Social Science & Medicine 373 (2025) 118021

Contents lists available at ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

Making sense of absent-yet-present others: Representing the liminal vegetative state beyond life and death

Edoardo Zulato [a,c,*], Paula Castro [b], Carolina Silvia Quagliarella [c], Lorenzo Montali [c]

[a] Department of Psychological and Behavioural Science, London School of Economics and Political Science (LSE), Houghton St, London WC2A 2AE, United Kingdom
[b] Department of Social and Organizational Psychology, University Institute of Lisbon (ISCTE-IUL) and CIS-Iscte, Avenida Das Forças Armadas, 1649-026, Lisboa, Portugal
[c] Department of Psychology, University of Milano-Bicocca, Piazza Dell'Ateneo Nuovo, 1, 20126, Milano, Italy

ARTICLE INFO

Handling Editor: Alexandra Brewis

ABSTRACT

Clinically alive yet enduringly unaware, individuals in a vegetative state are caught in their transition between life and death. In turn, their carers struggle to signify the ontological and interactional dilemmas emerging from their liminal relations with an *absent-yet-present* other and their suspension in time. Drawing on social representations and liminality theories, this study investigates how relatives and professionals deal with these dilemmas. In doing so, the study focuses on the role of relations and time in signifying an *absent-yet-present other*. We analysed 65 semi-structured interviews with relatives (n = 35) and professionals (n = 30) recruited from five Italian nursing homes between February 2019 and September 2021. A discourse-oriented thematic analysis shows how carers de-anchor patients from dichotomous categories and temporalities (e.g., life/death, person/body, past/future), representing them as existing in an ontological paradox: *both/neither* and *and/nor*. The analysis also shows how carers deal with the dilemmas of interacting with a voiceless patient by engaging in collaborative identity work. On the one hand, relatives draw on – and share – memories from the patient's past to construct a 'new identity' and 'present' for their loved ones. On the other, professionals add 'clinical identities' rooted in medical characteristics and promote corporeal communication with voiceless patients. The study highlights how carers can signify their (shared) present, everyday caring activities, and deal with an only apparently meaningless situation by mobilising the patients' pasts and promoting a corporeal sociality.

1. Introduction

Following a severe brain injury, individuals may enter a *vegetative state* – a clinical condition in which they are *wakeful* but persistently *unaware* (West, 2014). Being *wakeful*, they retain basic life functions (e.g., respiration, digestion, sleep-wake cycles) and spontaneous reflexes (e.g., facial grimaces or shedding tears). Being *unaware*, they show no signs of experiencing themselves and the surrounding environment (RCP, 2020). In other words, while clinically alive, vegetative-state individuals are believed to be incapable of interacting with others.

This condition is often the unintended consequence of resuscitation and/or surgery to save an individual's life after brain-injury (Kitzinger and Kitzinger, 2013). When stabilised, individuals are moved to rehabilitation structures aimed at restoring awareness. If awareness is not recovered within six months, their state is then labelled as 'permanent', and they are moved to long-term care structures (e.g., nursing homes) (RCP, 2020). With the support of artificial hydration, nutrition, and contingent medical treatments, individuals can survive in this condition for a relatively long time; an average of 4–5 years, with survival beyond 10–15 years not being uncommon, and documented cases extending up to 40 years (Leonardi et al., 2013b). However, they do so without realistic chances of recovery (Donis and Kräftner, 2011).

In these care homes, vegetative-state individuals are caught 'in a technologically produced border zone between life and death' (Kaufman, 2003, p. 2250), enduringly suspended in time and paradoxically 'here and not-here' (Kitzinger and Kitzinger, 2014, p. 255). Thus, they are in a so-called *liminal hotspot* (Greco and Stenner, 2017), stuck in their transition towards death. They are not alone in this zone, with relatives spending a significant amount of time with them in the care homes and a multidisciplinary team of professionals (e.g., physicians,

---

* Corresponding author. Department of Psychological and Behavioural Science, London School of Economics and Political Science; Houghton St, London WC2A 2AE, United Kingdom.

E-mail address: e.zulato@lse.ac.uk (E. Zulato).

https://doi.org/10.1016/j.socscimed.2025.118021
Received 16 January 2025; Received in revised form 12 March 2025; Accepted 24 March 2025

nurses, physiotherapists, psychologists, social workers) accompanying both patients and relatives (Covelli et al., 2014). In this situation, family and professionals are called to engage together in the constant struggle of making sense of and dealing with an *absent-yet-present other*, their suspension in time, and their relationship with them. Besides, this also involves constructing their relations with each other (i.e., relatives-professionals), dialogically creating understandings of these individuals and of how to take care for them (Zulato et al., 2022).

However, these are not easy tasks, as the vegetative state makes hitherto highly shared meanings inadequate in conceptualising the person's state. As with most liminal hotspots, it does so by defying the adequacy of clear-cut meaning binaries – past/present, life/death, subject/object, and sick/healthy (Bird-David and Israeli, 2010; Zulato et al., 2022). Thus, relatives and professionals face ontological and interactional dilemmas (Motzkau and Clinch, 2017) about the nature of their relative or patient status and the everyday problem of interacting with a perpetually *absent-yet-present* other.

The scarce literature focusing on these dilemmas has so far mainly taken a descriptive, non-processual approach, and atemporal perspective, thereby neglecting how meaning-making is a processual and dialogical achievement realised in self-other relations (Marková, 2023). In other words, neglecting *how* and *what for* meaning and action in vegetative care are achieved in the threefold self-other relations between patients and their relatives, relatives and professionals, and professionals and their patients. Second, despite recent calls (Greco and Stenner, 2017; Power et al., 2023) and empirical work (Stenner et al., 2019) within social psychology, research has also neglected the role of time in constructing these relations. Drawing on Mead (1932/1980), Stenner and colleagues (2019) emphasise that the past is always subject to reconstruction, functional to sustain an emerging present and anticipate a foreseeable future. This is particularly relevant in the construction of the 'self', requiring us to constantly stretch 'back to the past and forward to the future' (Stenner et al., 2019, p. 183). Likewise, Power and colleagues argue (2023) that understanding present action requires examining how individuals envision their future (i.e., the future pulls action forward). Thus, despite these calls, many studies have treated all carers alike, neglecting that some of them are there as relatives and attend to a *person* with whom they share a past, while others are there as professionals, caring for *patients* they did not know before.

To address these lacunae, this paper analyses interviews conducted with relatives and professionals caring for vegetative-state individuals in Italian care homes. The Italian context is particularly relevant as – unlike in many other countries – patients' lives are sustained unless they have previously refused treatment in a living will. Currently, only 0.4 % of the Italian population has expressed their will, resulting *de facto* in the continuation of life-sustaining measures for most patients (De Luca, 2024).

Here, we look at how carers – in and from their different positions – construct meaning between self(s) and other(s), past and future, to represent, deal with, and act upon the dilemmas and paradoxes of a liminal situation. We are doing so by adopting processual, dialogical, and temporal ontologies, as offered by the theory of liminality (Greco and Stenner, 2017) and the dialogical approach to social representations (Marková, 2023; Moscovici, 1972).

2. Caring for an absent-yet-present other

The literature has so far mainly focused on the impact that caring for vegetative-state individuals has on carers' well-being, needs, and quality of life. Studies with relatives show how they experience a significant financial, physical, and psychological burden (Soeterik et al., 2017). Research also identifies a *prolonged grief disorder* among relatives, as their bereavement experience extends over time, isolating them from their social networks (Chiambretto et al., 2010). Likewise, studies involving professionals reported relevant rates of burnout and emotional exhaustion (Leonardi et al., 2013a; Pinel-Jacquemin et al., 2023). Moreover, studies show divergence between relatives and professionals, highlighting the need for improving practical support, information, and accommodations (Alimohammadi et al., 2023; Cipolletta et al., 2016).

In this way, most research has mainly taken a descriptive, non-processual approach, focused on the individual level. Less attention was given to investigating how relatives and professionals relationally make sense of the ontological and interactional dilemmas arising within the everyday of the care homes.

The few studies addressing these parcel out the vegetative state into different aspects, such as end-of-life decision-making (Kitzinger and Kitzinger, 2013), the construction of the patient's awareness (Nettleton et al., 2014; Zulato et al., 2022) and their identity (Bird-David and Israeli, 2010). Concerning identity, research shows how, for their relatives, the person can be the *same* – resulting from a shared past – and *a different* person – resulting from the changes in appearance and in their role in the caregiver's life (Covelli et al., 2014; Giovannetti et al., 2015). Moreover, ethnographic research (Bird-David and Israeli, 2010) evidenced that patients were contextually de-personified – at the diagnosis stage – and re-personified using personal life stories. Concerning awareness, studies showed how both relatives and professionals can shift between *organic* and *interactional* understandings of patient awareness (Edgar et al., 2015; Zulato et al., 2022). The former denies awareness, while the latter attributes it to the patient's bodily reactions.

In sum, despite bringing insights into identity and awareness, previous research did not fully consider dialogical and temporal processes leading up to the emergence of new representations of the vegetative state (see Andreouli et al., 2019). First, it neglects *how* and *what for* those representations are dialogically achieved in the everyday threefold 'dialogue' between *patients*, *relatives*, and *professionals*. This means that all carers were mostly treated as alike, without addressing how meaning-making is differently achieved within different self-other relationships. Second, even when addressing this with a dialogical approach, such as investigating how relatives and professionals mutually assign themselves duties, rights and roles in the wards (Zulato et al., 2022), research has left identity work regarding the patients underexplored. Third, research did not fully explore the role of time in making sense of this state. This could mean, for example, investigating the role that a (shared) past and an imagined future play in signifying the identity of an *absent-yet-present other*, their care, and 'suspended present'.

3. Theoretical framework: dialogical and processual perspectives

To address these gaps, we combine the dialogical approach to social representations (Marková, 2023) and the theory of liminality (Greco and Stenner, 2017). Dialogicality addresses how meaning-making about vegetative-state individuals is achieved from different social positions and within different self-other relationships. Liminality offers a temporal perspective and informs how transitions and liminal hotspots (i.e., stuck transitions) are understood and managed.

Social representations are shared systems of meanings – e.g., values, norms, practices – that allow individuals to make sense of and deal with relevant phenomena (Sammut et al., 2015), as the vegetative state. Initially, two main psycho-social processes were considered for the construction of these systems: anchoring and objectification (Bauer and Gaskell, 1999). Anchoring consists of making sense of new phenomena through already-familiar, shared meaning categories, as comparing the vegetative-state person to a 'zombie' (Kitzinger and Kitzinger, 2014). Objectification makes the abstract concrete, as reifying awareness in the image of 'brain activity' (Zulato et al., 2022). However, meaning-making does not occur in monologue, in a temporal vacuum, or in one direction only (Bauer and Gaskell, 1999; Billig, 1988; Zulato et al., 2023). First, meaning-making presupposes dialogicality, here conceptualised as the capacity to conceive, understand, and act in the world by considering the other's perspective (Marková, 2003). Thus, meaning is constructed in self-other relations, mediated through the never-ceasing dialogue with present and/or imagined ‘others’ (Marková, 2023; Moscovici, 1972). In this ‘dialogue’, meaning-making is achieved through imagining, considering, or dismissing the other’s perspective (Castro and Santos, 2020; Gillespie, 2008; Zadeh, 2017). These perspectives can be the ones of relatives and professionals but also the ones of the *absent-yet-present* individual they are caring for. Second, meaning-making involves memory of the past, but this memory is reconstructive (Stenner et al., 2019) and it also relies on projects individuals hold for the future (Bauer and Gaskell, 1999). Third, individuals do not only familiarise themselves with the ‘new’ by including it in old meaning-categories. Instead, they can reconstruct, revisit and challenge these inclusions when confronted by others or seeking change (Castro, 2019; Howarth, 2006). This can be done by de-anchoring and de-objectifying, namely uprooting social objects from specific social categories as relevant for meaning-making (Andreouli et al., 2019; Billig, 1988; Zulato et al., 2023).

This is particularly relevant in the case of transitions, in which social objects are moved away (i.e., de-anchored) from previous meanings, norms and practices (i.e., representation), but new ones are not yet in place. Liminality is precisely the *in-between* phase of transition betwixt representations: ‘no longer’ and ‘not yet’ (Stenner, 2021). Although liminality is an everyday aspect of life – as humans and their common sense are in ‘constant motion’ (Stam, 2011, p. 4) – some transitions get stuck and prolong over time. Here, an ontological paradox arises, in which the object at stake can be understood as *both/neither* and *and/nor* at the same time (Greco and Stenner, 2017), such as being both/neither alive and/nor dead simultaneously in the case of vegetate-state patients (Zulato et al., 2021). Moreover, this paradox creates a *paralysis* of both understanding and practice (Motzkau and Clinch, 2017). For instance, caring for vegetative-state patients leaves carers in a ‘suspended’ present where imagining any future is difficult (Chiambretto et al., 2010). However, the theory of liminality offers insights into how these paradoxes can be managed. The first is by *polarisation*, reducing its ambivalence by re-anchoring the object to already-known meaning categories, as re-representing the patient as either alive or dead (Edgar et al., 2015). The second is to create novel representations, capable of going beyond the binaries and inventing meaning categories, norms, and practices, namely a pattern shift (Greco and Stenner, 2017).

Thus, this article aims to investigate how family members and professionals dialogically make sense of – and potentially resolve – their liminal relations with an *absent-yet-present* other and their suspension in time. Drawing on the dialogical approach to social representations (Marková, 2023), as well as the processual and temporal ontology articulated through the theory of liminality (Greco and Stenner, 2017), we focus simultaneously on two aspects: (1) how families and professionals – from different self-other relations – deal with the ontological and interactional dilemmas posed by the vegetative state and signify *an absent-yet-present* other; (2) what role the past and future play in sustaining these carers’ everyday person/patient construction.

4. Method

Semi-structured interviews (n = 65; Age: 23–81; mean = 51.2) were conducted with 35 relatives, 19 healthcare professionals, and 11 mental health and social care professionals recruited from five nursing homes in Northern Italy (see Table 1). The demographics of interviewees align with the typical distribution of caregivers for vegetative-state patients in Italian nursing homes (Leonardi, 2010). The research was conducted in collaboration with *Samudra Insieme APS*, an organisation supporting families and professionals caring for patients with prolonged disorders of consciousness. Through this organisation, we contacted and met the directors of five nursing homes. All the directors agreed to participate in the project, signed a collaboration agreement, and granted us access to their nursing homes. Directors introduced our research to both family and professional carers during official meetings. Additionally, we posted a description of our research on notice boards in the nursing home common areas, inviting carers to participate voluntarily in the research.

Table 1
Participants’ demographic.

Informal Caregivers (n = 35)	n	%	Formal Caregivers (n = 30)	n	%
Gender			**Gender**		
Men	18	51.4 %	Men	9	30.0 %
Women	17	48.6 %	Women	21	70.0 %
Highest Education			**Highest Education**		
PhD	2	5.7 %	PhD	2	7.0 %
Tertiary	5	14.3 %	Tertiary	21	70.0 %
Secondary	22	62.9 %	Secondary	7	23.0 %
Primary	6	17.1 %	Primary	0	0 %
Relationship with Patient			**Profession**		
Partners/Spouses	18	51.4 %	Nurse	7	23.3 %
Children	10	28.6 %	Care Technician	6	20.0 %
Parents	6	17.1 %	Physiotherapist	5	16.7 %
Siblings	1	2.9 %	Psychologist	4	13.3 %
			Physician	3	10.0 %
			Music Therapist	2	6.7 %
			Social Entertainer	2	6.7 %
			Social Worker	1	3.3 %

Two semi-structured interview guides (see supplementary materials) for relatives and professionals were developed based on prior literature and research aims. Two psychologists working for *Samudra* and experienced with both groups reviewed and validated these guides. Interviews lasted an average of 92 min (range: 49–144) for relatives and 74 min (range: 32–150) for professionals. Three of the authors conducted all interviews between February 2019 and September 2021, and the Ethics Committee of XXX provided approval.

Interviews were conducted in Italian and transcribed verbatim. Transcripts were analysed using discourse-oriented thematic analysis, combining thematic (Braun and Clarke, 2006) with pragmatic discourse analysis (Batel and Castro, 2018). Thematic analysis identified the main representational content constructed around the vegetative state, following Braun and Clarke’s (2012) six-phase procedure. This process involved inductively (i.e., bottom-up) coding segments of the corpus and organising them into themes (Joffe, 2011). Coding was conducted using NVivo. Additionally, pragmatic discourse analysis examined the dialogical processes through which these themes were constructed (Zulato et al., 2023). Within the coded segments, we applied a deductive (i.e., top-down) approach to identify the role of temporality (e.g., past, present, future), psycho-social processes (e.g., de-anchoring), and self-other relations (e.g., use of pronouns) in re-constructing the patient (Batel and Castro, 2018). Then, we analysed the relational functions and consequences of each content from the perspective of each self-other relation: relative/professional-vegetative-state individual, and relative-professional. Thus, compared to other analytic procedures, discourse-oriented thematic analysis allowed us to move from a merely descriptive account of carers’ experiences (Batel and Castro, 2018). During the process, the research team discussed codes, themes and perspectives, making reformulations by consensus.

5. Analysis

The analysis identifies similarities and differences regarding how families and professionals – from different positions – signify the vegetative state. These cut across four themes, each accounting for different features of *liminal hotspots* (Greco and Stenner, 2017).

Regarding ontological dilemmas, the status of the vegetative-state person is similarly represented by both relatives and professionals as paradoxically *absent-yet-present* and stuck in their transition towards death (themes 1 and 2). Thus, the vegetative state is de-anchored from the (often) dichotomous meanings and temporalities used to make sense of the person – such as life/death and past/future. Regarding the interactional dilemmas (theme 3), carers represent vegetative-state individuals as *voiceless other(s)*, unable to engage in purposeful communication; with different relational implications for relatives, and a pragmatic one for professionals. In this context, professionals share their expertise with relatives to interact with patients through body-based communication. Moreover, both types of carers overcome these dilemmas by engaging in 'identity' work (theme 4). Relatives create a 'new identity' and a 'new present' by drawing on memories of the person's past identities to guide interaction with them (i.e. identity bricolage). Professionals ascribe patients a 'clinical identity' based on their clinical characteristics and can also access a (self-other) mediated version of the patient's past through the relatives' accounts. Thus, identity emerges through a dialogical interplay – relatives provide past references and professionals combine these with clinical characteristics.

Here, we present a detailed analysis of the abovementioned contents and processes. In the following extracts, the use of italics highlights the central content of our analyses, whereas the use of bold highlights its processual elements, such as temporal elements and those illustrating dialogical aspects. The quotations presented follow good practice in doing qualitative analysis (see Batel, 2020); namely, the extracts presented aim to be the most paradigmatic of interviewees' accounts. The extracts reported in this article were first translated from Italian to English by the first author and then reviewed by all authors to ensure equivalence of meaning.

6. Theme 1: Upsetting dichotomous categories

In dealing with the ontological dilemmas, relatives and professionals compare the patient's present state with their past. As a result, they converge in representing vegetative-state individuals as not fully a person 'anymore': neither aware nor fully alive and – for their relatives – no longer the same. Yet, being 'still' alive in a biological sense, they are depicted as paradoxically preserving residual personhood. Extracts 1 show how carers partially de-anchor these individuals from traditional categories (e.g., 'life', 'person') for making sense of humans, as not so helpful in this case. At the same time, they anchor vegetative-state individuals to de-personifying categories and images (e.g., 'body', 'vegetable'), signifying a living but unaware state.

Extracts n.1

(a) Partner 18: **He** is in a state in which the *brain* ***stops*** *working* in the area controlling *awareness.* Therefore, *all* ***he*** *can do, is not caused by his will* **anymore.** Moving, opening ***his*** eyes, waking up… is **no longer** due to ***his*** will, but *it's a body that* ***continues*** *to go on by itself.* (Woman, 50)

(b) Physiotherapist 3: **It's still** a *person* who is *living* in the sense that ***they*** *have a pulse.* However, sometimes you feel that *it's just a body*, that *it's there*, that it's *vegetating*, that *it's alive, but alive only in the sense of vital signs.* Because *real life* is more… precisely, *it means there is an interaction.* The image of a *vegetable* describes this situation well. (Man, 44)

(c) Partner 3: *It's an absence in the presence*, you remain attached to *this life* that **goes on** like this, *that can* ***no longer*** *give you what* ***was*** *there* ***before*** (Woman, 44).

Breaking the correspondence between an organic and a social life, vegetative-state individuals are represented as living in an in-between and paradoxical state where they are simultaneously *both/neither* and *and/nor*: neither fully alive nor dead, neither fully present nor absent, neither a body nor a person.

From a dialogical perspective, it is also noteworthy how these interviewees use the vocabulary of the *other* – the relative resorting to the medical vocabulary (e.g., the brain 'area controlling awareness') and the professional calling attention to the social dimension (e.g., 'interaction') as core to human life. There are also dialogical differences, as professionals – caring for multiple patients – tend to generalise (e.g., 'they', 'patients'), while relatives – caring for a loved one – personalise their comparisons (e.g., 'she').

Moreover, knowing who the person was, relatives compare the patient's present with their past personality, values, and actions. Therefore, only relatives mention discrepancies between the patient's past and present identity. For instance, occurring physical changes after the acute event, coupled with contrasts between the current state and their former self, lead relatives to represent their patients as having lost their identity.

Extracts n.2

(a) Partner 3: Because *my* husband **was** full of life, ***he*** **was** an ibex always in the mountains, ***he*** **was** a daily runner, ***he*** read a lot, I **talked** to him a lot, **we talked** a lot. […]. Because the *real person is not what you see in the wheelchair or on the bed.* (Woman, 44)

(b) Partner 5: If ***she*** was truly conscious, ***she*** *would not accept it*, ***she*** would not accept it. Knowing *the dynamic person* ***she was before***, ***she*** *would not want to* face such a situation. (Man, 68)

(c) Child 7: The impact was devastating because ***I didn't recognise him***…[…] ***he's*** a fairly thin *man* and so seeing *him*…as if ***he*** **was** a 100 kg *person*, I said: '*That's not* ***him***'…***I recognised him*** by the hair on his chest and the *complexion of* ***his*** *skin.* (Woman, 46)

In Extracts 2, family members struggle to recognise individuals who are now physically different (Giovannetti et al., 2015) and cannot live according to their past ways. The role of the present-past comparison is further highlighted by the word 'recognising', underscoring how temporality and relation contribute to identity. Re-cognising involves a dialogical relationship in which the *other* acknowledges someone's identity (Amer and Obradovic, 2022), but – here – it also involves a reconstructive comparison between the past-person and the person now seen (Stenner et al., 2019).

To make sense of these changes, relatives anchor the vegetative state to more familiar clinical conditions associated with loss of self, such as Alzheimer's disease: '*He* does *not have his identity anymore*, like an *Alzheimer* in an advanced stage…where you don't **recognise** the patient **anymore**' (Child, 4; Man, 52). These words further exemplify how relatives conceptualise the vegetative state as a condition leading to the irrevocable loss of the ability to reproduce and perform a sense of self and – consequently – to receive recognition from significant others. In turn, without direct biographical knowledge, professionals cannot make these detailed past-present comparisons. Therefore, these extracts dealing with recognition and identity are specific to relatives.

In sum, upsetting the shared and mutually-exclusive meaning categories (e.g., life/death, presence/absence, body/person), the vegetative state raises a paradox. This paradox stems from a 'social death' occurring in the absence of an organic one. Thus, carers represent the vegetative state-relative/patient as *absent-yet-present* others. This paradox is doubled for their relatives, as they deal with someone who is both the 'same' and 'different' person simultaneously.

7. Theme 2:Stuck in transition

A further way of dealing with the ontological dilemma is to focus on the present-to-future comparison. As a result, participants represent the patient as being 'not yet' what they could be: neither recovered nor dead yet and unlikely to transition to either state soon. In other words, carers converge in representing the patients as stuck in transition, forced to a liminal hotspot where the process of dying is indefinitely prolonged. For family members, this means they are also in the same hotspot, as shown by Extracts 3.

Extracts n. 3

(a) Partner 3: It's a feeling of waiting, *a* ***waiting*** *room*, that's it, that's it! […] A waiting room, ***waiting*** *forever*, waiting for whatever is to come, and *you* don't know if it **will** ever come. (Woman, 44)

(b) Partner 2: It's **never-ending** *mourning*, **renewing** every day. *You* **never** come to an **end** (Woman, 52).
(c) Child 3: *It's almost like you go into a coma too* […]. I focus too much on **my father's** problems, and *you* exclude everything else: family, daughter, friends... (Man, 46)

In this hotspot, described as a 'never-ending mourning', relatives struggle to move forward or imagine an alternative future; as the chances of recovery are described as unlikely ('you don't know if it will ever come'). Thus, they are also caught in transition and portray their life as suspended in the present. For instance, as also found in other studies (Cipolletta et al., 2016), relatives refer to the struggle to detach from their caring duties and the difficulty in returning to normality, such as meeting friends or dedicating to hobbies.

Moreover, these extracts show the centrality of inner dialogue for meaning-making (*self-as-the-other*) (Gillespie, 2024). This is present in Extracts 3, where the 'You' refers to the self talking to itself and – then – reflecting on a difficult situation.

In turn, professionals – witnessing this time-suspension from the outside – converge in representing this state as a stuck transition, but with a different dialogical dynamic. As illustrated in Extracts 4, they reflect on the other's ordeal of stuckness.

Extracts n. 4

(a) Psychologist 3: […] ***They*** stay in this *limbo*. Instead, if the person dies, it's true, it's bad, it's dead, it's gone. However, there is that ***closing*** *of the rite of passage*. (Woman, 38)
(b) Music therapist 1: ***Their*** **life has frozen** and so I mean ***they*** *are* ***standing*** there. (Woman, 50)
(c) Social worker 1: ***You*** *clock out and go home*, but at the end of the day, ***these*** **wives**, **husbands**, **children**… ***Their*** frustration and pain are **ongoing** (Woman, 44).

'They' and 'their' are the pronouns that present dialogical centrality here. At the end of their working day, professionals go home and continue with their lives. It is the *others* (relatives) who remain stuck. Moreover, professionals also implicitly acknowledge the role of medical intervention in sustaining this limbo for many years (e.g., 'closing of the rite of passage').

In sum, while in the previous theme carers partially de-anchored vegetative-state individuals from what they used to be, here they only partially anchor them in what they could become. As with liminal hotspots, vegetative-state individuals are recognised as enduringly stuck in their transition, not 'anymore' and 'not yet'. Thus, with their differences, carers re-present the vegetative-state patient as upsetting past and future, occupying a much more ambivalent meaning space regarding this temporality: a suspended present. Again, this limbo is narrated differently within two relational frames. The one of professionals who witness this suspension from the outside, and the one of relatives who are part of it.

8. Theme 3:An Other without a voice

Individuals in a vegetative state also pose interactional challenges for their carers, as they cannot speak or provide any direct feedback: an *Other without a voice*. This raises distinct challenges for different carers. For professionals it raises the practical problems of understanding the patients' needs, the outcomes of their care, and whether their actions are legitimate.

Extract n. 5

(a) Nurse 7: *Patients you can't have a* ***dialogue with*** […] To understand what ***they*** *have is not easy*. Because it's like *dealing with* ***animals*** that you *have to* ***try to understand*** *when there is something wrong*. Here it's the same…*you have to try to understand when* ***they*** *are suffering*. (Man, 49)
(b) Psychologist 4: A piece of *authorisation is missing*, that is, if the ***patient*** wants your help […] In my opinion, *it's an important piece of legitimacy*. (Woman, 36)
(c) Physician 3: With ***them***, of course, *verbal communication is not there*. Although ***they*** still have **their** own way of **communicating.** Not thoughts, but *well-being or discomfort*, with the *body they* **communicate** it well (Woman, 43)

Extracts 5 show professionals' struggle in assessing the validity of their care. First, they refer to the need for constant monitoring of the patients, as they cannot communicate their needs or physical problems (e.g., 'you have to try to understand'). Second, the absence of a patient's request is represented as the lack of consent and, by extension, legitimacy to provide care. Third, the lack of feedback makes it impossible to understand whether patients appreciate caring practices. So, the body becomes the main instrument to assess the patient's well-being (e.g., 'with the body *they* communicate it well').

Families, in turn, are more oriented towards relationships, still concerned with understanding the person's needs and with ensuring the interaction is pleasant for them. They seek clues that the individual might be comfortable or enjoying certain activities, and – while having continuous doubts – they also may feel they interpret them well, like with new-born babies.

Extract n. 6

(a) Partner 5: I think music could be very good for **her**, but I'm not sure about that. If **she can't answer you***, you don't know if it's because* ***she*** *liked it or not*...because the one who really *should be happy* is ***her***, but ***she*** **can't give you an answer.** (Man, 68)
(b) Parent 5: It's like when you have a *new-born baby* […] When the baby cries, ***mom*** *knows* if they *cry because they are colicky, or they are hungry, or they want to be cuddled*, it's the same with them. (Man, 57)
(c) Partner 3: *The olfactory* ***stimulation***, I make ***him*** feel *smells*, I do that too. For example, I take the tangerine peel and *make* ***him*** *smell it.* I do these things a lot. (Woman, 44).

Thus, the absence of feedback also makes it difficult for relatives to assess the outcomes of their practices. However, they refer to their privileged relationship with the person, alluding to the fact that they can infer what they are communicating to them (e.g., 'mom knows'). It is not a case that, rather than anchoring the vegetative state to 'animals' or other patients, relatives referred to 'new-born babies' (Covelli et al., 2014).

Moreover, they engage in sensory stimulation – deploying the five senses – as a means of transmitting any contact to the patient, being a relevant relational goal for them; as in the words of a daughter: 'So, to make her understand that I am here, I caress her' (Woman; 41). Together, these strategies help overcome the difficulties of interacting with a voiceless patient.

In sum, carers face different concerns when interacting with a *voiceless other* and engage in peculiar body-based communication to serve different pragmatic purposes. Through the body, professionals interpret the degree of comfort/discomfort of the patient (e.g., bodily reactions as feedback) and – in turn – get a sort of feedback from the patient (i.e., liked or disliked activities). Likewise, recure to physical contact to transmit their presence to the person and establish a relationship with them. This is achieved through the mediation of professionals who share their expertise with relatives and thus mediate this self-other relationship. For instance, every nursing home officially promotes stimulation activities and protocols to engage with the patient through a corporeal sociality, as in the words of Social Entertainer 1: 'We developed these *sensorial fairy tales*. We took Rodari's tales and *transformed their text into different senses*. And this became a way to *allow* ***communication*** between these children and their father' (Woman, 44).

Altogether, these extracts show how meaning-making efforts are placed within self-other relations. These relations are between carers but also with a voiceless, *absent-yet-present* other whose perspective is almost impossible to take or imagine (Marková, 2023). Nevertheless, the relative/patient is part of the dialogical meaning-making effort. Finally, this theme stresses how liminal hotspots *paralyse* any definitive understanding and social action (Motzkau and Clinch, 2017), but also favours the emergence of novel practices, as in the case of a 'peculiar way' of communication using the body as a medium. Thus, through the knowledge shared by professional roles (e.g., music therapists, social entertainers, psychologists), carers can construct a new form of 'sociality' that overcomes verbal communication, namely a pattern shift (Greco and Stenner, 2017).

9. Theme 4: Identity bricolage

Likewise, rather than passively witnessing this paradox, carers actively engage in identity work to reconstruct the patient's self through everyday caring practices. Again, this is achieved within two different self-other relationships. First, in the case of relatives, this is done by re-socialising the patient, maintaining their physical aspects, and mobilising their past into the present.

Extract n. 7

(a) Parent 4: **When** it's ***his*** birthday, I bake sweets and *invite everyone* here to eat. These are **events** that ***we*** celebrate (Woman, 61).
(b) Partner 7: Last night I was telling ***him*** that Juventus lost. In short, *I keep* ***him up to date*** *on everything. I* ***updated him*** *on* becoming a grandfather, because in December **he has become** a grandfather but…but I try to show ***him*** the pictures, I tell ***him*** about the baby. In short, I try to inform ***him.*** (Woman, 55)
(c) Parent 5: ***Her*** sister, who works as a cosmetician, often gives **her** a *manicure* and a *pedicure*, so ***she*** is always *tidy and beautiful* (Man, 57)

Extracts 7 show that relatives actively kept the patient inserted in a set of social relationships (e.g., 'I invite everyone') and updated about the significant matters concerning their life: 'he has become a grandfather'. Again, this involves temporality as suggested by the expression 'keeping up do date'. Thus, informing the patient – often in an I-You dialogue format ('I was telling *him* that') – allows us to unstuck them from a 'suspended present' and re-attune their life to the pace of others. In this way, the person can be re-inserted within their social network and – in turn – re-personified. This attempt is also institutionally promoted by organising various social activities – e.g., music therapy – and hiring professionals with relational expertise, such as social entertainers trying to overcome the patients' 'social death' (Social Entertainer 2).

As shown by Parent 5, relatives re-personify their loved one also by caring for their physical aspect (e.g., 'manicure', 'pedicure'), or – in other words – by maintaining their face (Goffman, 1959). For instance, for relatives, keeping the patient in good shape and good-looking is paramount. In turn, this practice also aims to maintain the patient's dignity, as further stressed by partner 11: 'those are small things to maintain his dignity' (Woman, 69).

Lastly, relatives also actively mobilise the patient's past identity and – in turn – use this as an interactional guide with a voiceless patient.

Extract n. 8

(a) Partner 2: Shirts, photos, panels with family pictures, with friends, with ***our*** children, of **his** cycling group. *It is all hanging in the room* (Woman, 52).
(b) Child 4: ***She was*** *always passionate about politics* and so **she *would read*** *the newspaper* 'Il Foglio'. So, I **now** come here with this, I read ***her*** articles […] Or there is a program on television that I *feel* ***she liked*** *more than the others*, which **she usually watched.** When I'm about to leave, maybe I'll show ***her*** the first part of 'Otto e mezzo'. (Man, 45)

Extracts 8 show the twofold function of this past, providing relatives and others (i.e., professionals) with the patient's biographical background and clues for interaction with the patient. It is not a case that relatives make this background visible, reified in frames, photos, and other objects. In this way, professionals' access to the patient's identity is mediated by the professional-relative dialogue, as exemplified by Music Therapist 1 (see extract 9). Moreover, besides the biographical elements they can get from relatives, professionals mainly represent the patients' identity in terms of their clinical characteristics.

Extract n. 9

(a) Nurse 3: Every *patient* has ***their*** *own* ***story*** and, therefore, **it requires time to know *them.*** There are some who do *not urinate* for a whole day and ones whose *temperature easily goes up;* just one actually. Thus, when ***he*** has a temperature, or ***he*** does not urinate, *you know how to solve the problem*, but you get to know ***them* over time.** (Man, 44)
(b) Physiotherapist 5: *There are heavier patients than others. Those* who have more secretions, ***they*** are *heavy* because you must clean ***them*** often (Man, 31).
(c) Music therapist 1: *I start with an interview* [with the relative]. *I ask* ***them*** the patient's **musical history**, where they come from, whether ***they*** **liked** listening to music […] I ask about *hobbies*, about what the ***patient*** **used to do** (Woman, 50).

Extracts 9 show how professionals managed to know – clinically – each patient over time and – in turn – divide them into 'good' and 'bad' (Bird-David and Israeli, 2010) based on the struggle they face when taking care of them. Thus, unlike relatives, most professionals constructed identities in more practical terms and did so over time. For instance, the patient's identity mainly emerges from the medical interaction with the patient, and – simultaneously – it is reconstructed from the relatives' accounts. These offer a practical interactional guide to direct their professional activity. Again, this stresses how relatives and professionals are inserted in different dialogical frameworks, here characterised by different relational timing. The former have a broader knowledge of the patient, not starting from scratch. The latter, lacking a shared past, dialogue with both the patients and relatives in the attempt to do identity work.

In sum, carers differently re-present the relative/patients beyond the alive/dead dichotomy, again realising a pattern shift (Greco and Stenner, 2017). Relatives do so by creating a 'new present' from their memories of the patients' past practices and ways of being to re-socialise them and guide interaction with them. Professionals construct patients' identities by drawing on their clinical characteristics and defining them as 'good' or 'bad' patients – giving them a clinical identity. In turn, they draw on relatives' stories, who mediate their knowledge of the patient. Thus, this pattern shift is achieved in a threefold self-other relationship between relative/professional-patient and relatives-professionals.

10. Discussion

This study highlights how the vegetative state is represented through a threefold self-other relationship involving vegetative-state individuals, their relatives, and professionals. We added to the existing literature by bringing processual, dialogical, and temporal perspectives of the vegetative state.

Using a temporal approach (Greco and Stenner, 2017), we showed how seemingly intractable dilemmas around ontology emerge through comparisons of past-present ('no longer', 'not anymore', 'still') and present-future ('not yet'). Our analysis showed how carers de-anchor the vegetative state from the conventional binary meaning categories (e.g., alive/dead, present/absent, person/body) and temporalities (e.g., past/present/future), re-presenting these relatives/patients as in a paradoxical condition (e.g., an *absent-yet-present* other and suspended in the present). This corroborates previous studies documenting shifting and ambivalent understandings of vegetative-state patients (Edgar et al., 2015; Zulato et al., 2022), but we read this through liminality theory (Greco and Stenner, 2017). With this, our analysis first highlights how liminal hotspots raise paradoxes and upset mutually-exclusive meaning categories, norms and practices. Second, it supports previous evidence on liminality, further showing how liminal experiences often originate through comparing the present situation with the past (Karataş and Balas, 2024). Our findings also show how the vegetative state can trouble carers' action (Motzkau and Clinch, 2017) – as their interaction with a voiceless other prevents them from receiving feedback for their caring practices. While prior research has linked this evidence to challenges in end-of-life decision-making (Kitzinger and Kitzinger, 2018; Zulato et al., 2023), we inform on its impact on everyday, mundane interactions within the nursing home setting.

Moreover, unlike previous research identifying polarising strategies (Zulato et al., 2023), our analysis also informs on how carers manage ontological and interactional dilemmas through a creative re-signification process, namely a pattern shift (Greco and Stenner, 2017). Carers collaboratively de-paradoxify the vegetative state – by multiplying otherwise binary categories – life and death – and doubling them into a social and organic life/death. Hence, they manage to contrast an otherwise 'social death' through a newly emerging sociality. This sociality is scaffolded by sharing and recurring to meaning resources, tools, mediums, or technologies, so-called 'liminal affective technologies' (Stenner and Greco, 2018). First, family members create a 'new present' and 'identity' by drawing on their memories of the patients' past practices and ways of being to re-socialise them and guide interaction with them (i.e., identity bricolage). In turn, this past is made visible in the wards through sharing stories, decorating their room and leaving instructions. Thus, it can also be actively used also by professionals who do not have direct access to these past identities. Additionally, professionals construct patients' identities by drawing on their clinical characteristics, defining them as 'good' or 'bad' patients and linking them with specific care practices – giving them a clinical identity (Bird-David and Israeli, 2010). For instance, having a complex clinical situation or being a needy patient requires more attention from the professionals, making it more challenging to interact with the patient.

Second, to overcome the 'present' problem of interacting with a patient without a voice, caregivers creatively constructed a peculiar communication based on bodily communication. Both professionals and relatives interact with the patient by establishing non-verbal communication, such as using the body and the five senses as a medium of interaction. This corporeal sociality is – again – mediated by *ad-hoc* devised affective mediums, such as music or 'sensory tales', that are promoted by institutional roles in the nursing home (e.g., music therapist, social entertainer, psychologists).

Overall, our analysis offers insights into the broader relationship between psychological temporalities. Far from being a linear process, past-to-future succession is creatively re-crafted to inform present social action. On the one hand, the past highlights differences between the patient's previous state (e.g., de-anchoring from life or personhood) and identity (i.e., a lost self). On the other, comparison with a potentially meagre future puts patients – and those caring for them – in a suspended present (see also Chiambretto et al., 2010). Thus, our findings suggest that it is the past – and not the future (Power et al., 2023) – that pulls the action forward. It is precisely within this past that carers find resources to reconstitute the patient/relative and – thereby – resolve ontological and interactional dilemmas. As discussed by Stenner and colleagues (2019) on ADHD, we hereby witness the temporal reconstruction of 'what it was' to provide a way out from polarising representations (e.g., alive or dead). However, here, this reconstruction is realised by the other (i.e., relatives), as the patient is unaware.

Finally, our research adds a dialogical perspective to this literature, showing how past and futures are contextualised within different relational settings, the one of a shared past and common suspended present. Thus, our findings corroborate that the re-making and de-paradoxifying of vegetative-state individuals results from different self-other relations, serving a pragmatic function in different patient-carers relationships. For instance, having a shared past and a relational concern, relatives notice how the patients have lost their identity and struggle to communicate their presence to them. While relatives re-socialise the patient, professionals re-construct them in terms of a clinical identity as they struggle to orient their caring practices (Bird-David and Israeli, 2010). Thus, differently from previous research we show *how* and *what for* the vegetative state is made sense of and dealt with. Moreover, extending from the professional/relative-patient self-other dyad, we have shown how the vegetative state is also interpreted through a collaborative dialogue between professionals and relatives. Professionals contribute technical expertise in communicating with patients (e.g., using five senses), while relatives provide biographical insights. In this way, we add to previous literature (Edgar et al., 2015; Zulato et al., 2022), focusing on the conflict between carers in making sense of this state.

11. Conclusions

In sum, the present study contributes to our understanding of how a paradoxical condition – as the vegetative state – is understood and managed by different carers, through their different dialogical positions and relations. As a result, we further show how meaning-making is always achieved in dialogue with present, absent, or imagined 'other(s)' (Castro and Santos, 2020; Marková, 2023); here, for the first time, we show how meaning-making of the vegetative state is achieved in the three-fold 'dialogue' involving an *absent–yet–present* other. This holds important implications in showing how relatives and professionals can signify their (shared) present, everyday caring activities, and deal with an only apparently meaningless situation. In such a situation, patients and their carers are enduringly forced into a liminal hotspot, and meaning-making is the only psychological option, as the Italian legislation does not allow treatment withdrawal, unless differently specified by the patient's living will. Moreover, by looking at these findings, we ultimately show how – despite the difficulties of voicelessness and lack of feedback – carers put in place a dialogical effort that allows them to maintain personhood in the vegetative state. Without this relational effort, *absent-yet-present* others would remain merely absent. In other words, the vegetative-state relative/patient emerges in dialogue.

CRediT authorship contribution statement

Edoardo Zulato: Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Paula Castro:** Writing – review & editing, Writing – original draft, Supervision, Conceptualization. **Carolina Silvia Quagliarella:** Investigation, Formal analysis, Data curation. **Lorenzo Montali:** Writing – review & editing, Supervision, Formal analysis, Conceptualization.

Ethics approval

The study was evaluated by the Local Commission for Minimal-Risk Studies of the Psychology Department, operating under the University Ethics Board, at the University of Milano-Bicocca (approvals # RM-2018-149).

Declaration of Interest statement

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Acknowledgments

We want to thank Dr Sandra Obradović for her precious comments and insights on the manuscript draft. We also want to thank *Samudra Insieme* for proposing and collaborating on this research.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.socscimed.2025.118021.

Data availability

The data that has been used is confidential.

References

Alimohammadi, E., Arast, A., Vlaisavljevic, Z., Abdi, A., Ramadhan, H., 2023. The experiences of the caregivers caring for the patients in persistent vegetative state due to traumatic brain injury. SAGE Open Medicine 11, 20503121231177550. https://doi.org/10.1177/20503121231177550.

Amer, A., Obradovic, S., 2022. Recognising recognition: self-other dynamics in everyday encounters and experiences. J. Theor. Soc. Behav. 52 (4), 550–562. https://doi.org/10.1111/jtsb.12356.

Andreouli, E., Kaposi, D., Stenner, P., 2019. Brexit and emergent politics: in search of a social psychology. J. Community Appl. Soc. Psychol. 29 (1), 6–17. https://doi.org/10.1002/casp.2375.

Batel, S., 2020. Re-presenting the rural in the UK press: an exploration of the construction, contestation and negotiation of media discourses on the rural within post-carbon energy transitions. Energy Policy 138, 111286. https://doi.org/10.1016/j.enpol.2020.111286.

Batel, S., Castro, P., 2018. Reopening the dialogue between the theory of social representations and discursive psychology for examining the construction and transformation of meaning in discourse and communication. Br. J. Soc. Psychol. 57 (4), 732–753. https://doi.org/10.1111/bjso.12259.

Bauer, M.W., Gaskell, G., 1999. Towards a paradigm for research on social representations. J. Theor. Soc. Behav. 29 (2), 163–186. https://doi.org/10.1111/1468-5914.00096.

Billig, M., 1988. Social representation, objectification and anchoring: a rhetorical analysis. Social Beahviour 3 (1), 1–16.

Bird-David, N., Israeli, T., 2010. A moment dead, a moment alive: how a situational personhood emerges in the vegetative state in an Israeli hospital unit. Am. Anthropol. 112 (1), 54–65. https://doi.org/10.1111/j.1548-1433.2009.01196.x.

Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. Qual. Res. Psychol. 3 (2), 77–101. https://doi.org/10.1191/1478088706qp063oa.

Braun, V., Clarke, V., 2012. Thematic analysis. In: Cooper, H., Camic, P.M., Long, D.L., Panter, A.T., Rindskopf, D., Sher, K.J. (Eds.), APA Handbook of Research Methods in Psychology, Vol 2: Research Designs: Quantitative, Qualitative, Neuropsychological, and Biological. American Psychological Association, pp. 57–71. https://doi.org/10.1037/13620-004.

Castro, P., 2019. In defence of social psychology attending to the institutional dimension: potentialities for extending comprehension of the ecological and political. Portuguese J. Soc. Sci. 18 (2), 137–152. https://doi.org/10.1386/pjss_00002_1.

Castro, P., Santos, T., 2020. Dialogues with the absent other: Using reported speech and the vocabulary of citizenship for contesting ecological laws and institutions. Discourse & Society 31 (3), 249–267.

Chiambretto, P., Moroni, L., Guarnerio, C., Bertolotti, G., Prigerson, H.G., 2010. Prolonged grief and depression in caregivers of patients in vegetative state. Brain Inj. 24 (4), 581–588. https://doi.org/10.3109/02699051003610490.

Cipolletta, S., Pasi, M., Avesani, R., 2016. Vita tua, mors mea: the experience of family caregivers of patients in a vegetative state. J. Health Psychol. 21 (7), 1197–1206. https://doi.org/10.1177/1359105314550348.

Covelli, V., Cerniauskaite, M., Leonardi, M., Sattin, D., Raggi, A., Giovannetti, A.M., 2014. A qualitative study on perceptions of changes reported by caregivers of patients in vegetative state and minimally conscious state: the "time gap experience". Sci. World J. 2014, 1–9. https://doi.org/10.1155/2014/657321.

De Luca, A., 2024. Osservatorio Permanente Delle DAT. I Testamenti Biologici Nei Comuni Italiani. Associazione Luca Coscioni per la libertà di ricerca scientifica APS. https://lookerstudio.google.com/reporting/856a479b-25eb-4850-8dcd-5fd595d1c2f8/page/p_typhw3svad.

Donis, J., Kräftner, B., 2011. The prevalence of patients in a vegetative state and minimally conscious state in nursing homes in Austria. Brain Inj. 25 (11), 1101–1107. https://doi.org/10.3109/02699052.2011.577047.

Edgar, A., Kitzinger, C., Kitzinger, J., 2015. Interpreting chronic disorders of consciousness: medical science and family experience: interpreting chronic disorders of consciousness. J. Eval. Clin. Pract. 21 (3), 374–379. https://doi.org/10.1111/jep.12220.

Gillespie, A., 2008. Social representations, alternative representations and semantic barriers. J. Theor. Soc. Behav. 38 (4), 375–391. https://doi.org/10.1111/j.1468-5914.2008.00376.x.

Gillespie, A., 2024. Challenges for conceptualising otherness. Possibility. Soc. Stud. 2 (2), 245–251. https://doi.org/10.1177/27538699241233630.

Giovannetti, A.M., Černiauskaitė, M., Leonardi, M., Sattin, D., Covelli, V., 2015. Informal caregivers of patients with disorders of consciousness: experience of ambiguous loss. Brain Inj. 29 (4), 473–480. https://doi.org/10.3109/02699052.2014.990514.

Goffman, E., 1959. The Presentation of Self in Everyday Life. Penguin.

Greco, M., Stenner, P., 2017. From paradox to pattern shift: conceptualising liminal hotspots and their affective dynamics. Theor. Psychol. 27 (2), 147–166. https://doi.org/10.1177/0959354317693120.

Howarth, C., 2006. A social representation is not a quiet thing: exploring the critical potential of social representations theory. Br. J. Soc. Psychol. 45 (1), 65–86. https://doi.org/10.1348/014466605X43777.

Joffe, H., 2011. Thematic analysis. In: Harper, D., Thompson, A.R. (Eds.), Qualitative Research Methods in Mental Health and Psychotherapy, first ed. Wiley, pp. 209–223. https://doi.org/10.1002/9781119973249.ch15.

Karataş, H., Balas, Ş., 2024. The liminal experience of awaiting for a cadaveric kidney donation: "I would not wish it on even my enemy!". Soc. Sci. Med. 363, 117466. https://doi.org/10.1016/j.socscimed.2024.117466.

Kaufman, S.R., 2003. Hidden places, uncommon persons. Soc. Sci. Med. 56 (11), 2249–2261. https://doi.org/10.1016/S0277-9536(02)00225-3.

Kitzinger, C., Kitzinger, J., 2014. This in-between: how families talk about death in relation to severe brain injury and disorders of consciousness: interdisciplinary Perspectives. In: Van Brussel, L., Carpentier, N. (Eds.), The Social Construction of Death. Springer Nature.

Kitzinger, J., Kitzinger, C., 2013. The 'window of opportunity' for death after severe brain injury: family experiences. Sociol. Health Illness 35 (7), 1095–1112. https://doi.org/10.1111/1467-9566.12020.

Kitzinger, J., Kitzinger, C., 2018. Deaths after feeding-tube withdrawal from patients in vegetative and minimally conscious states: a qualitative study of family experience. Palliat. Med. 32 (7), 1180–1188. https://doi.org/10.1177/0269216318766430.

Leonardi, M., 2010. Funzionamento e disabilità negli stati vegetativi e negli stati di minima coscienza. Coma Research Centre - Fondazione IRCCS Istituto Neurologico Besta.

Leonardi, M., Pagani, M., Giovannetti, A.M., Raggi, A., Sattin, D., 2013a. Burnout in healthcare professionals working with patients with disorders of consciousness. Work 45 (3), 349–356.

Leonardi, M., Sattin, D., Raggi, A., 2013b. An Italian population study on 600 persons in vegetative state and minimally conscious state. Brain Inj. 27 (4), 473–484. https://doi.org/10.3109/02699052.2012.750758.

Marková, I., 2003. Dialogicality and Social Representations: the Dynamics of Mind. Cambridge University Press.

Marková, I., 2023. The Making of a Dialogical Theory: Social Representations and Communication, first ed. Cambridge University Press. https://doi.org/10.1017/9781009295000.

Mead, G.H., 1932. The Philosophy of the Present. University of Chicago Press.

Moscovici, S., 1972. Theory and society in social psychology. In: Israel, J., Tajfel, H. (Eds.), Context of Social Psychology: A Critical Assessment. Academic Press.

Motzkau, J.F., Clinch, M., 2017. Managing suspended transition in medicine and law: liminal hotspots as resources for change. Theor. Psychol. 27 (2), 270–289. https://doi.org/10.1177/0959354317700517.

Nettleton, S., Kitzinger, J., Kitzinger, C., 2014. A diagnostic illusory? The case of distinguishing between "vegetative" and "minimally conscious" states. Soc. Sci. Med. 116, 134–141. https://doi.org/10.1016/j.socscimed.2014.06.036.

Pinel-Jacquemin, S., Althaus, V., Boissel, A., 2023. Patients in permanent vegetative or minimally conscious states: a literature review of the psychological and health impacts on healthcare personnel. Work 68 (3), 807–820. https://doi.org/10.3233/WOR-203414.

Power, S.A., Zittoun, T., Akkerman, S., Wagoner, B., Cabra, M., Cornish, F., Hawlina, H., Heasman, B., Mahendran, K., Psaltis, C., Rajala, A., Veale, A., Gillespie, A., 2023. Social psychology of and for world-making. Pers. Soc. Psychol. Rev. 27 (4), 378–392. https://doi.org/10.1177/10888683221145756.

RCP, 2020. Royal college of physicians. Prolonged Disorders of Consciousness Following Sudden Onset Brain Injury: National Clinical Guidelines. RCP.

Sammut, G., Andreouli, E., Gaskell, G., Valsiner, J., 2015. Social representations: a revolutionary paradigm? In: Sammut, G., Andreouli, E., Gaskell, G., Valsiner, J. (Eds.), The Cambridge Handbook of Social Representations. Cambridge University Press, pp. 3–11. https://www.cambridge.org/core/product/identifier/9781107323650%23CT-bp-1/type/book_part.

Soeterik, S.M., Connolly, S., Playford, E.D., Duport, S., Riazi, A., 2017. The psychological impact of prolonged disorders of consciousness on caregivers: a systematic review of quantitative studies. Clin. Rehabil. 31 (10), 1374–1385. https://doi.org/10.1177/0269215517695372.

Stam, H., 2011. Wicked problems and the construction of theory in psychology. In: Stenner, P., Cromby, J., Motzkau, J., Yen, J. (Eds.), Theoretical Psychology: Global Transformations and Challenges, pp. 2–11. Concord.

Stenner, P., 2021. Theorising liminality between art and life: the liminal sources of cultural experience. In: Wagoner, B., Zittoun, T. (Eds.), Experience on the Edge: Theorizing Liminality. Springer International Publishing, pp. 3–42. https://doi.org/10.1007/978-3-030-83171-4_1.

Stenner, P., Greco, M., 2018. On the Magic Mountain: the novel as liminal affective technology. Int. Pol. Anthropology. 11 (1).

Stenner, P., O'Dell, L., Davies, A., 2019. Adult women and ADHD: on the temporal dimensions of ADHD identities. J. Theor. Soc. Behav. 49 (2), 179–197. https://doi.org/10.1111/jtsb.12198.

West, M.P., 2014. Acute care setting. In: Paz, J.C., West, M.P. (Eds.), Acute Care Handbook for Physical Therapists, Fourth. Elsevier, pp. 1–9. https://doi.org/10.1016/C2011-0-05707-1.

Zadeh, S., 2017. The implications of dialogicality for 'giving voice' in social representations research. J. Theor. Soc. Behav. 47 (3), 263–278. https://doi.org/10.1111/jtsb.12136.

Zulato, E., Montali, L., Bauer, M.W., 2021. Understanding a liminal condition: comparing emerging representations of the "vegetative state". Eur. J. Soc. Psychol. https://doi.org/10.1002/ejsp.2794 ejsp.2794.

Zulato, E., Montali, L., Castro, P., 2023. Regulating liminality: making sense of the vegetative state and defining the limits of end-of-life action. Br. J. Soc. Psychol. 62 (4), 1733–1752. https://doi.org/10.1111/bjso.12653.

Zulato, E., Montali, L., Quagliarella, C., 2022. "Is there anyone in there?": caregivers and professionals' mutual positioning to take care of vegetative state patients. In: Fatigante, M., Zucchermaglio, C., Alby, F. (Eds.), Interculturality in Institutions. Springer International Publishing, pp. 141–160. https://doi.org/10.1007/978-3-031-12626-0_7.