



UNIVERSITY OF PADOVA

Department of Philosophy, Sociology, Education, and Applied Psychology

Master Degree in Clinical, Social and Intercultural Psychology

Final Dissertation

**Behind the Caring Veil: Unveiling Vicarious Grief, Ambiguous Grief and
Reflective Function among Nurses and Healthcare Assistants in Prolonged Care
for Vegetative State Patients**

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Academic Year 2023/2024

INDEX

INTRODUCTION	3
CHAPTER 1	5
PERMANENT VEGETATIVE STATE: CLINICAL AND LEGAL PERSPECTIVES AND CHALLENGES	5
1.1 UNCOVERING THE COMPLEXITIES OF PERMANENT VEGETATIVE STATE: FROM DEFINITION TO DIAGNOSIS	5
1.2 POST-DIAGNOSIS REALITIES: INTENSIVE CARE AND MEDICAL COMMITMENT IN PVS CASES	12
1.3. IN THE SHADOWS OF LIFE AND DEATH: LEGAL AND ETHICAL CONSIDERATIONS IN THE VEGETATIVE STATE	15
CHAPTER 2	23
CARE AND GRIEF MANAGEMENT IN THE CONTEXT OF THE VEGETATIVE STATE	23
2.1 GRIEF COMPLEXITY: THE CASE OF HEALTHCARE PROFESSIONALS	23
2.2 BRIDGING AMBIGUOUS LOSS AND VICARIOUS GRIEF IN THE CARE OF INDIVIDUALS IN VEGETATIVE STATE	27
2.3 THE IMPACT OF PERSONAL BELIEFS: REFLECTIVE FUNCTION SHAPING APPROACHES TO END-OF-LIFE CARE	33
CHAPTER 3	39
RESEARCH DESIGN AND METHODOLOGY	39
3.1. UNIVERSITY COLLABORATION AND RESEARCH PARTNERSHIP	39
3.2 RESEARCH QUESTIONS	39
3.3 RESEARCH DESIGN	40
3.3.1. <i>Qualitative methodology</i>	40
3.3.2 <i>Data collection: Semi-structured Interviews</i>	40
3.3.3 <i>Participants</i>	43

3.3.4 <i>Data Analysis: Thematic Analysis</i>	43
3.4 RESULTS	44
3.4.1. <i>Coexistence of an ethical, occupational, and operational assessment of the PVS Condition</i>	45
3.4.2. <i>Balancing Patient Bonds and Personal Life</i>	49
3.4.3. <i>Thriving Through Difficulties</i>	53
3.4.4. <i>Personal Evolution and Reflections Beyond the Workplace</i>	56
CHAPTER 4	60
DISCUSSION	60
CONCLUSIONS	66
ACKNOWLEDGMENTS	68
REFERENCES	69

INTRODUCTION

The Permanent Vegetative State (PVS) remains a contentious topic in the medical field, sparking ongoing debates regarding its definition and diagnosis (Rathor et al., 2018). Coined by Jennett and Plum in 1972, the term “Vegetative State” describes individuals who exhibit wakefulness but lack apparent self-awareness (von Wild et al., 2012). This study aims to comprehensively explore the caregiving experiences of healthcare professionals working with PVS patients, particularly nurses and healthcare assistants who play crucial roles in their long-term care. Motivated by a desire to understand these experiences, the qualitative research delves into the perspectives of nurses and healthcare assistants within the context of PVS. Special attention is given to understanding possible vicarious grief and ambiguous loss experiences of these professionals. Additionally, the study wants to understand how reflective function influences healthcare professionals’ understanding of patients’ mental states, as well as its impact on end-of-life approaches and grief experiences during patient care. The research is conducted in collaboration with the I.S.A.C.C nursing home, which has a dedicated department for PVS patients. This unit provides continuous care thanks to nurses and healthcare assistants.

To elucidate the approach taken in addressing the themes, we briefly outline the structure and contents of the dissertation.

The first theoretical chapter thoroughly examines the characteristics that complicate the diagnosis and prognosis of PVS, discussing the evolution of the term and of the diagnosis, and elucidating why it remains a subject of ethical and legal debate. The chapter provides an understanding of the diagnostic criteria and challenges inherent in assessing patients with PVS. Additionally, it explores the evolving perspectives on the ethical considerations surrounding the care of individuals in a vegetative state, shedding light on the multifaced nature of this clinical condition.

The second theoretical chapter delves into the emotional challenges faced by healthcare professionals. The chapter provides an overview of grief experiences, with a specific focus on ambiguous loss and vicarious grief. Reflective Function, introduced as a potential crucial aspect of understanding healthcare professionals’ experiences, is further explored within the context of PVS care. By delving into the emotional complexities of

caregiving, this chapter aims to illuminate the profound impact of caring for individuals in a vegetative state on the emotional well – being of healthcare professionals.

The third chapter outlines the research methodology, explaining the choice of qualitative analysis and detailing the use of semi-structured interviews with nurses and healthcare assistants from the I.S.A.C.C. nursing home. Thematic Analysis (TA) is employed for data analysis, aiming to uncover themes and patterns in participants' experiences. The chapter elucidated the logic behind the chosen methodology, emphasizing its suitability for capturing the nuanced perspectives of healthcare workers in PVS care settings. From the results of the TA, four themes emerge: coexistence of an ethical, occupational, and operational assessment of the PVS condition, balancing patient bonds and personal life, thriving through difficulties, personal evolution and reflections beyond the workplace.

In the fourth chapter, the research findings are discussed, drawing connections with theoretical constructs from earlier chapters. This will help to understand how the theoretical frameworks can be linked to participants' experiences in the PVS department. Limitations of the study and suggestions for future research directions are also addressed, fostering a deeper understanding of the emotional, professional, and relational landscapes of healthcare professionals dedicated to caring for patients in PVS.

CHAPTER 1

PERMANENT VEGETATIVE STATE: CLINICAL AND LEGAL PERSPECTIVES AND CHALLENGES

1.1 Uncovering the Complexities of Permanent Vegetative State: From Definition to Diagnosis

The Permanent Vegetative State (PVS) constitutes a continually debated field of study within the medical community (Jennett, 2005). Controversies have permeated the very definition and diagnosis of this condition since its emergence (Davison & Cartilage, 2020). This chapter aims to explore the diagnostic and prognostic criteria associated with PVS in detail. Moreover, it further seeks to analyze the debates surrounding these criteria and to clarify the complexity of this condition and its ethical, scientific, and medical implications.

The term "Vegetative State" (VS) was initially introduced by Bryan Jennett and Fred Plum (1972), in their groundbreaking article *Persistent Vegetative State after Brain Damage. A Syndrome in Search of a Name*. The term was intended to describe individuals who, despite showing no clear behavioral or clinical indications of self-awareness or awareness of their surroundings, remained in a wakeful state (von Wild et al., 2012). They retained enough autonomic functions to sustain survival with appropriate supportive care (*ibidem*). It is worth noting that the expression "vegetative state" refers to the preserved vegetative nervous functions, encompassing varying degrees of preserved sleep-wake cycles, respiration, digestion, and thermoregulation:

«The word vegetative itself is not obscure: *vegetative* is defined in the Oxford English Dictionary as "to live a merely physical life, devoid of intellectual activity or social intercourse (1740)" and *vegetative* is used to describe "an organic body capable of growth and development but devoid of sensation and thought (1762)"» (Jennett and Plum, 1972 p.736).

Originally, the nomenclature "PVS" did not inherently connote permanence or irreversibility, i.e. a non-modifiable time, (von Wild et al., 2012); instead, it denoted a prolonged state, i.e. a persistent and yet modifiable time, of wakeful unconsciousness (Giacino, 2004). Approximately a decade later, Plum and Posner ushered in a conceptual

shift by proposing that "PVS" signifies the vegetative state in its permanent manifestation (*ibidem*). As reported by von Wild et al. (2012), in 1994, the Multi-Society Task Force on PVS established temporal criteria of more than one year for post-traumatic aetiology (i.e., Traumatic Brain Injury) and three months for non-traumatic aetiology (i.e., hypoxic – ischaemic, metabolic, or congenital) to delineate irreversibility, thus introducing the notion of the "Permanent Vegetative State", where the term *permanent* can be considered as a prognostic adjective (Noé et al., 2019).

In the introduction of the concept of *permanence* within the context of the vegetative state, a multitude of complex legal and ethical issues concerning end-of-life matters arises (Jennett, 2005). The very term "vegetative" has sparked controversies and debates, as it is deemed dehumanizing (von Wild et al., 2012): its usage bears the potential to marginalize and devalue individuals, as it is linked to an absence of sensation and thought, further reinforcing the perception that they lack fundamental human qualities (Johnson & Lazaridis, 2018). However, the term in question has become deeply ingrained in contemporary discourse to such an extent that suggested alternatives, such as "the wakeful unconscious state" (Jennett, 2005), rarely find adhesion. Nevertheless, it is noteworthy that over the past decade, an emergent critical trend in the terminology has manifested (Noé et al., 2019), which will be addressed later.

The criteria for diagnosing the PVS have undergone extensive scrutiny by diverse research groups. Nonetheless, their utility and practical applicability within diagnostic practice are occasionally constrained. The diagnostic process assumes significance, given that its formulation may lead to the suspension of active medical interventions (Wade & Johnson, 1999). The diagnostic process pivots around demonstrating the absence of a specific condition, specifically, the lack of awareness (*ibidem*). The achievement of this objective necessitates meticulous and systematic observation, frequently entailing the involvement of additional observers, including the patient's family members. The latter often need to maintain close and frequent contact with the patient to stay connected to them (Cipolletta et al., 2015) and so their active involvement contributes valuable insights and close observations that may improve the diagnostic process. Furthermore, it is crucial to identify the pre-expressed wishes of patients and the values held by their families early on, as these can be of significant value (Giacino et al., 2018). Within this context, a critical distinction must be drawn between the objective observation of overt behaviors and the

potentially subjective interpretations thereof. Hence, there exists an evident essential to convey unequivocal instructions to family members and healthcare personnel, directing them to relay observed behaviors devoid of room for interpretative subjectivity (Wade & Johnson, 1999). Due to the inherent complexities involved in diagnosis, mistakes in assessing the vegetative state are common (Wade, 2018). This highlights the crucial importance of thorough diligence and the possession of a well - judged level of clinical expertise by the medical practitioner.

The concept of PVS has been criticized for not effectively addressing the varied clinical presentations seen in patients with consciousness disorders (Giacino & Whyte, 2005). To address this concern, experts in neurology and neurorehabilitation were convened to establish consensus-based definitions and statistically relevant clinical diagnostic criteria for consciousness disorders, as illustrated by the work of the MSTF, as outlined by Giacino (2004). The MSTF report received approval from prestigious medical organizations including the American Academy of Neurology (AAN), the Child Neurology Society, the American Neurological Association, the American Association of Neurological Surgeons, and the American Academy of Pediatrics (*ibidem*).

Von Wild et al. (2012) assert that the diagnostic criteria for the identification of PVS require the fulfillment of the following conditions:

1. The absence of any recognizable manifestation of self-awareness or environmental awareness.
2. The complete absence of voluntary responses to visual, auditory, tactile, or noxious stimuli.
3. The clear absence of any indicators that suggest the comprehension or expression of language.
4. The manifestation of sleep-wake cycles, characterized by the recurrent alternation of eye closure and opening, evocative of neonatal patterns.
5. The preservation of hypothalamic and brainstem functions to a sufficient extent, thereby sustaining respiration and circulatory processes.

Wade and Johnson (1999) offer valuable insights to enhance our comprehension of sensory evaluation. Based on their work, the following elements of clinical assessment serve to clarify better the assessment of the PVS:

- the absence of a reflexive eye closure in response to direct visual threat, necessitating intricate cortical processing, is considered a diagnostic criterion. Occasional deviations, such as the sporadic orientation of the gaze toward auditory stimuli or novel visual cues, may occur. However, any prolonged and deliberate visual exploration of the surroundings warrants concern, signifying potential residual awareness.
- In the context of auditory evaluation, it is imperative to establish the patient's responses to various auditory stimuli, including telephones, music, and familiar voices.
- Regarding somatic sensory evaluation, the examiner should elicit information regarding the patient's cooperation during nursing procedures and assess the responses to tactile and other sensory stimuli.
- Certain forms of motor activity, whether spontaneous or induced by sensory stimulation, are within the expected spectrum, such as limb movements and yawning.

In addition, health professionals may utilize sophisticated imaging technologies/techniques, such as computed tomography (CT) or magnetic resonance imaging (MRI), to meticulously assess both the structural and functional parameters of the patient's cerebral cortex (Von Wild et al., 2012; Giacino et al., 2018).

While the listed observations are indeed valuable, it is important to acknowledge that, despite the rigorous clinical assessments, there exists a notable risk of misdiagnosis among patients in the vegetative state (Cruse et al., 2011). Wade's review (2018) emphasizes that some misdiagnoses stem from the misinterpretation of observations, with a common tendency to attribute agency to behavior and events. This challenge is further compounded by the wide spectrum of physical and cognitive impairments present in these patients. The diversity of impairments complicates the accurate interpretation of behaviors, making it difficult to distinguish those that may indicate conscious awareness from those that are random and non-purposeful (Giacino et al., 2018). As evident, the diagnostic process of PVS is intricate and predisposed to diagnostic fallacies, thus underscoring the necessity of a multidisciplinary approach where clinical history, neurological examinations, and imaging studies converge synergistically to facilitate and guide the precise diagnosis of PVS.

Thus, it can be deduced that the diagnosis, or more precisely, the prognosis of PVS, introduces a noteworthy level of uncertainty. This uncertainty becomes salient within a clinical evaluation that concerns the absence of awareness in a person who exhibits no overt indications of a conscious mental state (Borthwick & Crossley, 2004).

The criticisms directed at this mode of observation regard precisely on its reliability (Fins, 2019). Consciousness (or unconsciousness) is deduced, while behavior is directly observable (Wade & Johnson, 1999). Furthermore, while behavior may appear to be an objective category and neutrally observable category, it is crucial to recognize, as mentioned before, that behaviors always involve an act of interpretation. The question of awareness takes on a central and urgent significance: while it's easy to suggest behaviors as evidence of psychological awareness, demonstrating that the absence of these behaviors can only be attributed to a lack of psychological awareness is a more intricate task (Borthwick, 1996).

Thomas A. Mappes (2003) identifies two distinct potential responses to the issue of the reliability of PVS diagnosis: 1) the patient may display signs of consciousness, which diagnosing professionals might overlook; 2) the patient may present no concrete evidence of consciousness, yet still preserve some residual form of awareness.

It is significant to underscore that the prognostic outlook for PVS significantly depends on the underlying etiology. Patients affected by degenerative central nervous system disorders, such as Alzheimer's disease, manifest an inexorable progression of their condition, thereby rendering the prognosis in this scenario comparatively less equivocal (Mappes, 2003). Nevertheless, a distinct paradigm unfolds for PVS patients of post-traumatic genesis, where the prospect of diagnostic misjudgment and the potential for improvement after the diagnosis become pivotal points of controversy.

The diagnosis of PVS is associated with a presumption of irreversibility of the condition. In recent years, skepticism regarding this presumption has surfaced, not only within the scientific community but also within the philosophical inquiry. As elucidated by Noé et al. (2019), such skepticism is underpinned by three principal considerations. Firstly, an expanded comprehension of clinical conditions has emerged, notably with the delineation of novel clinical entities such as Minimally Conscious States (MCS). This expansion

challenges the previously entrenched notion of irreversibility commonly linked to PVS¹. Secondly, the publication of cases reporting recovery outcomes after extended durations, which surpass the established criteria for irreversibility associated with PVS, has engendered substantive questions about the validity of these criteria. Finally, a rigorous reevaluation of methodological dimensions has been instituted, encompassing elements such as the selection of study samples, the temporal spans of follow-up periods, and the criteria employed in post-follow-up assessments. This reevaluation pertains to studies upon which the conclusions of the MSTF had previously been predicated. These methodological reexaminations have underscored the imperative for a more meticulous evaluation of the diagnosis.

As highlighted by Mappes (2003), the core of the matter lies in the domain of probabilities. As the temporal dimension of unawareness extends, the prospects for recuperation invariably diminish. However, it is of utmost importance to underscore that this paradigm constitutes a matter of probability rather than absolute certainty. As reported by Borthwick (1996), a vegetative state becomes permanent when the diagnosis of irreversibility can be established with a certain degree of clinical certainty, meaning that the possibility of the patient regaining consciousness is extremely low, if not rare. In practical terms, this can be better explained when a physician can communicate to the patient's family, with a high degree of medical certainty, that there is no possibility of consciousness recovery or that, even in the event of recovery, the patient would remain severely disabled. It still is a matter of probability, not certainty.

Despite the comprehensive neurological assessments encompassed within clinical observation, inclusive of reflex tests, responses to stimuli, and a spectrum of indicators of cerebral functioning, a residual element of uncertainty persists. This uncertainty is compounded by the fact that individuals often speak and act as if there is a cause behind observed events or behaviors: misinterpretation may be driven by biases stemming from personal background and expectations (Wade, 2018).

¹ Joseph J. Fins (2019) contributes with an illustration of the complexities characterizing the diagnostic landscape in this domain. The case in question pertains to a woman who had been in a vegetative state for over a decade but, remarkably, gave birth at the Hacienda Health Care facility following an incident of sexual assault committed by a member of the medical staff. This conspicuous episode illuminated a divergence from the Vegetative State, as the woman exhibited indications of minimal consciousness, notably expressing distress during childbirth.

The concern regarding the use of the adjective “permanent” and the noun “irreversibility” pertains to an evidence - based prognostic evaluation, inherently characterized by its probabilistic nature. This probability is evidence - based, in the sense that it states that with the available knowledge the prognostic process will likely develop in a certain way. The diagnostic and prognostic uncertainties cast a profound impact on the "prospective thinking" regarding PVS in many facets. Foremost among these facets is the intricate challenge of predicting the likelihood of recovery, an issue that is intimately interlinked with the deeply personal and private decision of endorsing or withdrawing life-sustaining treatments (e.g., Artificial Nutrition and Hydration, ANH). This decision-making process is inexorably influenced by the individual's values, beliefs, and predilections (Mappes, 2003) and brings a range of ethical and legal issues that are still debated today.

The critique surrounding the terms "permanent" and "irreversibility" in the context of prognostic evaluation aligns with the ongoing debate on terminology, reflecting the evolving understanding of consciousness recovery. This discussion not only holds significant implications for the challenges associated with predicting the likelihood of recovery but also extends to ethically and legally sensitive decisions surrounding life-sustaining treatments. The common misdiagnosis of patients with disorders of consciousness in institutional settings led to a significant change in guidelines, which suggest replacing the “permanent vegetative state” with the “chronic vegetative state” (Fins, 2019). Kondziella et al. (2018) found that public perceptions vary, with one in four individuals still favoring the term "vegetative state" over alternatives. Despite receiving limited attention in mainstream news, this shift holds profound implications for bioethics, especially considering the historical significance of the vegetative state in right-to-die cases. The revision challenges assumptions about irreversibility, acknowledging the potential for consciousness recovery in patients previously considered permanently vegetative. Fins and Bernat (2018) caution against overestimating recovery while emphasizing the ethical imperative to identify misdiagnosed cases or those experiencing cognitive motor dissociation, recognizing the progress in consciousness research and its normative implications. For the purposes of this thesis, a comprehensive exploration will consider both the historical use of "permanent" and the contemporary discourse advocating for alternative terminology.

The diagnosis of the Permanent Vegetative State is a complex and evolving field, marked by uncertainty. These uncertainties have far-reaching implications for medical practice and patient care. Moreover, the complexities surrounding the diagnosis of PVS have also given rise to legal and juridical debates that will be addressed in detail in the subsequent sections.

1.2 Post-Diagnosis Realities: Intensive Care and Medical Commitment in PVS Cases

An individual diagnosed with PVS displays responses to stimuli lacking psychological significance and awareness. As underlined by Giacino et al. (2018) in their practical guidelines on disorders of consciousness, the terminology used in the definition of the Vegetative State inherently carries assumptions, characterizing the phenomenon as irreversible. This uncertainty regarding irreversibility initiates a complex juncture wherein healthcare practitioners grapple with the juxtaposition of ethical imperatives and practical limitations. Understanding the process of individuals diagnosed with PVS becomes crucial in navigating the intricacies of providing care and making informed decisions about their well-being.

Various phases can be identified in the medical treatment process. The acute phase during hospitalization, the transitional or 'waiting' phase marked by stabilization and anticipation of recovery, and the irreversible or permanent phase characterized by the absence of hope for recovery (Lavrijsen et al., 2005), or as observed in some cases, an extremely limited hope. Consequently, those diagnosed with PVS are often placed under the care of long-term facilities (Tolle & Reimer, 2003): once the diagnosis of PVS has been established, patients are discharged to an appropriate medical facility, nursing home, or home care as the case warrants (Rathor et al., 2014). According to Cipolletta et al. (2015), family members frequently opt to relocate patients to a nursing home but still experience a sense of leaving the patient behind. The exigencies imposed by PVS extend beyond the individual to encompass a network of caregivers and familial units, necessitating an intricate and prolonged trajectory of care. Simply put, patients in PVS require especially intensive and long-term care, creating economic, physical, social, and mental pressures for caregivers and families.

Managing PVS patients remains a demanding challenge (Lavrijsen et al., 2005), one that extends beyond medical professionals to encompass relatives and society at large (Rathor et al., 2014). In their retrospective, descriptive review, Lavrijsen et al. (2005) found that long-term care was overseen by a multidisciplinary team, which included several nurses, physiotherapists, speech therapists, occupational therapists, dietitians, pastors, social workers, and psychologists.

In long-term facilities, nurses take on a central role in the intricate landscape of caring for and rehabilitating PVS patients. They emerge as pivotal figures, investing significant time in assisting individuals with PVS and actively contributing to their journey of *possible* rehabilitation. This unpredictable nature of late recovery in PVS cases introduces an additional layer of complexity, demanding nuanced understanding and continual adaptation by nurses who are strategically positioned not only to preserve physical well-being but to contribute significantly to the emotional and communicative dimensions of care. It constitutes a form of *care* labor, characterized by an often-unacknowledged facet of invisible work that imposes a burden upon healthcare practitioners (Pinel-Jacquemin et al., 2021).

Daily nursing care is intensive, encompassing tasks such as washing, changing, managing incontinence materials, administering artificial nutrition and hydration (ANH) six to eight times a day, frequent repositioning to prevent bedsores, applying splints, cleaning the tracheal tube, providing oral care, supplying laxatives and other medications, and regularly changing urinary catheters and nasogastric feeding tubes (Lavrijsen et al., 2005). Noteworthy interventions by nurses, including positioning the patient to sit upright without back support, while allowing their feet to touch the floor, footbath care, and administering oral care (Sato et al., 2017) are conducted routinely.

Neuro-orthopedic complications and recurrent bone fractures, are exemplified in the work of Lavrijsen et al. (2007): immobility and its attendant complications of patients with PVS in nursing homes become pronounced challenges, underscoring the collaborative imperative among healthcare professionals to mitigate fractures and address the emotional toll on caregivers.

Montagnino and Ethier (2007) contribute a narrative from the perspective of pediatric nurses, shedding light on the emotional complexities inherent in caring for children in PVS. The thematic emergence of sensorial offensive physical care underscores the

profound emotional impact of seemingly routine yet emotionally charged tasks, such as suctioning, tracheostomy care, and turning. The discomfort experienced by nurses is notably heightened, especially as the child grows larger: they articulate a sense of distress, particularly concerning the openness of the children's eyes and the aspect of their constantly open mouths (Montagnino & Ethier, 2007). Other factors such as screams, the sounds of difficult secretion and the care perceived as aggressive are reported (Pinel-Jacquemin et al., 2021). Themes of focusing on relatives and grappling with moral uncertainty (Montagnino & Ethier, 2007) further enrich the understanding of the emotional terrain: the intricate nature of the daily management of patients in a Vegetative State gives rise to potential psychological distress and, in certain instances, precipitates burnout among nurses and healthcare professionals in general (Pinel-Jacquemin et al., 2021).

The consideration of additional complications is essential in the analysis: as observed by Lavrijsen et al. (2005), patients exhibit significant comorbidities, including chronic constipation, spasticity with contractures, oral and dental issues, as well as recurrent infections of the airways, urinary tract, and skin. Chronic medications, particularly laxatives, are administered, and consultations with various medical specialists are sought. All patients rely entirely on comprehensive nursing, medical, and paramedical care, leading to the development of significant comorbidities that necessitate polypharmacy. The trajectory of their condition is contingent upon the comorbidities present, as well as the attitudes of both physicians and families.

The crux of the matter lies in the absence of a universally applicable solution, even when medical practitioners are in their conviction that the perpetuation of medical interventions yields no discernible benefit. This triggers a new level of complexity as the investigation into the *futility* of persisting with medical treatment beyond a certain period has been a source of concern for caregivers, family members, and society (Lavrijsen et al., 2005). There is an ongoing disagreement concerning the appropriateness of various treatment options and the factors that should be considered in the decision-making process.

Over time, the incidence of VS continues its upward trajectory owing to advancements in resuscitation techniques, concomitantly extending the life expectancy of these patients (Leonardi et al., 2009). The heightened frequency and protracted survival of individuals in a Vegetative State exacerbate the complexities inherent in their care (Goudarzi et al.,

2015): such patients persist in survival contingent upon the provision of artificial hydration and nutrition.

In this regard, it is imperative to allocate contemplative space to understand that the discourse surrounding nutrition, or its withdrawal, generates instances wherein healthcare personnel play a pivotal role. Their role extends beyond the conventional trajectory of care, assuming, in some cases, the character of providing support and accompaniment during the terminal phase of life.

The matter of VS transcends the clinical realm to encompass a legal dimension. The core of the debate presently revolves around the retention or withdrawal of nutritional interventions that sustain the patient—an issue that interlaces with various other discourses, encompassing debates on brain death, dignity, and the respective roles of medical professionals. The discourse concerning VS patients predominantly centers on the ethical belief of proportionality in reconciling the benefits and burdens of medical interventions (Leonardi et al., 2009).

In the upcoming sections, the legal dimension of the PVS discourse will be addressed, exploring the intricate intersection of medical ethics and law in the context of patients in a vegetative state.

1.3. In The Shadows of Life and Death: Legal and Ethical Considerations in the Vegetative State

The vegetative state poses a challenging scenario, emerging as one of the most ethically troubling diagnoses since its emergence (Bloore, 2004). Doubts have arisen regarding its status and concerning the therapeutic implications, such as the withdrawal of artificial nutrition and hydration. These decisions are intertwined with profound considerations about *life* and *death* (*ibidem*).

The determination of death is a complex and multifaceted issue, drawing on both scientific and profound ethical arguments. According to the National Bioethics Committee (1991), death is defined as the point at which an organism loses its integrity, marking an irreversible transition from life to non-life. Traditionally associated with the cessation of cardiac activity, the introduction of brain death in 1959 has added layers of complexity to this definition (Schiff & Fins, 2016). Brain death is characterized by a

clinical evidence of the complete and irreversible cessation of brainstem and cerebral function (Robba et al., 2019), including spontaneous respiration, and require the permanent cessation of these functions (Perez, 2022). To clarify, whether *cerebral* or *cardiac, death* signifies a singular event characterized by the unequivocal loss of the organism's functional unity.

The introduction of brain death has raised numerous controversies and bioethical debates (*ibidem*). This is primarily attributed to the implications of a neurological brain death diagnosis on patients, such as organ harvesting for transplant and interrupting the life support and futile therapeutically measures to patients that are not included in the transplant program (Mitre & Mitre, 2017).

Expanding upon this concept, brain death definition becomes particularly significant when juxtaposed with the vegetative state, which lacks legal recognition as death within any legal system. Schiff and Fins (2016) contribute valuable insights into the differentiation between brain death and disorders of consciousness, particularly the vegetative state. They place brain death on a life-spectrum continuum (*ibidem*), creating a conceptual framework that helps illustrating the evolving understanding of different brain states. At one end of this continuum, we find the absence of integrative function in brain death, where the organism lacks both bodily and brain integration. Progressing along the continuum we find the vegetative state, characterized by preserved brainstem function and a lack of integrative cerebral activity. In this state, patients may experience patterned behaviors, such as eye opening and reflex movements without a unified perception or consciousness. This conceptualization aims to alleviate uncertainties surrounding the definition of brain death and underscores the importance of considering the entire spectrum of brain states in the determination of death (Schiff & Fins, 2016).

Thus far, it is possible to affirm that the definition of death is framed in terms of reality and irreversibility. In contrast, the vegetative state presents a unique condition that does not align with these criteria. If the vegetative state does not meet the criteria for *death*, then it meets the *life's* one. This prompts a paradigm shift, urging the contemplation of the nature of life in a form that challenges preconceived notions and requires the reevaluation of the ethical breadth.

The ongoing debate surrounding the withdrawal of nutrition and life-sustaining support assumes a heightened significance (Larriviere & Bonnie, 2006). In contrast to other

clinical diagnoses where clinicians contend with issues related to disease management – such as the acceptance or rejection of recommended treatment, the availability of treatment, and the decision of whether to offer a treatment or not – the complexities faced in a case of a patient in a Vegetative State are notably more intricate (McLean, 1999). These complexities often bear a greater moral and ethical weight, leading medical staff to be involved in legal matters (*ibidem*).

The ethical and legal stance concerning this matter is frequently obscured and linked to moral uncertainty, with the central inquiry revolving around the irreversibility of the condition (Giacino, 2018) and the potential moral obligation to sustain patients (Smith, 1990). If irreversibility remains currently indefinable (Anderson, 2022), then cases of Vegetative State become inherently problematic within moral discourse (Ost, 2001).

Over the years, various cases in different countries, such as Terry Schiavo in the USA (Dute, 2005), Eluana Englaro in Italy (de Zulueta & Carelli, 2009; Maldonato, 2019), and Tony Bland in the UK (de Zulueta & Carelli, 2009; Pradella, 2005), have served as arenas for deliberations on a spectrum of political and legal issues. These encompass the exercise of state's rights, the extent of individual rights, the role of the judiciary, the reopening of the abortion debate, and the regulation of stem cell research (Pradella, 2005). The resonance of these cases has prompted collective contemplation and a reevaluation of societal attitudes towards end-of-life decisions (McLean, 1999). This ongoing process, underscored as a necessity by Dute (2005), signifies a continued need for reflection in future times. Notably, diverse approaches have been employed, reflecting variations in legal and political cultures. These critical differences manifest in the cultural values, thereby influencing the structure and jurisprudential foundation of legal systems (Pradella, 2005; Dute, 2005).

In virtue of their condition, an individual in a vegetative state retains the full legal status as a person, thereby warranting due respect and protection of fundamental rights. Within the discourse on the decision to withdraw nutrition from an individual in a Vegetative State, two fundamental considerations emerge, stemming from the premise that distinguishes it from brain death and from statements issued by the Courts on cases involving individuals in a vegetative state: the issue of dignity and that of acting in the best interests of the patient.

The concept of dignity is intricately interwoven with the foundational principle of the sanctity of life—a philosophical tenet that asserts the intrinsic value of human life (Zulueta & Carelli, 2009). This principle serves as a moral and ethical cornerstone, influencing perspectives on the preservation of life. While individuals generally possess the autonomy to dictate their manner of living under normal circumstances, the insistence on maintaining life at all costs raises concerns about the potential intrusiveness, burden, and even cruelty associated with such an approach with PVS cases (Zulueta & Carelli, 2009). In situations where patients are unable to make decisions regarding their medical condition, the responsibility for determining life-sustaining treatment falls upon the medical staff and family members. In the absence of explicit guidance from the patient, the authority to make such decisions is typically delegated to those in closest proximity to the individual.

The complexities of navigating the delicate balance between preserving life and upholding the dignity of an individual are underscored by the legacy of cases like that of Bland, as illustrated by Pradella (2005). This legal and ethical discourse scrutinizes the considerations associated with the *sanctity of life*. The principle does not categorically mandate the relentless provision of medical treatment, especially when such interventions cease to confer meaningful benefits upon the patient. The ethical underpinnings of the sanctity of life do not preclude the withholding or withdrawal of medical interventions when their continuation may lack clinical efficacy or result in suffering. This perspective underscores the importance of a context-specific approach when navigating the complex intersection of dignity, autonomy, and the sanctity of life in the realm of medical ethics and decision-making.

The consideration of the patient's best interest holds particular significance, as it is imperative to act most favorably for the patient in all instances. This ethical imperative becomes even more pronounced when addressing cases where the individual cannot articulate their preferences, adding a layer of complexity to the assessment process (Pradella, 2005). The determination of a patient's best interests gains heightened importance in such scenarios.

Moreover, the critical evaluation of a patient's best interests encourages reflection on the justifiability of prolonged medical sustenance. Scholars such as Lavrijsen et al. (2005) underscore the necessity of contemplating how long the continuation of medical

interventions can be ethically justified under these circumstances. An integral facet of this discourse involves preemptive decision-making at an earlier stage to forestall the protraction of medical interventions without tangible benefits. Efforts to mitigate delays in diagnostic processes and the communication surrounding the contemplation of withdrawing artificial nutrition are connected to concerns regarding the dignity and integrity of the individual.

In a comprehensive analysis conducted by Kitzienger and Kitzienger (2017), a case was meticulously examined wherein a patient, unequivocally diagnosed with PVS on multiple occasions, endured life-prolonging treatment for an unprecedented period exceeding two decades. This protracted medical intervention persisted despite the existence of established case law, professional guidelines, and statutory provisions. Collectively, these regulatory frameworks should have directed healthcare professionals towards a consensus that the continuation of life-sustaining treatment was both futile and contrary to the best interests of the patient.

The examination conducted by Kitzienger and Kitzienger (2017) brought to light a multitude of issues, notably the breakdowns in communication among various professionals, organizations, and relatives involved in the decision-making process. The findings underscored critical lessons derived from cases analogous to the one under scrutiny. Among these lessons is the imperative for both family members and healthcare staff to comprehend the medico-legal context thoroughly, coupled with access to high-quality information encompassing clinical, social, and ethical dimensions pertinent to the treatment of patients in similar conditions.

Moreover, the study emphasized the necessity of providing families with appropriate information and support, recognizing that they play a pivotal role in the decision-making process. Additionally, Kitzienger and Kitzienger (2017) highlighted the potential need for specialized training for healthcare staff to facilitate challenging conversations related to treatment decisions in such complex cases. Ensuring that staff members possess the requisite training and a comprehensive understanding of their responsibilities emerged as a crucial aspect for navigating ethically and legally intricate situations. Consequently, the study proposed that an integrated approach involving improved communication, informed decision-making, and ongoing education for healthcare professionals is essential to address the intricate challenges surrounding the treatment of patients in Vegetative State.

The discourse on the withdrawal of life-sustaining treatment prompts a critical examination of the implications for the quality of life, particularly when the life under consideration lacks certain human attributes, notably consciousness. This absence of essential characteristics introduces difficulties in the legal judgments made in cases involving patients in a Vegetative State, with some scholars expressing concern about the potential risks associated with such determinations (e.g., Ost, 2001). Kitzinger and Kitzinger (2018) emphasize that the discussion surrounding the options for treatment withdrawal should not be construed as an act of abandoning the patient or ceasing care provision. Rather, it revolves around the imperative of ensuring appropriate and person-centered care. In legal proceedings, the focus often shifts towards discerning and honoring the expressed preferences and wishes of the individual in question. The aim is to reconstruct and fulfill what the person would have desired for themselves, thereby aligning with principles of autonomy and patient-centered decision-making.

Zulueta and Carelli (2009) suggest that courts may consider criminal liability in cases where life-sustaining treatments are intentionally withheld from a patient with a duty of care. Thus far, it is important to acknowledge the importance of the various legislations addressing end-of-life issues to understand their approaches.

Specifically, Italy's perspective on this matter is outlined in Law n. 219/2017, titled "Provisions for informed consent and advance directives," effective from January 31, 2018. Article 4 of this law focuses on DAT, *Disposizioni Anticipate di Trattamento* (Advance Healthcare Directives), and will be further clarified.

The law establishes that every adult can express their wishes regarding medical treatments through DAT. They can also appoint a trusted representative to act on their behalf. The representative must be of legal age and can accept or decline the appointment. The person making the directives can revoke the representative at any time. If the DAT does not specify a representative or if the representative is unavailable, the wishes of the person making the directives remain valid. The medical professional is obligated to respect the DAT, except in cases of clear inconsistency or changes in the clinical condition. DAT must be formally drafted and are exempt from registration and fees. They can also be expressed through video recording in exceptional cases where the patient's physical condition prevents them from being present. The law regulates the advance planning of healthcare treatments to ensure respect for the patient's wishes. In the context of this

writing, not adhering to DAT means more than violating mere consent; it means violating the very idea of dignity crystallized within the individual (Maldonato, 2019).

Although the article is a step forward, it overlooks a significant issue: the cases of absence of advanced treatment directives. End-of-life decisions are not yet widely culturally accepted in Italy and as highlighted by Maldonato (2019), this could lead to a limitation in the actual number of DAT, creating normative uncertainties on how to behave in numerous cases. In the absence of DAT, there is no indication of the applicable discipline for the person who is effectively unable to decide for themselves.

However, in cases of the absence of advance directives, there is the possibility that the legal representative or support administrator may refuse proposed treatments, including life-saving treatments. If the rejected treatments are deemed appropriate and necessary by the doctor, then the decision will be referred to the supervisory judge upon the request of the legal representative of the concerned person or by the doctor or legal representative of the facility (Article 3, Law 219/2017). What is not clear is how the supervisory judge should conduct and make the decision (Maldonato, 2019).

For the history of the Italian theme, the case of Eluana Englaro represented a significant turning point. Although it occurred before the drafting of the article, the case provides important elements of analysis, also regarding legal cases and the methods with which end-of-life cases are operated or have been operated. As Maldonato (2019) exemplifies, two assessment criteria are highlighted: *best interest* and *substituted judgment*, which combined create a verification standard based on an objective diagnostic moment and a second moment of retrospective prognosis. The first moment requires a rigorous clinical evaluation to ascertain the irreversibility of the vegetative state, following international scientific standards. The second moment focuses on the subjectivity of the represented person, considering their personality, beliefs, and lifestyle before the state of unconsciousness. The assessment is carried out with the assistance of the substitute for the incapable subject. In the presence of these conditions, the judge can authorize the deactivation of healthcare devices. In their absence, the right to life prevails, regardless of the health and autonomy conditions of the subject. The specific case of Eluana Englaro is cited as an example of the application of *substituted judgment*, where the testimonies influenced the judicial decision. Maldonato (2019) suggests that legislation could use the mechanism of *substituted judgment* even in cases where the subject has not made advance

directives. The criteria of *best interest* and *substituted judgment* are thoroughly examined, highlighting the need for presumed will assessment rules that are as closely aligned with reality and in line with the patient's interest as possible.

The exploration of the vegetative state raises fundamental questions about the nature of life, death, and the ethical responsibilities that come with decisions about sustaining life. The challenges in defining death, the nuanced distinctions between the vegetative state and brain death, and the legal frameworks underscore a societal struggle to reconcile medical realities with ethical imperatives. The intertwining principles of dignity and best interests emerge not only as ethical touchstones but also as potential guideposts for legal decision-making. Noteworthy cases demonstrate the enduring societal impact, prompting ongoing reflections on individual rights, state intervention, and the evolving landscape of end-of-life choices. The Italian legal context, encapsulated in Law n. 219/2017, reflects a commendable step forward, but the challenges of cultural acceptance and normative uncertainties persist. As we navigate these complexities, the necessity for empathetic communication, comprehensive education, and a nuanced understanding of the ethical breadth surrounding the vegetative state, fostering a continued dialogue for future reflections and refinements are stressed in these profound ethical and legal dilemmas.

CHAPTER 2

CARE AND GRIEF MANAGEMENT IN THE CONTEXT OF THE VEGETATIVE STATE

2.1 Grief Complexity: The Case of Healthcare Professionals

The convergence of an ongoing biological activity and the absence of traditional markers of consciousness in individuals in a vegetative state (Guarniero et al., 2012) prompts an examination of the emotional and psychological responses that may arise in people taking care of them, specifically health care workers/personnel. Once recognized that ontological, medical, and juridical definitions of life and death as well as their identification are incredibly complex (Schiff & Fins, 2016), it becomes noteworthy to explore how the concept of grief intertwines within this context. In a few words, the confluence of life, grief, and the intricate dynamics with healthcare professionals in the context of vegetative state demands an academic inquiry that not only delves into the conceptual complexities but also acknowledges the emotional dimensions inherent in this terrain.

Official data in Italy indicates that 42.6% of deaths occur in hospitals, with an additional 9.2% taking place in healthcare facilities (ISTAT, 2015). These data provide insights into the challenges encountered by healthcare practitioners. Addressing the healthcare workers' proximity to instances of mortality and end-of-life scenarios necessitates a compelling recognition that the persistent closeness to patient death and suffering elicits a spectrum of profound physical and emotional responses, which may culminate in a sense of personal loss and grief (Groves et al., 2022).

The phenomenon of grief, as pointed out by Rabow et al. (2021), carries a double component within the human experience: a complex psychological and a normative one. Conventionally, grief has been conceptualized within the paradigm of an emotional response primarily linked to the death of an individual (Meller et al., 2019). Thus, it is crucial to recognize it as an intrinsic facet of human existence, an inevitability that everyone will encounter at some juncture in their life course (De Stefano et al., 2020). Active grieving becomes a manifestation of individuals continuously navigating the complex interplay of emotions, expressive modalities, and the temporal dimensions required for the assimilation of this life-altering change (Meller et al., 2019). This dynamic engagement with grief underscores the agency of individuals in making choices

throughout the grieving process, accentuating the personalized and evolving nature of this process. In this light, the discourse on grief transcends pathology, emphasizing its universality and significance in the broader context of the human condition. However, grief assumes diverse forms, occasionally culminating in pathological expressions, commonly referred to as "Complicated Grief" (Simon et al., 2020), transitioned to "Prolonged Grief Disorder" (PGD) in the fifth edition of the DSM (Lambruschi & Battilani, 2014). Individuals grappling with PGD find themselves entrenched in a state of crystallized and chronic mourning, differing from the normal grieving trajectory (Simon et al., 2020). The hallmark of PGD lies in its profound and persistent sense of longing and yearning for the dead individual, distinguishing from *typical* grief by the severity, intensity, and protracted duration of symptoms, ultimately leading to functional impairment (Eisma, 2023). Notably, its diagnostic relevance extends to those who have encountered significant losses on a broader spectrum (e.g., divorce, terminal illnesses, or the loss of a pet), including those who care for individuals whose pathology has led to a significant loss of autonomy and relation (Lambruschi & Battilani, 2014). The spectrum of grief extends to instances where the profound impact of loss emerges not from death itself but rather from the inexorable erosion of meaningful interactions (Varga & Gallagher, 2020). Consider, for instance, the scenario where an individual grapples with grief over the diminishing possibility of a meaningful relation due to the rapid progression of diseases like Alzheimer's (Large & Slinger, 2015; Sanders & Corley, 2003). In this context, grief becomes tangled with the irretrievable loss of the other individual's *personhood*, emphasizing as indispensable the element of irreversibility in the perceived loss (Varga & Gallagher, 2020). It is noteworthy that for grief to manifest authentically, the loss must be perceived as irreparable; if an indistinguishable replica of the lost entity could assuage the grief, then true mourning would not ensue (*ibidem*).

Varga and Gallagher's (2020) insights also offer a valuable lens to examine grief through an individual's practical identities. Practical identities, as expounded by Gils-Schmidt and Salloch (2022), function as guiding frameworks that shape norms, commitments, and an individual's self-understanding, forming the bedrock for their capacity to value, choose, and act, thus providing reasons for their decisions and actions. Taking the example of a medical professional, the practical identity comprises two pivotal components: meeting the formal requirements essential for practicing medicine and actively translating

acquired knowledge and skills into tangible medical practices (*ibidem*). Attachment to specific individuals assumes utmost importance within these practical identities, and the loss of such individuals can evoke a profound sense of mourning (Varga & Gallagher, 2020). Consequently, the death of a patient holds fundamental significance for healthcare professionals, impacting their practical identity at its core. The intricate interplay between grief and practical identities sheds light on yet another dimension of how loss can induce disorientation and a profound sense of identity loss. However, it is essential to keep in mind the importance of refraining from over-medicalizing the concept of grief (Rabow et al., 2021).

Nurses and healthcare workers, entrusted with the well-being of patients, bear a significant responsibility that extends beyond physical care to encompass emotional support (Holland et al., 2014). The cultivation of a resilient and proficient healthcare workforce is imperative, equipping clinicians to navigate the emotional complexities inherent in managing patients approaching the end of life (Meller et al., 2019). This emotional labor places them in a high-risk population for emotional distress, with potential ramifications leading to burnout (*ibidem*). To illuminate the weight of grief on their lives, Rabow et al. (2021) delve into the challenges faced by healthcare workers during the COVID-19 pandemic, shedding light on the complications of understanding, living, and accepting grief. Regardless of the circumstances surrounding a patient's death, whether anticipated or sudden, serene, or distressing, each situation is unique (Meller et al., 2019). Rabow et al.'s (2021) emphasis on the significance of end-of-life experiences and relationships underscores the necessity of a comprehensive approach to address grief. This is particularly true for healthcare workers dealing with individuals in vegetative states, where the quality of end-of-life experiences may be notably challenging (Kane, 2003; Moaddaby et al., 2021). Equally crucial is the acknowledgement of work-related grief and its potential impact on healthcare workers' professional, psychological, and social well-being (Rabow et al., 2021).

Building upon Rabow et al.'s (2021) analysis about healthcare workers, unprocessed grief manifests in feelings of guilt and failure, with burnout emerging as a direct consequence of the challenge of integrating escalating losses into one's professional trajectory and life. The myriad challenges faced by healthcare workers, encompassing conflicting

responsibilities, limited resources, and the overarching impact of policies and societal constraints, contribute to a pervasive sense of distress.

The COVID-19 pandemic has starkly illuminated the inadequacies in the support systems available for healthcare workers (Caimmi et al., 2021), concurrently unveiling a mental health crisis. Healthcare systems bear a primary responsibility to invest in grief support resources (Schulz, 2017), providing protected time for healthcare workers to seek support and process grief (Rabow et al., 2021; Anderson et al., 2010).

Up to this point, it is evident that grief and the possible consequence of PGD is a complex phenomenon. The situation involving individuals caring for patients in a vegetative state presents a paradoxical challenge inherent in the disorder. These individuals are both *absent* and alive, creating a dilemma in applying mourning strategies as the patients are not deceased (Cipolletta et al., 2014). Consequently, achieving a full resolution of grief becomes unattainable in such cases (Guarnerio et al., 2012), thereby heightening the risk of PGD.

Acknowledging illness, dying, and death as integral human experiences calls for a proactive approach to mitigate the risks linked to complicated or prolonged grief (Schulz, 2017), fostering both individual and systemic well-being. Thus, the forthcoming discussion will delve into the specific risks encountered by healthcare professionals in this context. Drawing insights from Polychronis Voultos' (2021) systematic review, this examination will navigate the intricate landscape of emotional challenges faced by nurses, encompassing compassion fatigue, vicarious trauma, and disenfranchised grief. Voultos (2021) meticulously elucidates the evolution of compassion fatigue, a central theme intertwined with psychological distress and exposure to traumatic material.

Nurses, during their professional responsibilities, confront myriad stressors that predispose them to compassion fatigue—a progressive process culminating in physical, social, emotional, spiritual, and intellectual fatigue (Cross, 2018). The repercussions, ranging from intrusive thoughts to depression, magnify the complexity of emotional engagement in nursing, particularly when circumstances deviate from the anticipated trajectory. Voultos' review identifies key factors contributing to compassion fatigue, with a focus on vicarious trauma and exposure to traumatic material. These elements are further compounded when coupled with disenfranchised grief (*ibidem*), a phenomenon characterized by the societal neglect of the experienced loss (Cesur – Soysal & Ari, 2022;

Tullis, 2017). This lack of societal acknowledgment is intertwined with burnout syndrome (Andrada et al., 2021). The exposure to death may deprive individuals of the opportunities for comprehensive and adequate grieving, leading to an accumulation of unresolved grief (Shorter & Stayt, 2010). The absence of acknowledgment for these losses becomes a substantial burden, while the collective acknowledgment of a patient's demise in the workplace could create an environment where individuals feel authorized to express their grief openly, both in private and public spheres (Meller et al., 2019; Rabow et al., 2021).

The interplay between psychological distress, compassion fatigue, and the emotional challenges confronted by healthcare workers necessitates a multifaceted approach to promote individual and systemic well-being. This is imperative as the delicate equilibrium between experiencing and suppressing grief in the context of professional-related losses contributes to emotional dissonance (Meller et al., 2019). Emotional dissonance denotes a disjunction between felt and expressed emotions, coupled with diminished emotional regulation (Tei et al., 2014). Demonstrating an emotional connection with a terminally ill patient and their families can present complexities in coping with the patient's death (Meller et al., 2019). Thus, a comprehensive understanding of these intricate dynamics is crucial for developing strategies that bolster the emotional resilience and well-being of healthcare professionals operating in this challenging domain.

Recognizing the delicate equilibrium between deriving satisfaction from work and succumbing to fatigue emphasizes the need to proactively establish risk-profile frameworks. As we examine the nuanced experiences of healthcare workers in dealing with loss, the complexities arising in situations where the lines between presence and absence, hope and despair, blur become evident. It is crucial to address these intricacies, particularly for those caring for patients in a vegetative state, to ensure the emotional welfare of healthcare professionals.

2.2 Bridging Ambiguous Loss and Vicarious Grief in the Care of Individuals in Vegetative State

Exploring the nuances of individuals in a vegetative state reveals a distinctive scenario that challenges a straightforward association with the conventional concept of grief. It

operates within a unique framework, emphasizing the need to acknowledge and validate experiences (Holland et al., 2014) for a comprehensive understanding of the dynamics of grief and loss. In light of this, we introduce two significant concepts: ambiguous loss and vicarious grief, which may play pivotal roles in navigating the complexities of caring for individuals in a vegetative state.

The concept of Ambiguous Loss originated in the 1970s when Pauline Boss introduced the constructs of *psychological absence* and *physical absence*. These constructs evolved into *boundary ambiguity*, and by the mid-1970s, the term "ambiguous loss" was coined (Boss, 2016). As outlined by Boss, the concept has undergone an evolution over the years, propelled by the work of scholars and has now become an integral part of the global lexicon, indicating its widespread recognition (*ibidem*). Ambiguous loss is defined as an unclear loss situation that remains unverified and lacks a resolution (Boss, 2007). There are two distinct types. The first involves physical absence and psychological presence, while the second entails psychological presence but physical absence (Boss, 2010). To illustrate, cases such as soldiers at war, missing or kidnapped individuals, immigration, and adoption are associated with the first type. In contrast, conditions like Alzheimer's, dementia, chronic mental illnesses, and substance addiction are linked to the second type (Boss, 2016). The central theme is that the person has lost attributes that define them psychologically, leading to grief for this aspect of their personhood (*ibidem*). The theory has undergone rigorous testing in various contexts. Rose Perez (2016) applied the concept to understand the lifelong grieving of individuals forcibly displaced from their homeland, focusing specifically on the case of Cuban Americans in exile. McGuire et al. (2016) utilized the ambiguous loss framework to guide the decentering of cisnormativity in families dealing with gender transition. The theory is also notably relevant to caregivers of Alzheimer's patients (Betz & Thorngren, 2006), where feelings of ambiguity towards their loved ones are significantly high (Sanders & Corley, 2003). Acknowledging the validity of this framework, Giovannetti et al. (2015) conducted a study involving caregivers of patients with Disorders of Consciousness, revealing common themes related to changes in roles, physical appearance, reactivity, identity, and relationships. The application of ambiguous loss extends to caregivers of individuals in a vegetative state, suggesting potential relevance and validity. Giovannetti et al. (2015) found that caregivers of such patients experienced ambiguity, leading to feelings of disorientation

and uncertainty. Clinical expressions of caregivers' experiences include factors like the frequency of visits, belief in the patient's psychological presence, and challenges in coping with uncertainty (Zaksh et al., 2019). Furthermore, research suggests that the framework of ambiguous loss is pertinent to caregivers of individuals with a brain injury (Kreutzer et al., 2016), where the interconnection of ambiguous loss and disenfranchised grief is highlighted (Thogersen & Glintborg, 2021).

Ambiguous loss is, by definition, a stressor event or situation, and the perception of this stress is termed *boundary ambiguity* (Boss, 2016). The goal is not to eliminate the stressor, as it is not feasible, but to strengthen individuals and create systemic resilience to manage the stress and anxiety of uncertainty (Masten, 2016; Kreutzer et al., 2016). Living with ambiguous loss requires long-term support (Boss, 2016). The theory emphasizes that the experience of ambiguity lies in the type of loss, which is unclear and irresolvable, rather than in the family or individual experiencing it. Distinguishing ambiguous loss lies in the stress and trauma caused by immobilizing ambiguity and some expressions and manifestations may require psychological intervention (Boss, 2016). The ambiguity associated with this loss impedes the natural grieving process and hinders the ability to process emotions, compromising decision-making and making it impossible to integrate the loss (Zaksh et al., 2018). Boss (2016) argues that the term "closure" lacks validity within the realm of human relationships, contending that it is incompatible with the concept of a psychological family. Upon further consideration, it becomes evident that this notion is also antithetical to the more general idea of a psychological existence. This additional perspective wants to underscore the inadequacy of closure in capturing the complexities inherent in human connections and the intricate fabric of psychological existence.

Effects may vary across disciplines, but it is generally recognized that individuals become socially and psychologically immobilized. Responding to ambiguous loss with absolute thinking, considering the person either definitively dead or unchanged, is common as the most usual coping strategies used in dealing with the loss are acceptance or avoidance (Dupuis, 2002). As a solution, Boss (2006; 2016) suggests dialectical thinking, a thought strategy that allows individuals to manage the stress of ambiguous loss by holding opposing ideas in their minds simultaneously. This is referred to as a *both-and* way of thinking (Boss, 2006), an approach that enables individuals to hold opposing ideas in their

minds simultaneously, facilitating them to live despite the uncertainty and ambiguity linked to the situation (Jackson et al., 2018). Indeed, dialectical thinking involves purposeful contemplation of opposing perspectives (Peng & Ames, 2001). In the context of the challenges faced by healthcare professionals, as discussed earlier, dialectical thinking becomes particularly relevant. In the complex and emotionally charged environment of caregiving for individuals in a vegetative state, it offers a valuable tool for navigating the intricate dynamics of grief and loss. The goal is to enable them to live despite *not knowing*, clarifying that their stress is not their fault but rather an ambiguity linked to the situation.

On the other hand, the inception of the concept of Vicarious Grief can be traced back to Kastenbaum's article in 1987, where he defined it as the sorrow experienced for the loss of another person, potentially fostering heightened levels of empathy and compassion. This notion aligns with the understanding that individuals frequently undergo vicarious emotions, wherein an emotionally salient element of an external person triggers corresponding reactions within oneself (Grynberg & Lopez-Perez, 2018).

These can be relevant also for healthcare professionals. Woolhouse and Thind (2012) shed light on vicarious trauma and emotions experienced by family doctors operating in disadvantaged urban areas. The study illuminated the emotional challenges and burdens faced by professionals dealing with a population marked by complex physical, mental, and psychosocial needs. The findings underscored the frustration and emotional toll of daily work, with healthcare providers often feeling isolated and judged by their traditional medical peers. Succeeding scholarly endeavors have expanded the theoretical framework of vicarious grief. Chochinov (2005) delved into understanding grief in response to global disasters, emphasizing the pain experienced by individuals even if not directly affected by catastrophic events. This broader perspective on vicarious grief holds implications for public health and policy-making, influencing the perception and processing of losses on a societal level (*ibidem*).

Refinement of the concept led to the identification of two types of vicarious grief (Jose et al., 2023; Varga & Gallagher, 2020): Type 1 involves the vicarious griever feeling what the direct griever experiences, while Type 2 is triggered by both vicarious and personal losses, meaning that the vicarious griever is experiencing their own grief while empathizing with the direct griever. The latter scenario can be particularly complex, as

the vicarious griever may grapple with indistinguishable losses or experience a destabilization of beliefs about reality, oneself, and the world (Varga & Gallagher, 2020). Such disruptions can precipitate a crisis of meaning and prompt a reevaluation of one's beliefs. The landscape of empathy-based constructs related to vicarious grief reveals a nuanced lacuna in the understanding of how indirect involvement with death and loss issues can trigger discomfort-related responses.

Although extensively explored in the context of vicarious grief, concepts such as vicarious trauma, secondary traumatic stress, and compassion fatigue may fall short in providing a comprehensive understanding of the concept. Moreover, prevailing literature on this subject predominantly concentrates on public grief during disasters or tragedies, resulting in a notable scarcity of evidence-based data concerning health professionals. The paucity of empirical studies applying and validating Kastenbaum's theory accentuates the persistent need for rigorous research. This imperative is particularly underscored in the realm of healthcare professionals, who grapple with distinctive challenges in their daily practice. A noteworthy example of such endeavors is the comprehensive study conducted by Jose et al. (2023) aimed at unraveling the experiences of vicarious grief among health professionals during the unprecedented circumstances of the COVID-19 pandemic. This robust study comprised two distinct phases, employing both survey and interview methodologies. The qualitative analysis of data clarified the multifaceted landscape of vicarious grief experienced by health professionals, offering a detailed portrayal of their encounters, obstacles, and strategies for managing emotions. A prevalent theme emerged, wherein participants, while witnessing the sorrow of others, found themselves reawakening personal emotions, particularly when resonating with the grief of afflicted relatives. Notably, the study highlighted the resurfacing of memories related to personal losses and previous experiences of grief, intensifying the emotional connection with their patients. Reinforcing this narrative, Richmond et al. (2021) emphasized the collective experiences of grief brought about by the pandemic, stressing its pertinence within the healthcare system. Their work, specifically oriented towards counselors in training, underscores the potential upturn of grief-oriented clinical work and the imperative to address this shift in the healthcare landscape. As health professionals grapple with heightened emotional involvement and the resurgence of personal grief, the significance of delving into the psychological impact of vicarious grief

is underscored, offering valuable insights for the enhancement of support mechanisms and mental health provisions within the healthcare domain. Additionally, it is important for institutions providing services to grieving to regularly assess their health professionals for vicarious grief and take organizational preventive measures to mitigate risks. While the existing literature on vicarious grief among healthcare professionals remains limited, the significance of understanding the vicarious impact of events in the healthcare realm has been notably underscored, often connected to other concepts (Sleep, 2015), particularly within the domain of vicarious trauma. Vicarious trauma encapsulates the condition experienced by individuals who are indirectly exposed to stressful situations through a third party (Drum, 2015). Within the healthcare industry, where practitioners are routinely confronted with scenarios that can cause pain, suffering, and harm upon those under their care, the relevance of vicarious trauma becomes particularly salient (Drum, 2015). The prevalence of vicarious traumatization extends beyond general healthcare settings, encompassing professionals working with vulnerable populations such as refugees and asylum seekers (Puvimanasinghe et al., 2015; Guinchard et al., 2022). Particularly, studies within specialized fields, such as sexual assault nursing, reveal a cognitive disruption akin to having experienced trauma firsthand (Raunick et al., 2015). Furthermore, the COVID-19 pandemic has brought to light the psychological phenomenon of vicarious trauma as leading to cognitive shifts that disrupt their capacity to deliver competent care (Kennedy et al., 2022; Li et al., 2020). These findings underscore the importance of delving deeper into the realm of vicarious grief within the healthcare system (Sleep, 2015). The existing evidence suggests that healthcare professionals, in their dedication to caring for others, are susceptible to vicarious traumatization across various contexts (Strom-Gottfried & Mowbray, 2006). Recognizing and comprehending the nuanced ways in which grief manifests in the healthcare sector becomes essential (*ibidem*), not only for the well-being of the professionals involved but also for optimizing the quality of care provided.

Two key conceptual frameworks, Ambiguous Loss and Vicarious Grief, stand out as valuable instruments for unraveling and comprehending the intricacies of grief encountered by healthcare professionals engaged with patients in a vegetative state.

Ambiguous Loss, as expounded by Boss (2016), provides a nuanced lens through which to examine unresolved loss situations. In the context of caregivers dealing with patients

in a vegetative state, this concept captures the intricate interplay between physical absence and psychological presence (Schiff & Fins, 2016; Stern et al., 1988). The transformative nature of the roles, physical appearance, reactivity, identity, and relationships associated with patients in a vegetative state generates a sense of disorientation and uncertainty for caregivers (Guarnerio et al., 2012). The application of Ambiguous Loss as a framework underscores the multifaceted nature of the challenges faced by caregivers in this realm. Simultaneously, the concept of Vicarious Grief sheds light on the emotional toll experienced by healthcare professionals who bear witness to the suffering and loss of their patients (Jose et al., 2023). As Type 1 vicarious grievers, healthcare professionals authentically share in the grief that should belong to the patients and their families. Additionally, as Type 2 vicarious grievers, they grapple with their own grief while empathizing with the direct griever, creating a complex emotional interplay that demands careful consideration.

In conclusion, the risk of developing disorders such as Prolonged Grief Disorder (PGD) among healthcare professionals is real (Guarnerio et al. 2012) and must be addressed. These insights, stemming from the analysis of vicarious or ambiguous grief, are pivotal and must be accorded priority in understanding the complex structure of their grief experiences.

2.3 The Impact of Personal Beliefs: Reflective Function Shaping Approaches to End-Of-Life Care

Healthcare professionals' active engagement and perspectives on decision-making, coupled with their beliefs concerning the mental states of patients, hold significant ramifications for their professional standpoint, especially in the realm of end-of-life care (Albanesi et al., 2020; Park et al., 2020). This pivotal consideration forms the cornerstone for the subsequent part, where the primary objective is to investigate whether these individual perspectives apply a tangible impact on how healthcare professionals navigate the challenges of grief inherent to patients' care. To achieve this, the forthcoming section will explicate the notion of Reflective Function, elucidating its practical ramifications within the healthcare milieu.

The inception of the Reflective Function concept emerged within the context of investigating trans-generational psychic processes (Katznelson, 2014). In 1991, Fonagy

et al. initiated their ongoing research by delineating the pre-reflective self as the immediate and unmediated experiencer of life, distinct from the reflective self, which serves as the internal observer of mental life. The latter engages in contemplation of both conscious and unconscious mental experiences, acknowledging that its behavioral representations are influenced by the content of others' mentation (Fonagy et al., 1991). The interconnected evolution and awareness of mental processes in oneself and others become apparent (Steele & Steele, 2015). Making sense of the world necessitates the invocation of constructs such as wishes, beliefs, regrets, values, or purposes to comprehend not only the mental world of others but also that of the self. This intricate cognitive function is attributed to the internal observer, affirming that the mind is inherently interpersonal and intricately connected to the evolution of social understanding (Fonagy et al., 1991). The capacity to reflect on the mental world of others and oneself presupposes an individual's perception of the world of intentions, feelings, and beliefs as a secure environment for exploration. This capacity implies several crucial distinctions, including differentiating between one's mind and others', intentions and effects, and the ability to imagine one's experience of external reality as just one among many (Seligman, 2007). In their examination of the reflective function, or *mentalization*, within clinical settings and experimental studies investigating the organization of the self, Fonagy et al. (1991) contended that the developed sense of safety, originating from the shared mental processes between infant and caregiver, endures as a relatively stable facet of mental functioning. This enduring sense of security proves to be pivotal for the child in fostering a feeling of safety within the world (Seligman, 2007). However, it is crucial to note that the reflective self is not static; it possesses the inherent capacity for continuous learning, reassessment of assumptions, and the integration of novel cognitive frameworks, facilitating ongoing evolution (Nerken, 1993). Thus, even if early research implies that reflective function primarily takes shape within attachment relationships (Katznelson, 2014), subsequent investigations over the years have suggested a broader scope of influential factors. Beyond the foundational role of attachment, peers, teachers, mentors, and the broader sociocultural context are identified as increasingly significant determinants in shaping the development of this pivotal capacity (Luyten et al., 2017). Mentalization stands as both an origin and a consequence within the intricate and potentially transformative process of making oneself emotionally available to others,

delving into one's personal history and internal life, and thereby unlocking life's various opportunities. The conceptual coherence and practical relevance of mentalization are evident as individuals navigate the landscape of interpreting the thoughts, feelings, intentions, and desires of those in their social environment. As articulated by Mitchell (2009), researchers have undertaken the ambitious task of understanding the neural underpinnings of social cognition in mentalization. They have identified a concise and reliable network of brain regions engaged when individuals engage in mentalizing about the minds of others, prominently featuring the medial prefrontal cortex, temporo-parietal junction, and medial parietal cortex. The involvement of these brain regions suggests that comprehending the minds of others entails a cognitive process wherein individuals project themselves into scenarios distinct from their current experiences. Mentalization taps into the cognitive ability to envision inhabiting the mental landscape of another person (*ibidem*). Consequently, perceivers construct mental representations of a target's experiences, forecast the thoughts and feelings likely to arise in such situations, and posit that the target of mentalization will share similar cognitive and emotional states. This predictive process or the deliberate suppression of one's own mental states empowers individuals to infer complex emotional states in others, recognize that individuals can interpret behavioral cues as indicative of underlying thoughts and feelings (Mitchell, 2009).

Reflective Function denotes the capacity to engage in contemplation about one's thoughts and emotions and to adopt an external perspective when considering oneself and an internal perspective when considering others (Luyten et al., 2017). In the years since its conceptualization, the perceived *failure* of reflective function was initially regarded as a predisposing factor for various psychopathologies, particularly within the realm of personality disorders (Chiesa & Fonagy, 2014). However, a nuanced understanding has emerged through evolving research, challenging the notion that reflective function is strictly tied to pathological conditions. Notably, it has been posited that traumatic experiences, in and of themselves, do not inherently compromise reflective function (Ringel, 2011); rather, it is the subsequent inability to sustain reflective function in the aftermath of trauma that may elucidate the intergenerational transmission of trauma and disruptions in infant attachment (Luyten et al., 2017). Moreover, an expanding body of literature has delved into the examination of reflective function beyond clinical contexts,

exploring its role in studies on stress, coping mechanisms, and in non-clinical populations (Schwarzer et al., 2022; Klementyeva, 2021; Zhou et al., 2023). These investigations have revealed a more comprehensive spectrum of reflective function associations, indicating its correlation with heightened resilience to stress (Zhou et al., 2023) and an increased capacity for tolerating ambiguity (Klementyeva & Ivanova, 2021). This broadened perspective contributes to a more inclusive understanding of reflective function, emphasizing its relevance not only in clinical settings but also in the broader context of individuals' psychological well-being and adaptive functioning.

This incorporation of reflective function into the discussion involving healthcare workers and patients in a vegetative state is not intended to pathologize, but rather to elucidate the impact of mentalization on end-of-life considerations. As the vegetative state inherently poses challenges, comprehending patients' mental states adds an additional layer of stress, necessitating a nuanced exploration. Exploring studies that delve into the role of reflective functions in non-clinical populations becomes imperative, as it may be considered an influence on perceived stress. Zhou et al. (2023) proposed that reflective functioning moderates the association between pandemic-related job stressors and adaptive/maladaptive cognitive regulation in healthcare workers. Their findings indicated that both hyper- and hypo-mentalizing contribute to psychological symptoms.

Schwarzer et al. (2022) contribute to recent theoretical frameworks, suggesting that mentalizing serves a protective function in non-clinical populations, aiding resilient adaptation to stressors. The study explores the relationship between self-rated coping behavior and mentalizing, emphasizing its imaginative ability to interpret behaviors in terms of mental states. Results support the hypothesis that robust mentalizing acts as a coping resource, mitigating the negative impact of stress and reducing reliance on negative coping behaviors. This underscores the relevance of strong mentalizing capacities in health psychology (Calaresi & Barberis, 2019), advocating for interventions to enhance mentalization.

Benbassat (2020) posits that the reflective function enhances the accuracy of perceiving intra and interpersonal realities, linking it to empathy and extending concern to broader circles. The concept encapsulates and fosters the intersection of psychology and ethics, highlighting psychologists' pivotal role in investigating factors influencing reflective function (Halfon & Besiroglu, 2020) and advocating for societal change.

This inquiry is directed towards comprehending how healthcare professionals engage in mentalization concerning individuals in a vegetative state and the resultant impact on their stress, grief, or perceived loss. As delineated by Seligman (2007), grief signifies a perceptible distance between oneself and one's objects, promoting empathy and prompting a cognitive reorganization that leads to the formation of new meanings. The transformative nature of grief facilitates the development of novel cognitive patterns, contributing to a more profound self-understanding and an enhanced comprehension of the experienced loss, as the reflective self-engages in interpretation and meaning making (Nerken, 1993).

Despite the absence of explicit research investigating the interplay between reflective function and nurses caring for individuals in a vegetative state, it is crucial to acknowledge that their experiences within this challenging context profoundly shape their approach to end-of-life matters. Nurses' perceptions wield a substantial influence on their approach to end-of-life care, as evidenced by studies in the field. Park et al. (2020) emphasize the crucial role of nurses' perceptions in the administration of end-of-life care (EOLC). Positive perceptions of death and favorable attitudes toward EOLC have been significantly associated with better nursing performance. The study highlights the challenges nurses face, including fear, uncertainty, and emotional exhaustion, which can compromise emotional support for patients and responsiveness to their cues. Additionally, nurses' performance is intricately tied to their perceptions of death (*ibidem*). Moreover, nurses' impact extends beyond patient care to influence broader life decisions and ethical considerations. Demyan et al. (2021) explore how healthcare providers' personal preferences can impact medical decisions, especially in guiding patients and families through aggressive interventions for EOLC. The study reveals that physicians may be unknowingly influenced by their preferences, as demonstrated in decisions regarding procedures like tracheostomy and gastrostomy. This raises critical questions about the factors guiding healthcare workers' recommendations for treatments they might not choose for themselves. Furthermore, Moaddaby et al. (2021) delve into the challenges posed by futile care and its impact on nurses. Despite technological advancements in extending lives, the question of whether these treatments truly enhance the quality of life remains. Nurses, being at the forefront of patient care, grapple with moral challenges associated with futile care, leading to stress, physical disorders, and emotional symptoms.

The study underscores the correlation between nurses' moral distress and their perception of futile care, emphasizing the need for explicit guidelines and organizational support to address these ethical dilemmas (*ibidem*). The multifaceted relationship between nurses' perceptions, moral distress, and the legal and organizational aspects of care highlights the complexity of navigating end-of-life decisions in healthcare settings.

The nuanced and emotionally charged nature of nurses' interactions with patients in a vegetative state significantly influences their reflective processes, especially when making inferences about the mental state of the patient. The absence of explicit communication from patients in this state poses a unique challenge, requiring nurses to rely on subtle cues, physiological responses, and their own interpretations. In this context, nurses may grapple with the uncertainty of whether the patient is consciously experiencing their surroundings, emotions, or perceiving stimuli.

Moreover, how nurses *mentalize* and make inferences about the patient's movements could impact their grief experience. In this landscape where research is yet to provide explicit insights, understanding and addressing the influence of reflective function becomes significant. Exploring these dimensions can offer valuable insights to optimize support systems, enhance coping mechanisms, and ultimately elevate the quality of care provided in end-of-life scenarios. Research exploring the specifics of these inferences and their emotional consequences can further enhance our understanding and guide the development of tailored interventions to support healthcare professionals in navigating this challenging environment.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1. University collaboration and research partnership

The present study originates from a collaboration with the I.S.A.C.C. nursing home, situated in the province of Vicenza. The facility provides eight beds for accommodating individuals in a Permanent Vegetative State. As stated in the regulations, admission to units for patients in a PVS is reserved for those individuals in a vegetative state and/or patients with minimal consciousness, clinically stabilized but at risk of complications, requiring high medical and nursing support. Admission to the ward is accompanied by a care plan aimed at maintaining clinical stability, vital functions, patient stimulation, rehabilitation for the prevention and treatment of secondary complications, pain assessment, complication prevention, responsiveness, and consciousness evaluation. These residents are provided with care, rehabilitative, nursing, and support services, along with psychological assistance for their families. The health and social care service also includes nurses, available 24 hours a day, who are responsible for health and social care assistance, and healthcare assistants, also available 24 hours a day, who address the residents' care needs through direct interventions.

3.2 Research questions

The research inquiry of this study aims to investigate the experience of vicarious grief and ambiguous loss among healthcare assistants and nurses employed at the I.S.A.C.C nursing home. Additionally, the study wants to explore the impact of reflective function on the understanding of patients' mental states and its consequential influence on end-of-life approaches and grief experiences when providing care for patients in a vegetative state. In the context of long-term care, particularly with individuals in a vegetative state, maintaining a neutral attitude is not always feasible (O'Conner-Von & Bennett, 2020). This is partly attributed to the empathic bond that develops over time (Ghaedi et al., 2020) with both the patients and their families. Consequently, healthcare workers and nurses may undergo experiences of grief due to the meaning of the relationships formed and their sustained contact with instances of mortality (Shi et al., 2022). The investigation of vicarious grief and ambiguous loss is thus central to this research, given the inherent

challenges faced by healthcare professionals in navigating such emotionally complex situations.

3.3 Research Design

3.3.1. Qualitative methodology

Embracing qualitative methodology as the reference framework, this research endeavors to unravel the layers of healthcare workers' experiences. The choice of qualitative methodology hints at a commitment to a nuanced exploration, allowing for flexibility in approach and the extraction of insights into the lived experiences, attitudes, and behaviors of participants. In accordance with Aspers and Corte (2019), qualitative research designs function as prospective plans aligning research objectives with the systematic collection and analysis of data, with the overarching objective of comprehending social phenomena through the lens of participants situated in authentic contexts. This methodology emphasizes adaptability, allowing for dynamic shifts in focus throughout the research trajectory to accommodate emergent discoveries (*ibidem*). Data collection techniques can comprehend interviews, observations, focus groups, and document analysis, with the researcher assuming a pivotal role as the instrument of data gaining (Mohajan, 2018). As underscored by Chai et al. (2021) and Roberts et al. (2019), qualitative research methodology finds applicability in the exploration of complex interventions, and the enhancement of practices within specialized domains such as healthcare.

3.3.2 Data collection: Semi-structured Interviews

In the pursuit of research objectives, the adoption of semi-structured interviews has been deemed suitable, given their recognized flexibility and extensive utilization as a method for qualitative data collection (Bearman et al., 2019). The reasoning for selecting semi-structured interviews in this study is, indeed, rooted in the overarching aim of comprehending participants' personal beliefs and experiences regarding their work with patients in a vegetative state. Semi-structured interviews are distinguished by a predetermined set of questions or topics, allowing interviewers the opportunity to probe deeper based on participants' responses, making them a widely used tool in qualitative research across diverse disciplines, including nursing, social sciences, and health services (Kallio et al., 2016). This methodological choice aligns with the research's focus on gaining insights into the subjective viewpoints of the participants. The development of a

meticulously crafted semi-structured interview guide is integral to the methodological rigor of this research. This process involves the identification of prerequisites, drawing from existing knowledge, and formulating preliminary questions, contributing to the objectivity and trustworthiness of the research (DeJonckheere et al., 2019). Semi-structured interviews offer distinct advantages, particularly in elucidating motivations, choices, behaviors, attitudes, and beliefs, often uncovering valuable information not initially anticipated by the researcher (Adams et al., 2015). This approach affords researchers the latitude to delve comprehensively into participants' experiences, perceptions, and opinions. The employment of this method underscores the importance of a comprehensive exploration of the dimensions inherent in the experiences and perspectives of healthcare workers dealing with patients in a vegetative state. The administration of interviews proceeded only after receiving approval from the Ethics Committee. The semi-structured interviews were conducted on the Zoom online platform, with duration ranging from 30 to 45 minutes. This time frame provided participants with the flexibility to delve into aspects they deemed important or urgent.

Participants were invited to reflect and share their experiences and reflections on the constructs investigated in the research. The data were provided directly by them and exclusively processed for purposes related to the conduct and dissemination of institutional activities, specifically scientific research within the project. Before participating in the research, participants received comprehensive information and signed an informed consent form. Participation was entirely voluntary, and interviews were recorded with the participant's consent. A singular interviewer conducted all interviews across the entire research duration.

The interviews were conducted in the Italian language and later translated into English for the purpose of this exposition. The interview explored experiences related to three main constructs: vicarious grief, ambiguous loss, and reflective function. The questions covered various thematic areas:

- General experiences of working with patients in PVS: an introduction with questions about their overall experiences of working with patients in a vegetative state, challenges, and emotions related to lack of progress or the management of patients' bodies in PVS. Example question: *"What are the most challenging*

moments you have faced in dealing with the body of a PVS patient with physical conditions such as hypertonia and/or deformities?"

- Handling the complexity of patients' ambiguous condition: an exploration of how they manage the complexity of the patients' ambiguous condition. Example question: *"Staying on difficulties related to emotions and sensations in your profession, how do you handle the complexity of the 'simultaneous presence and absence' of PVS patients? Hence, how do you try to maintain the connection and closeness with the patient despite their ambiguous condition of physical presence and psychological absence?"*
- Importance of emotional connection with patients: understanding the importance of emotional connection with patients, examining approaches used to cultivate relationships with family and patients. This was to strengthen the understanding of the relationship between emotional connection and the grieving experience. Example question: *"Let's talk about the importance of empathic connection in your work, and how crucial it is to build a bond and develop affection towards patients, to try to understand them better, considering the limited communication possibilities. Have you ever had experiences where you felt particularly connected or close to a patient or their situation?"*
- Exploration of reflective function: questions about reflections on the life and mental state of patients, and whether their work has had effects on their personal choices regarding end-of-life, such as future directives for relatives, or opinions on therapeutic obstinacy. Example question: *"Have there been moments when you perceived that a patient could recognize or respond to you in some way, even subtly? Can you share one or more examples of such experiences?"*
- Identifying support sources and coping strategies: identification of useful and relevant support sources, understanding personal coping strategies, assessing the effectiveness of professional support, and identifying opportunities for improvement. Example question: *"Your work may involve stress and emotional tension periods. How do you take care of yourself during these difficult moments, and what are your strategies?"*

This structure aims to comprehensively explore various dimensions of the participants' experiences related to the research constructs, ensuring a nuanced and insightful understanding of the topics under investigation.

3.3.3 Participants

The participants were recruited using snowball sampling, a purposeful method employed for hard-to-reach populations in qualitative research (Kirchherr & Charles, 2018). Snowball sampling is a non-probabilistic methodology involving the selection of cases through the relational networks of initially contacted individuals (Marcus et al., 2017). This approach effectively accesses vulnerable populations and facilitates scientific research and community-based data collection (Naderifar et al., 2017). It has been proven effective in recruitment across various domains, such as the case of nursing students during the Covid-19 pandemic (Leighton et al., 2021).

Nurses and healthcare assistants from the I.S.A.C.C. nursing home participated in the study. No specific duration of service in the PVS department was stipulated for participation, making it accessible also to individuals who were no longer engaged in the department but had previously operated for a period in the past. The research involved 13 Healthcare Assistants and 1 Nurse. Their professional experience in PVS varies significantly, with periods of time ranging from 3 months to 8 years. It is important to note that two of the participants, at the time of the interview, were working in other wards.

3.3.4 Data Analysis: Thematic Analysis

For the purposes of the qualitative data analysis, the research adopted Thematic Analysis (TA), a qualitative analytic method renowned for its exploration of themes and patterns in qualitative data (Braun & Clarke, 2006). The TA methodological approach finds application across diverse disciplines, including psychology, where it is recognized for its theoretical flexibility and accessibility (Buetow, 2010). The method encompasses systematic processes such as organizing, coding, writing, theorizing, and reading, ultimately culminating in the development of a comprehensive thematic schema (Tuckett et al., 2005; The Qualitative Report, 2022). The objective is to identify recurring patterns of meaning within the dataset. Following the guidelines of Braun and Clarke (2006), these main phases can be delineated: 1) Familiarization with the data, during which researchers observe and search for patterns of meaning and potential points of interest. It is crucial to

review the data multiple times in this phase. 2) Generation of initial codes, aimed at organizing the data into meaningful clusters. It is important to note that initial contradictions may arise, which should be carefully considered. If these contradictions appear to accurately represent the data, researchers proceed to the next step. 3) Once the focus shifts to the codes themselves, researchers begin a process of grouping. This phase involves interpretation and analytical decision-making. It concludes when codes have been grouped together, with unpaired codes either forming a separate group or being classified under an *ad hoc* category. 4) Finally, these groups are further clustered to create overarching themes that capture the complexity of the analyzed dataset. TA is a process which is ongoing, organic, and iterative (Swain et al., 2018).

The analysis was conducted in Italian and then subsequently translated into English. The use of thematic analysis unveiled distinct themes in participants' experiences with patients in PVS, enhancing the detailed exploration and comprehension of patterns within the qualitative data.

3.4 Results

The following paragraphs present the findings from the qualitative thematic analysis. As it was described in the previous chapters, the qualitative thematic analysis adopted an iterative/abductive approach, integrating both top-down (more theoretically oriented) and bottom-up strategies. After multiple readings of the 14 interview transcriptions (i.e., the familiarization phase), a total of 288 codes were identified. Later, the list of codes became the ground for analysis and efforts were directed towards grouping similar codes or those sharing common aspects into broader categories/clusters. A total of 21 categories/clusters were delineated. Through a process of thematization of these clusters, four overarching themes were refined:

1. **Coexistence of an ethical, occupational, and operational assessment of the PVS condition.** This theme encompassed the integration of the following subcategories: Patient humanization, Assessment of the patient's mental state, Uncertainty of beliefs, Gratifications of care, Personal ethical evaluation of the condition of SVP, and Death as a relief for the patient.
2. **Balancing Patient Bonds and Personal Life.** This theme encompassed the integration of the following subcategories: Importance of creating an empathetic

bond, The role of patients' family members, The impact of one's life story on bonds, The impact of caring for young patients, Consequences of an overly strong bond, and Attempting to separate personal life and work.

3. **Thriving Through Difficulties.** This theme encompassed the combination of the following subcategories: Challenges in interacting with patients' bodies, Communicative challenges in patient care, The role of the working group, Tips for improving the work environment, and Elements that impact work well-being.
4. **Personal Evolution and Reflections Beyond the Workplace.** This theme encompassed the incorporation of the following subcategories: Reflections on the lack of progress in patients, Reflection on how life changes after working in the SVP unit, Considerations on external perception of the PVS, and Personal strategies for managing emotional workload.

3.4.1. Coexistence of an ethical, occupational, and operational assessment of the PVS Condition

The present theme emerges from the convergence of various codes and categories, each helping to outline different assessments about the work in the PVS unit. These assessments stem from participants' narratives and are:

- Occupational Assessment, i.e., a process in which an individual reflects on what their job mandate entails and evaluates their efficiency in fulfilling these assigned responsibilities. According to the participants, in the PVS framework, it consists in providing care and quality assistance to the patients. Perceiving patients as *normal* individuals, and interacting with them accordingly, is significant for fulfilling their job's mandate. To do so, participants have emphasized their commitment to communicating with patients. When in contact with them, they clarify procedures, ask questions, demonstrating an engagement with the patient, regardless of the patient's responses.
- Operational Assessment, i.e., a process in which an individual examines and evaluates their skills and outcomes within the context of their professional assignment. This assessment aims to measure the effectiveness of their work. In this framework, it involves evaluating the signals of patients as proof of the effectiveness of their job. Signals from patients, such as eye movements or facial

expressions, are understood as indicators of an effective and good work. This evaluation is sustained by maintaining the belief that patients may comprehend their efforts. This type of approach with patients is important as their responses are interpreted as signals of good work and satisfaction derived from it. So, patient signals guide care but also provide gratification.

- Ethical Assessment, i.e., a critical and reflective examination conducted by an individual regarding moral and ethical principles. This process involves careful consideration of values and ethical norms associated with one's role and person. Participants develop an ethical evaluation regarding the prospect of living with PVS. In the realm of this assessment, they concur on the perception of death as a potential relief for patients burdened by PVS. Following their expertise in the field, they express a strong desire to avoid finding themselves in a similar clinical condition, occasionally formalizing advanced directives to forestall such an eventuality. Feelings of undesirability associated with life under such circumstances come to the forefront.

In the development of assessments of their work in the PVS unit, participants found it crucial to humanize the patients. Participants draw inferences about the patient's mental state through non-verbal signals like physical relaxation and smiles. There is, indeed, a consensus among participants that these cues represent understandable forms of communication. Even if there is a simultaneous questioning of these inferences, these latter retain significance as guiding factors in the assessment process.

The exploration of these assessments sheds light on the intricate interplay between operational, occupational, and ethical perspectives within the realm of SVP. The observed coexistence arises from the delicate balance required to navigate the professional, personal, and ethical dimensions when interacting with patients in this medical condition. The following text extracts serve as examples of the presented theme.

«From a nursing perspective, I try to provide comfort to them by monitoring signs and symptoms and relying on parameters. But at a certain point, it's also about understanding the person [...] if they're agitated, I try everything, but above all, I seek to understand and comprehend their needs.»

(Erica, Nurse)

In this extract, Erica highlights the importance of understanding patient needs, in line with the concept of humanizing patient care. The interviewee's approach of trying various methods to comfort an agitated patient, and, above all, seeking to understand their needs, aligns with the essential empathetic approach to fulfill the professional mandate of providing quality care and humanizing interactions with patients.

«I also notice how the person presents themselves to me because, anyway, with these people, while I'm with them, how can I say, I treat them as if they were normal, [...], I talk to them as if they were normal, I don't start talking about bolognese pasta because that would just make them crave it, [...]. I ask how they are, you know, just like if they were anyone else [...] And I do the thing of the eyes, I say... 'Close your eyes for me,' or 'let me understand that you are here with your eyes,' etcetera [...] maybe that closing of the eyes in that way simply had to happen, it wasn't a response to me, I can't presume it... but anyway, of the current vegetative states here, everyone understands, everyone does. Then, whether I'm right or not, no one can say, but anyway.»

(Sara, Healthcare Assistant)

In Sara's words, it is emphasized treating patients as *normal*, engaging in conversations and interactive tasks, aligning with the occupational assessment of providing care and quality assistance. The participant acknowledges the uncertainty surrounding the interpretations of patients' responses, highlighting the inherent challenges in assessing individuals in a vegetative state. Despite this uncertainty, the commitment to interactive and empathetic approaches remains a crucial aspect of their work, bridging the occupational and operational dimensions. This quote underscores the complexity of working with patients in a vegetative state and the balance between professional duty, personal engagement, and the uncertainty in interpreting non-verbal cues.

«However, the beauty is precisely that you can provide assistance even at the level of the soul, in quotes, right? Even with people who don't speak. You don't need to know what they have done, what they have suffered, what they

have rejoiced, right? They are there. And in that moment, you are there for them, giving your best.»

(Giulia, Healthcare Assistant)

Giulia emphasizes the profound nature of providing assistance beyond physical needs, extending to the level of the soul. The ability to offer support to individuals who cannot communicate verbally is seen as a sensible aspect of their work. The response expressed underscores the commitment to patient care, focusing on being present in the moment and giving their best, no matter what. This perspective aligns with the occupational assessment, emphasizing the dedication to fulfilling the job mandate, which goes beyond technical tasks and encompasses a compassionate and holistic approach to patient care.

«For example, a person who does not respond to direct eye contact, because these were the most challenging for me, and I had to perform a simple check. There, I would caress their head or cheeks, and I would see a bit of a gaze... the eye turning towards me, and it didn't seem just because they sensed movement, but it was something sweet that I saw in the person that made me feel like... "I like what you're doing." Or it happened to someone else who was very rigid and would curl up; I started massaging, gently caressing, and I saw them relaxing, and I could dress them more, and this made me happy, of course. It seemed that compared to before when I just did it, because technically I had to perform certain tasks, there was a connection with I don't know... I saw a return of my actions. Positive, clearly.»

(Sofia, Healthcare Assistant)

Sofia's words elucidates a distinction between the mere execution of caregiving and its execution through an approach centered on patient communication and on an endeavor to grasp their needs. This quotation sheds light on the occupational and operational assessments within the context of working with patients in a vegetative state. The approach of using gentle gestures like caressing and massaging is not only a part of the occupational assessment but also becomes a means for operational assessment. The participant perceives positive responses from the patients, such as the gaze turning

towards them or the person relaxing during the massage. This observation not only validates the effectiveness of their work but also contributes to their sense of satisfaction, forming a connection between the operational and occupational dimensions.

«They have very strong sufferings, so... at the moment of death, I'm somewhat thankful that it has come, because anyway, you realize... among colleagues who see each other every day, we would never want us to be like that.»

(Martina, Healthcare Assistant)

Martina expresses a kind of gratitude for the moment of death in patients in PVS, as it is seen as a relief from intense suffering. This reflects ethical considerations and a shared desire among colleagues to avoid a similar fate.

«Well, let's say that I have already made a living will because I have talked to my children and I have absolutely said no. Working in this field, seeing what the families go through, and what kind of life they lead, I said, no, let me go.»

(Monica, Healthcare Assistant)

In this extract of the interview, the participant, having worked in the field, has already filled a living will, firmly stating a preference against living in a vegetative state. This decision is influenced by witnessing the challenges faced by patients and families in similar situations.

3.4.2. Balancing Patient Bonds and Personal Life

This theme holds significant importance as it outlines two essential needs, as articulated by the participants. On one hand, there's the creation of a relationship with patients; on the other, the separation of the professional sphere from the personal one. As participants acknowledge the importance of building a strong connection to prevent work from becoming “mechanical”, they also recognize that such a connection entails unavoidable consequences. This requires the need to learn how to separate personal and professional life. Establishing a connection is often an inevitable consequence of the continuous and constant interaction between healthcare workers and patients. Participants highlight how caregiving involves ongoing contact throughout the day and over extended periods, given

that patients typically stay for prolonged length of time. These patient relationships can have various and intense emotional impacts. Various factors influencing the nature of this connection emerge in the interviews. Narratives elucidate the influence of participants' life stories and their present life stage on how they engage with and are impacted by patients. Instances are underscored where personal loss or the illnesses of loved ones affect the connection formed with patients. This intricate interplay is notably accentuated when patients, in some manner, evoke personal memories, thereby highlighting the relationship between participants' professional roles and their individual life experiences. The emotional impact sometimes impedes the separation between personal and professional life, intertwining personal matters with professional ones. The presence of family members is also emphasized as crucial. They give information about patients' histories, presenting an opportunity to better understand them and create a more tailored connection. At the same time, bonding with family members serves as an additional source of gratification—recognition of one's work from an external perspective. Another significant aspect emphasized by participants is the influence of the patient's age on the way they connect with patients and the consequences of this connection on the individual. Young individuals evoke intense emotional impact, and a stronger bond, often associated with memories of emotionally close figures, such as sons or daughters. In all of the instances presented, participants acknowledge that this deep connection entails inevitable consequences, such as discomfort and sadness. Consequently, participants delineate their acquired ability and the necessity to distinctly separate the private from the professional sphere, perceiving such distinction as essential for survival and personal preservation. Within the professional context, where distancing is imperative for the preservation of one's well-being, patients' family members are also encompassed. Participants often underscore the establishment of a connection with them, underlining the relevance of refraining from assimilating their sufferings. The following text extracts serve as examples of the presented theme.

«So, I treat them all truly as if they were my family because you have to consider that there are some who actually have family members coming to visit them, and others who have no one at all, I mean... At the thought of having to, in quotes, touch you, work on you because you're a piece of meat,

I pick you up, I move you. I'd rather go to the factory to work; that's how I see it [...] This is a small society because, anyway, these are people you see every day, live with every day, but also a bit like a family because, I mean, I'm here every day, I spend more time here than at home. Let's be honest.»

(Sara, Healthcare Assistant)

Valentina emphasizes treating patients like family, highlighting the importance of forging a personal connection in caregiving. By viewing patients as more than just cases to be handled mechanically, the participant acknowledges the significance of emotional engagement in their work. Their comparison of patient care to a small society and family underlines the immersive nature of their daily interactions.

«The difficulty is perhaps having too much empathy towards patients because, especially in the beginning of my experience... I brought everything home, I even dreamed about them at night, in the sense that I was too empathetic. So, I had to learn to have a proper detachment; then, over time... I'm not saying I have a complete detachment, but I had to learn to have a bit of a shield, so as not to... not take on all the patient's problems because it's not easy.»

(Asia, Healthcare Assistant)

This quotation reveals the participant's struggle with excessive empathy towards patients, describing the initial challenge of bringing work-related emotions home. The acknowledgment of needing to establish a proper detachment reflects the participant's awareness of the emotional toll of caregiving. The mention of learning to have a "bit of a shield" over time indicates the development of mechanisms to prevent overwhelming personal involvement in patients' problems. This insight underscores the necessity for healthcare workers to strike a balance between empathy and professional detachment for their own well-being. It highlights the ongoing process of self-regulation in emotional involvement, illustrating the participant's recognition of the challenges and the need for emotional boundaries in the caregiving profession.

«Like now, there is a girl who is the same age as my daughter, who is 19 years old. So, every time you enter, when you see this girl who is growing physically, but who is not there, it's a bit... It's uncomfortable. It's more discomfort. It's understandable, but maybe it is because I have a daughter of the same age.»

(Alice, Healthcare Assistant)

The discomfort expressed by Asia is not just professional but resonates with a personal connection, possibly intensified by the participant's own daughter being of a similar age. This quotation emphasizes the deeply emotional and sometimes challenging aspects of caregiving, particularly when personal experiences and connections intersect with professional responsibilities. It underscores the intricate interplay between a healthcare worker's individual life experiences and their roles.

«As I was saying before, it's hard to accept seeing a condition like this in adolescents. And even if they are not part of your family, you still feel emotionally affected.»

(Asia, Healthcare Assistant)

The participant highlights the emotional challenge of witnessing difficult conditions in adolescents, underscoring the impact on herself. The mention of the patients' young age underlines the emotional investment healthcare workers have with their young patients. This insight reinforces the interconnectedness of personal and professional emotions in the caregiving context, shedding light on the particular sensitivity involved when caring for young individuals facing PVS.

«Then there's also each of our own experiences and the specific moment of life. For example, I found myself having a bit of difficulty when my grandmother passed away, and in the ward, I encountered a person who had exactly the same issues as my grandmother and... the same difficulties because she too was at the end. [...] Because I tried to... “okay, it happened this way, let's close it, I have to restart my work, I have to be careful about

what I do”, and I found myself in the same situation. It was difficult at that moment. After the first few days, well, things got better. Because, anyway, I still had to process my grief, I couldn't... but more than grief, the suffering.»

(Martina, Healthcare Assistant)

Martina illustrates the challenge healthcare workers face when their personal experiences intersect with professional duties. Her difficulty in coping with a patient's situation mirroring her grandmother's highlights the emotional complexity of care in the PVS unit. This instance reinforces the theme of healthcare professionals needing to navigate the fine line between personal emotions and professional responsibilities. It emphasizes the continuous emotional processing required in healthcare roles, where personal grief and suffering may unexpectedly align with patients' conditions, demanding a delicate balance for caregivers like Martina.

3.4.3. Thriving Through Difficulties

This theme gathers various thematic clusters to explore challenges in patient care and factors influencing the overall work quality in the PVS unit. Through participants' narratives, the theme identifies the difficulties in care and those characteristics perceived by participants as easing these challenges within the PVS work environment. Testimonies highlight communication difficulties with patients and the nuanced interactions with their bodies, marked by specific struggles of assistance and often subject to rigorous care standards, encompassing non-verbal cues and airway management. It is emphasized how the presence of patients with conditions other than SVP in the ward's wing alleviates the workload. Within this contextual framework, narratives elucidate the impact of the working team, colleagues, and the organizational structure, including shift dynamics, on individual well-being both during and outside working hours. Participants underscore the indispensability of personal and character traits fostering resilience for effective functioning within this department. Notably, instances are recounted wherein colleagues, confronted with challenges, opted to exit the PVS unit. In pursuit of enhancing the work environment, participants advocate for the implementation of psychological support, and specialized medical and technical training tailored to the unique needs of patients in these conditions. Additionally, they propose dedicated meetings for sharing experiences with colleagues, under an expert supervisor, and targeted exercises designed to fortify

collaboration and encourage the overall efficacy of the working group. The following text extracts serve as examples of the presented theme.

«In a ward like ours, the SVP, there are basic needs, yes, and there's no doubt about that, but real assistance comes from the belly and let's say from the stomach up because they have issues specifically with the airways. So how can an operator... who is trained, of course, who knows how to do it, knows how to handle, knows how to position, anything you want. But it's not just that, because there are patients there with whom you have to communicate in a non-verbal language, right? Because if a resident makes a grimace or if I see them tense, not just the abdomen or shoulders, but especially in the face. I mean, you have to be able to read their language, right? Because that's all you have to work with... [...], it took me three months to get used to not being afraid to stay alone in the ward.»

(Giulia, Healthcare Assistant)

Giulia emphasizes the unique and intricate needs of PVS patients, particularly the challenges related to airway management and non-verbal communication. This highlights the specialized nature of care required in the PVS unit, underscoring the distinct difficulties that healthcare providers face in addressing these specific needs. Understanding and adapting to these challenges are crucial for maintaining a high standard of patient care in this particular setting. The quote adds a valuable perspective to the overarching theme by shedding light on the intricacies that make patient care in the PVS unit difficult and demanding.

«Then it compensates a bit with the other communicative patients, so there the brain disconnects a bit, and it's fine that way. Before, there was only an SVP nucleus, and there it was a bit heavier. And, having other communicative guests where you do... words, jokes, laughter, perhaps in a more... it seems not, but there it's more about compensating a void that you might only find with that type of patients.»

(Antonio, Healthcare Assistant)

The participant suggests that the presence of more communicative individuals in the ward serves as a form of compensation. The mention of "words, jokes, laughter" implies a more interactive and lively atmosphere that contrasts with the heavier emotional burden when dealing exclusively with SVP patients. This observation resonates with the section's exploration of the working environment and its influence on individual well-being. It implies that a diverse patient population contributes to a more balanced and emotionally fulfilling work environment for healthcare providers in the PVS unit. This insight highlights the potential benefits of such diversity in enhancing the quality of care and the well-being of healthcare professionals.

«So nowadays, my workdays vary depending on the workgroup. I mean, I have other thoughts compared to the guest in a vegetative state.»

(Asia, Healthcare Assistant)

This observation aligns with the theme's exploration of the influence of the working team, colleagues, and organizational structure on individual well-being.

The participant's comment suggests that the nature of the workgroup can significantly influence the emotional and cognitive aspects of the job. It underscores the interpersonal aspects of the work environment and highlights the need for a supportive and cohesive team to navigate the complexities of caring for patients in the PVS unit effectively.

«This is part of the character; it has nothing to do with the place because even with people who speak, I mean, even with the others, but then I see a return from people. It's not something explainable; it's something related to character, something personal. So, it also depends on how a person does this job, like all the others because, I repeat, every job has its passion.»

(Sara, Healthcare Assistant)

This quote underscores the participant's perspective on the role of personal character in performing the job within the PVS unit. By emphasizing that the impact is more about individual character than the physical environment or the nature of the patients, the

participant highlights the subjective and personal nature of the challenges and rewards associated with work. This aligns with the theme's exploration of personal and character traits fostering effective functioning within the PVS unit. It reinforces the idea that, beyond technical skills and patients, the intrinsic qualities and passion of healthcare providers play a crucial role in navigating the challenges and finding fulfillment in their roles within the PVS department.

«Always talk to the psychologist. For me, it's the person who can help us the most in facing it. We can also talk about this young girl, about some specifics of the guests, about some particular cases, about some guests in a vegetative state, maybe the psychologist can. For me, yes, it's a figure that could help us.»

(Elisa, Healthcare Assistant)

Elisa's narrative is relevant to the theme as it not only emphasizes the importance of psychological support but also provides insight into ways to enhance the overall work environment in the PVS unit. The participant's recommendation to engage with a psychologist reflects a proactive approach to addressing the emotional challenges associated with the job. By recognizing the potential benefits of discussing specific cases and guests in a vegetative state with a psychologist, the participant offers a practical solution that contributes to the well-being of healthcare providers. It reinforces the idea that fostering a supportive and mentally healthy workplace is crucial for effective functioning within the PVS unit.

3.4.4. Personal Evolution and Reflections Beyond the Workplace

This thematic area emerges from the convergence of various subgroups, highlighting significant shifts in the paradigm of thought concerning life, death, and life circumstances following the experience and employment in the SVP department. Participants have shared reflections on the evolution of the meaning attributed to daily matters in their existence, emphasizing the importance of living in the moment and appreciating the small instances of life. In some instances, this has led to a reluctance to plan for the long term, as the awareness that life can change suddenly has become central to their perspective. The lack of progress among PVS patients has prompted reflections underscoring the sense

of powerlessness that stems from it and the difficulty for outsiders to fully comprehend this condition. The recognition of life's unpredictability and the transformative experiences within the SVP unit have prompted individuals to adopt strategies that emphasize living in the present and managing emotional burdens. The strategies include activities designed not solely for distraction but also for fostering an appreciation of one's surroundings and self. These activities may encompass aspects such as self-care, engagement in hobbies, nurturing family connections, and fostering friendships. The following interview extracts serve as examples of the presented theme.

«And so, you really realize that life is nothing! Because, you know, today I'm here, working, going out...an accident, and I end up in these conditions. It makes you appreciate life more! Because really, a person like this makes you appreciate life more. And many times, I say, people get angry, people like that... but if they were to come to a ward like this and see what's here, maybe there would be fewer mean people, and there would be less... I don't know, yes, for me, yes, life has changed so much, it makes me see life in a different way.»

(Monica, Healthcare Assistant)

Monica highlights a profound shift in her perspective on life following her experience in the SVP department. The emphasis on the fragility of life and the unpredictability of circumstances is evident. The mention of an accident leading to a drastic change in conditions emphasizes the sudden and uncontrollable nature of life events. This text extract underscores the transformative impact of the SVP experience on one's outlook and the potential for increased appreciation for life.

«Sometimes when I'm out having certain conversations with acquaintances, friends, etc., I start making discussions that might go beyond, but I stop because I say, as they are not working in an environment like mine, they can't understand. But I've learned to live so much in the moment, I don't make plans for the next year, next summer. I live so much in the next 10 days, but I don't make plans that are too long. That's the only thing I always say because I have

a daughter who is 19 years old, and I always say, 'Take care, if this happens, you should do this.' 'Live, live! Try to live life to the fullest every day,' because life doesn't have... You should never count on anything. I live a lot in the moment. I try to behave well, do the best I can, always live in the present. Because seeing these things here makes you reflect.»

(Alice, Healthcare Assistant)

This participant's perspective echoes the theme of living in the moment and refraining from making long-term plans due to the experiences in the SVP department. The decision to withhold certain discussions with acquaintances and friends reflects a recognition of the potential gap in understanding between those who haven't worked in a similar environment and the unique challenges faced. The emphasis on living in the present and encouraging her daughter to do the same underscores the lasting impact of the transformative experiences within the SVP unit. This quotation further supports the narrative of a shift in mindset towards a more immediate and appreciative approach to life.

«More than anything, we think that we are nothing. I mean, I say I am nothing. Sometimes I get worked up over trivial things, and then I look and say, why am I bothering, why am I getting angry. On these things, I can think, sometimes you arrive home and say, who makes us go on? When you see these people, a whole life of work, a lifetime of making sacrifices, and they end up like this.»

(Giovanna, Healthcare Assistant)

This participant's reflection encapsulates a recalibration of priorities following their exposure to the challenges within the SVP department. The acknowledgment of feeling like "nothing" is a stark realization, hinting a sense of powerlessness. The participant's admission of occasionally getting worked up over trivial matters contrasts with the profound challenges faced by others, leading to a questioning of the significance of minor frustrations. The reference to individuals enduring a lifetime of work and sacrifices only to end up in difficult circumstances reinforces the theme of life's unpredictability and the potential for unexpected turns. This quotation highlights the participant's internal

reflection and suggests a shift towards a more grounded and appreciative perspective on life. But also a heightened awareness of the fragility of life.

«Sports are a lifesaver. Sports are a lifesaver, as you are outdoors, in the midst of nature, under the sun, in the fresh air. So, this is already an extra stimulus because it really energizes you. [...] Or some hobbies, reading, singing, music, playing the guitar, so for those things, I go smooth as oil.»

(Antonio, Healthcare Assistant)

Antonio's mention of sports as a "lifesaver" connects to the paradigm shift in the participants' perspectives, emphasizing the importance of activities that foster an appreciation for life. Engaging in outdoor activities, surrounded by nature and fresh air, reflects the desire to live in the present and find solace in the small instances of life. The reference to hobbies like reading, singing, and playing the guitar provides insights into the strategies adopted by individuals to manage emotional burdens, echoing the section's focus on transformative experiences within the SVP unit. These activities not only serve as distractions but also contribute to a broader approach of self-care and nurturing personal well-being. This quotation reinforces the idea that individuals are actively incorporating positive activities into their lives following their experiences in the SVP department.

CHAPTER 4

DISCUSSION

This chapter aims to examine the outcomes of thematic analysis in response to the research question, which focuses on understanding the experiences of Healthcare Assistants and nurses, when providing care for patients in the context of PVS. The research question investigates how participants experience contact and work with PVS patients and how this influences their experiences of losses. Through thematic analysis, four key thematic areas have been identified. They offer valuable insights into the emotional, professional, and relational aspects involved in providing care in the PVS unit. In the next section, we will delve into some of the findings considered important for this dissertation, trying to understand their possible application and implications.

Among the themes presented in the previous analysis, the participants' tendency to humanize patients emerges as of significant importance. Participants emphasized the value of seeing patients as *normal* people. This value has practical implications in their approach, as they strive to understand patients' signals to proceed in providing quality care. During interviews, participants underscored the importance of interpreting signals such as movements, gazes, and rigidity as crucial elements to guide their assistance effectively. This also serves as a form of communication with the patient, considered as a prerequisite for quality care. Communication plays a vital role in the interaction and relationship between healthcare workers and patients. This caring attitude aligns with existing literature on humanized care, which emphasizes the need to address not only clinical but also emotional and psychological aspects of patient needs (Sanz–Osorio et al., 2022). Humanized care involves recognizing and respecting the dignity of patients (Vaeza et al., 2020), emphasizing their worthiness and uniqueness (Buchini et al., 2014), along with a justice-based approach promoting equality among patients (Kadivar et al., 2018). Contact and relationship with patients are essential elements of humanized care (Riveros, 2020). The participants' interviews also revealed a connection between humanizing patients and the operational evaluation of their work. They consider patient signals as evidence of effective work, with a focus on the interpretation of non-verbal cues like eye movements and facial expressions. Existing literature supports this connection, showing that humanized management enhances satisfaction among nursing professionals (Min-xia, 2010), positively impacting overall health and work-related

responsibilities (de Castro et al., 2020; Suazo, 2020). The participants expressed a significant sense of responsibility, especially in situations where patients lack familial support and face isolation. This resonates with prior research on family caregivers of patients in PVS, where caregivers see themselves as primary interpreters of patients' needs (Cipolletta et al., 2016). The acknowledgement of these responsibilities could also clarify why participants consider it especially important to attribute significance to their role in interpreting patients' signals. Introducing this reference framework is deemed crucial because, despite the abundance of literature on humanized care, there exists a gap in addressing the specific context of the PVS unit. Investigating this gap could uncover factors and obstacles affecting the provision of humanized care, providing valuable insights into potential areas for improvement. This is especially noteworthy in this scenario, where clear signals for personalized care are limited and subjected to interpretation.

As central elements in patient care approaches, we consider it appropriate to gain a deeper understanding of healthcare workers' inferences about the mental state of patients in PVS. This process of understanding and attributing meaning to others' behaviour can be rooted in the capacity for mentalization, operationalized by the Reflective Function. Mentalization, as elucidated by Safiye et al. (2023), refers to the human ability to understand mental states. It entails grasping one's own and others' subjective mental states, encompassing the interpretation of reasons, causes, and motives behind events (Bateman & Fonagy, 2019). This ability impacts personality resilience and adaptive competences (Safiye et al., 2023). During interviews, participants emphasized the significance of recognizing patients' behaviors and attributing meaning to them. However, the clinical condition of PVS, as we have seen in the introductory chapters, is particularly complicated in terms of delineating patients' awareness of themselves and of the external world. Indeed, alongside the acknowledgement of patient signals as carrying meaning, doubts and uncertainties persist in the participants' statements. They pointed out the presence of uncertainties, acknowledging that they can never be certain whether a patient's movement is a reflex or a response. Nevertheless, they maintain a predisposition to interpret responses as meaningful. In this regard, two modes of mentalization would be interesting to explore in the research context: hypermentalizing and hypomentalizing. Hypermentalizing entails making excessive assumptions about intentional mental states

without critical assessment, resulting in overconfident adherence to one's perspectives (Zhou et al., 2023). On the other hand, hypomentalizing is characterized by uncertainty regarding the accurate appraisal of mental states, reflecting a lack of assumptions (*ibidem*). Understanding whether there is a tendency toward hyper- or hypo-mentalization among healthcare professionals dealing with PVS could represent a new and meaningful line of research to pursue. Free et al. (2023) emphasize the crucial role of health nurses' ability to mentalize in facing challenges in communication. Moreover, awareness of mental states is a dominant factor behind the resilience level of healthcare workers (Alici et al., 2022) and an important component of effective communication (Satran et al., 2020). Effective mentalizing fosters a balanced approach, enabling healthcare professionals to navigate the complex dimensions of their work. Understanding whether there is a tendency for hyper or hypo-mentalizing, or if there is a balance, is important for comprehending how healthcare workers in PVS units process the communication challenges of the clinical condition of PVS. To achieve this, evaluating the Reflective Function using tools such as the Reflective Functioning Scale (Fonagy et al., 2016) would offer the research more reliable results (Taubner et al., 2013).

When asked what they would do in a scenario resembling that of the patients, the participants showed reluctance towards the condition. They argued that it is not a meaningful life, and as a result, in many cases, they have already given instructions (*DAT, Disposizioni Anticipate di Trattamento*) to their families not to proceed with Artificial Nutrition and Hydration (ANH). This sentiment aligns with existing research suggesting that PVS is perceived as more unfavorable than death. People often prefer early mortality over enduring PVS (Gray et al., 2011; Graham, 2017). In accordance, participants do not perceive the actual demise of patients as traumatic; rather, it is seen as a relief from suffering. So, participants strive to provide humanized care when offering assistance, but when questioned about the clinical condition, some of them argue that there isn't much difference between life in a bed and death. These approaches are not contradictory, but we understand they may indicate a perceived ambiguity. According to Bird-David & Israeli (2010), patients in PVS exhibit a fluid, relational personhood fluctuating between presence and absence, causing confusion for caregivers about their ontological nature. This means that the approach to patients can change during the caregiving period, shifting from a perception of the patient's presence to absence. Indeed, the coexistence of

participants' occupation and operational assessment with an ethical one of patients could suggest a perceived ambiguity in their approach. This coexistence of presence and absence could fall within the experience of ambiguous loss, a psychological state arising from uncertainty in the presence or status of a person, wherein they may be physically present but psychologically absent, or *viceversa* (Kreutzer et al., 2016). Previous research on relatives caring for patients with consciousness disorders indicates that ambiguity regarding relational boundaries impedes caregivers' ongoing grief reactions and hinders their ability to integrate the loss (Zaksh et al., 2018). Coping with situations where the relative is simultaneously present and absent poses significant challenges (Giovannetti et al., 2014). The potential for healthcare workers to undergo grief experiences (Meller et al., 2019) makes this a promising area for exploration. Testoni et al. (2023) emphasize the relevance of studying healthcare workers' experiences of ambiguous loss, given their role as formal caregivers for patients (Ku et al., 2013). Given the unclear ontological state of PVS patients (Holland et al., 2014), further investigation into healthcare workers' ambiguous loss experiences holds promise for expanding understanding in this critical domain. To further assess these observations, using scales such as the new Ambiguous Loss Inventory Plus (ALI+) (Comtesse et al., 2023) would provide precise and reliable data.

If we move on the second theme that emerged from the analysis, titled “Balancing between Empathic Bond and Personal Life”, some reflections come to light. The empathic bond formed with patients holds significant importance in the overall quality of care (Font-Jimenez et al., 2019). According to the interviews with participants, the strength of this relationship varies based on different characteristics. When patients recall loved ones or are particularly young, the emotional connection that develops is much stronger. These instances can intersect, such as in the case of young patients for participants who have children of the same age. In these situations, participants reported emotions like sadness or distress for the patients or patients' parents. Imagining themselves in the parent's position in the case of young individuals or envisioning their loved ones in the patients' place can cause some suffering. Intense exposure to suffering and its daily routine, especially during challenging personal times, has been defined as problematic during interviews. These narratives lead us to consider how emotions or grief are often experienced vicariously. As Varga and Gallagher (2020) mentioned, vicarious grief can

be triggered by both vicarious and personal losses, meaning that the person empathizing is experiencing their grief while empathizing with the other. According to Jose et al. (2023), healthcare workers, while witnessing the sorrow of others, found themselves reawakening personal emotions, particularly when resonating with the grief of afflicted relatives. The study highlighted the resurfacing of memories related to personal losses and previous experiences of grief, intensifying the emotional connection with their patients (*ibidem*). Our participants' references to personal losses and memories of grief linked to contact with patients suggest the presence of vicarious grief experiences, especially when the individual had some unresolved grief. There is evidence that healthcare workers respond emotionally to patients' deaths and experience grief (Khalaf et al., 2018), and for this reason, there is a need for further investigation into this particular experience of grief. This could also suggest that contact with end-of-life situations may awaken or trigger vicarious or anticipated grief experiences. Further exploration is needed to prevent burnout associated with the emotional labour of nursing work, which involves managing the emotional demands of relating to patients (Delgado et al., 2017).

Connected to the consequences of a strong emotional bond, there is a highlighted need among participants to separate work from personal life. This separation is driven by the desire to preserve their well-being. Participants have learned to create a shield, indicating the profound impact of caring for patients in PVS, an impact that at some point requires detachment. This may signal a balance between engagement and detachment, crucial for coping with cumulative demands and losses in their work (Carmack, 2007). Participants describe how they have learned to make a clear distinction between work and personal life, suggesting that they are fully engaged while at work but leave patient care behind when off duty. We think it would be important to understand if this separation is really a valuable measure of the well-being of the workers. Indeed, participants spend a considerable amount of time at work. In this regard, it would be interesting to know if they consider work-related struggles less important and deserving of less attention just because they occur at the workplace. In a labor – based socio-economic system where the time spent at work is a significant portion of the day, the quality of interactions and emotions experienced should be considered. Participants themselves suggest meetings with colleagues and supervisors to improve relationships among them and to discuss the struggles and impactful patients currently in the PVS unit. As a result of working in the

PVS department, participants report a deeper appreciation for life's small moments and a willingness to live more fully. However, there is also a tendency to avoid making long-term plans. This could indicate a shift in how individuals assess their life perspective, possibly linked to feelings of powerlessness and limited control over the long-term outcomes of their lives. These consequences should be taken into account to better understand the work in the PVS unit and strive to improve the well-being of those providing care within it.

CONCLUSIONS

In conclusion, this study has tried to explore the experiences of healthcare assistants and nurses caring for patients in PVS at the I.S.A.C.C nursing home. The exploration delved into the realms of vicarious grief, ambiguous loss, and the influence of reflective function. Employing a qualitative methodology with thematic analysis through semi-structured interviews, the research exposed insights into the emotional, professional, and relational dimensions entwined in the provision of care within the challenging context of the PVS unit. The thematic analysis produced four primary themes, illuminating the coexistence of ethical, occupational, and operational assessments of the PVS condition; the delicate balance between patient bonds and personal life; thriving through difficulties; and personal evolution and reflections beyond the workplace. These themes provide a rich tapestry of understanding the complexities faced by healthcare professionals in navigating emotionally charged situations. While this study has contributed valuable insights into the experiences of healthcare assistants and nurses caring for patients in a PVS unit, it is crucial to acknowledge certain limitations that may impact the generalizability and exhaustiveness of the findings. Firstly, the study's sample size was relatively small, primarily comprising healthcare assistants, with only one nurse participating. This limited representation may not fully capture the diversity of perspectives and experiences within the healthcare workforce. Future research should aim for a more extensive and varied participants, including professionals from different healthcare disciplines (e.g., physiotherapists) and varying levels of experience. Furthermore, participants, perhaps due to the duration of the interviews, might have been inclined not fully opening up about the emotional challenges they face. Incorporating additional methods could offer a more comprehensive understanding of the emotional nuances over time. Additionally, this research was conducted in a specialized nursing home in the Veneto region, known for its healthcare system in Italy. So, as the participants were predominantly from a region with a robust healthcare system, the findings might not fully represent the challenges faced by healthcare professionals. Future studies could benefit from a multi-site approach, encompassing various regions and healthcare facilities to capture a more comprehensive view of the experiences of professionals providing care for PVS patients. As discussed before, future research should prioritize understanding healthcare workers' experiences of loss and grief, as well as the impact on their life perspectives while working in PVS

units. Their voices are essential and warrant attention, as they play a crucial role in our society's well-being. In summary, while this study has made steps in providing visibility to the experiences of healthcare professionals providing care for PVS patients, recognizing and addressing these limitations is essential. By doing so, future research can contribute to a more comprehensive and deep understanding of the emotional, professional, and relational landscapes of those dedicated to the challenging task of caring for patients in a Permanent Vegetative State. Moreover, as we conclude, it is imperative to emphasize the importance of valuing and acknowledging the crucial work of healthcare assistants and nurses, ensuring their well-being and recognizing their unique contributions within the broader healthcare community.

ACKNOWLEDGMENTS

I wish to take the opportunity to express my gratitude to the people who provided support and guidance throughout the entire process of the creation and writing of this thesis.

Firstly, I extend my sincere gratitude to my supervisor, Professor Ines Testoni, for her support, trust, and expertise in the field, which provided me with invaluable guidance.

I would also like to express my appreciation to Dr. Ciro De Vincenzo, my co-supervisor, for his extensive knowledge, patient guidance, and invaluable feedback. His contributions have significantly enriched this work.

Special thanks are also due to Dr. Adriana Frenda for her diligent coordination of meetings with the I.S.A.C.C. nursing home and her unwavering support throughout the entire process.

Lastly, I extend my heartfelt gratitude to all the nursing staff and healthcare professionals whose participation was indispensable to the creation of this study.

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