers to all my queries.
3. I voluntarily agree to participate in the research.
4. I agree to collection and processing of any personal information gathered during the research within the bounds of the existing legislation and regulations of the Institutional Review Board.
5. I agree that my personal information, which will be otherwise kept secured by the investigator(s), is accessed by government institutions prescribed by laws and regulations and the SNU Institutional Review Board for auditing purposes.
6. I understand that I can withdraw the participation in the research whenever I want without any risk to me.
7. After agreement to the above, I will receive the copy of the consent form, and I promise to keep the copy until the end of the research.
8. I agree to the **audio-recording, video-recording, or both** while participating in the research.
9. I know that my personal identifiable information (e.g. full name, house address) is being collected, and I allow it to be used for research.

______________________	__________	_________________
Name of Participant	Signature	Date (year/month/day)
______________________	__________	_________________
Name of Investigator (consent received)	Signature	Date (year/month/day)

Consent form (for Researchers)

Title of the research: Family caregiving to patients in a persistent vegetative state in I India: A multi family member perspective

Principal Investigator: Thoinu Karam (Master’s Course, Department of Child and Family Studies, College of Human Ecology, Seoul National University)

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______________________________	_____________	______________________
Name of Participant	Signature	Date (year/month/day)
______________________________	_____________	______________________
Name of Investigator	Signature	Date (year/month/day)

Abstract in Korean

구문초록

인도의 지속식물인간상태 환자에 대한 가족 돌봄: 다중 가족 구성원 관점으로

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아동가족학과

본 연구의 목적은 지속식물인간상태(PVS)의 환자를 집에서 간병하는 인도 가족 구성원들의 적응과 회복탄력성에 관한 가족 과정을 탐구하는 것이다. 선행연구에서는 지속식물인간상태의 환자들은 지속적인 의료 개입과 광범위한 돌봄이 필요하기 때문에 집에서 간병하는 것이 어렵다고 보았다. 하지만, 인도에서 지속식물인간상태 판정을 받은 환자들은 상태가 어느 정도 안정화된 이후 간병 기간의 길이 때문에 주로 병원에서 퇴원을 권유 받는다. 이에 가족 구성원들은 환자를 집에서 간병하게 된다. 따라서 정부의 지원과 적절한 의료 체계의 부족으로 인해, 지속식물인간상태의 환자는 온전히 가족에 의존할 수밖에 없으며, 가족들은 종합적인 간병과 관련 비용을 책임져야 한다. 그러므로 가족 구성원들은 간병 부담과 경제적 부담 및 관련 요구들에 효과적으로 반응할 수 있어야 한다. 선행연구에서는 지속식물인간상태의 환자가 있는 가족구성원들이 모호한 상실, 절망, 불안, 식욕부진, 불면증 및 기타 여러 심신증을 경험하는 것을 확인할 수 있는데, 주목할 부분은 의료 기술의 발전으로 지속식물인간상태의 환자의 생존율이 높아지고 수명이 연장됨에 따라 가족 구성원들에게 추가적인 어려움이 생긴다는 것이다.

본 연구는 다중 가족 구성원 인터뷰 분석(Multi-Family Member Interview Analysis, MFMIA) 기법을 사용한 질적연구이다. 연구 참여자는 유의 추출법을 통해 모집한 6명의 가족 간병인이다. 반구조화된 두 번의 심층 면담을 통해 각 가정에서 가족 간병인 두 명의 내러티브를 수집하였다. 두 명 중 한 명은 환자의 배우자, 다른 한 명은 환자의 자녀였다. 이를 통해 가족 간병인의 경험이 보다 넓은 사회적 맥락에 의해 어떠한 영향을 받는지, 그리고 그들의 개별 경험이 지속식물인간상태의 환자에 대한 돌봄의 맥락에서 가족 역동과 회복 탄력성에 대한 보다 광범위한 이해에 어떻게 기여하는지를 탐구할 수 있었다.

연구 결과, 연구에 참여한 모든 가족의 경험을 관통하는 다섯 가지 상위 주제가 도출되었다. 다섯 가지 상위 주제는 1) 역경과의 투쟁; 2) 가족 가치; 3) 가족의 신념 체계; 4) 가족의 단결과 강화된 가족 유대; 5) 사회적 지지에 대한 인지였다. 연구 결과는 가족들이 돌봄 부담, 모호한 상실감, 가족 유대의 긴장, 인식하는 사회적 지위의 격하, 코로나 19 팬데믹으로 인한 돌봄 어려움, 적절한 의료 서비스와 적당한 가정 돌봄 서비스의 부족과 같은 문제로 어려움을 경험했음을 보여준다. 한편, 연구 결과 이러한 역경에

직면한 가족들이 가족 가치와 가족의 신념 체계, 사회적 지지를 자원으로 힘을 얻고 동기 부여를 받는 것으로 나타났다. 그들은 적응과 회복에 필요한 힘과 동기를 얻기 위해 이러한 자원들을 역동적인 가족 과정에 동원하고 활용했다. 이러한 연구 결과는 가족들이 어려움을 경험할 때, 강한 가족 가치와 신념 체계, 확장된 사회적 네트워크의 지원 등의 자원에 여전히 의존하고 있음을 시사한다. 이러한 결과는 가족 가치관과 신념 체계, 사회적 지지 체계가 역경의 시기에 강한 회복탄력성의 원천이 된다는 것을 보여준다.

또한, 본 연구의 결과는 유연성과 응집성 측면에 있어 가족 기능의 눈에 띄는 변화를 보여준다. 나아가 이러한 변화의 정도는 가족별로 차이가 나는 것으로 나타났다. 본 연구는 각 가정이 그들의 자원과, 그들이 지지하는 가치, 신념 체계, 그들의 열망에 기초하여 어떻게 독특한 적응 과정과 회복 경로를 구성하는지에 대한 통찰력을 제공하였다는 의의가 있다. 본 연구에서 두 가정은 역경에 대해 효과적으로 대응하고, 적응하는 모습과 회복력 있는 가정의 특성을 보여주었지만, 한 가정은 가까스로 적응하고, 견뎌내는데 필요한 정도의 자원만 가지고 있었다.

집에서 지속식물인간상태의 환자를 간병하는 것이 상당한 부담이 된다는 본 연구 결과를 고려할 때, 가족들은 적응과 회복을 위해 전문가와 비용 효율적인 재가 돌봄 서비스에 대한 접근이 필요하다. 본 연구 결과는 이러한 역경에 직면한 가족들이 함께 긍정적인 태도를 갖고 통제감을 느낄 수 있게 하는 등 회복탄력성을 기르는데 초점을 맞춘 서비스가 필요함을 시사하는데, 이러한 서비스는 가족 구성원들이 돌봄에 필요한 새로운 기술을 개발하고, 가족 관계를 더욱 돈독히 하는 기회를 제공할 수 있다. 더욱이, 이러한 서비스는 각 가정의 자원, 가치, 신념 체계를 기반으로 각 가정의 특별한 요구에 맞춤형으로 제공되어야 하며, 이를 통해 가족의 적응력과 역경을 관리할 수 있는 역량을 극대화할 수 있을 것이다.

주요어: 가족 회복탄력성, 돌봄, 다중 가족 구성원 관점, 지속식물인간상태, 가족 적응 과정

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