

Nursing, Caregiving and Psychological support in Chronic Disorders of Consciousness: a scoping review

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Abstract. *Background and aims:* The major disorders of consciousness include Coma, Vegetative State, and Minimally Conscious State. The care and the management of patients with Disorders of Consciousness (DOC) have raised several important ethical, social and medical issues. Aim of this review is to evaluate the role of nursing and psychological support in DOC management, in order to improve the quality of life of both patients and their caregivers. *Methods:* Studies dealing with DOC, nursing and caregiving published in the last 20 years (from January 2000 to June 2020) were identified by searching on PubMed, Web of Science and Cochrane databases. *Results:* This review highlights the important role of DOC caregivers in the complex management of these frail patients, as well as the need for a specific support and counselling of caregivers. This psychological support may be given by nurses, as they are the healthcare professionals more involved in DOC care and cure. *Discussion:* Over the last years, specific recommendations for the assessment and rehabilitation of patients with DOC have been promulgated by neurorehabilitation organizations to provide some guidelines for the care and cure of such frail patients. Indeed, DOC patients need a multidisciplinary approach in which both caregivers and nurses have a pivotal role. *Conclusions:* As the family is a critical and fundamental aspect in the management of DOC patients, it should be considered an integral part of care in the future guidelines. (www.actabiomedica)

Key words: Disorders of consciousness; caregiving; nursing; psychological support

Introduction

Disorders of consciousness (DOC) are states of prolonged altered response to external stimuli, with important problems in diagnosis and treatment (1,2). DOC are categorized into three different stages based on the degree of awareness and the self and environmental consciousness: coma state (CS, a state of complete absence of response to environmental stimuli), vegetative state (VS, a state with no evidence of behavioural response but with presence of awake-sleep cycle and spontaneous and stimulus-induced arousal) and minimally conscious state (MCS, in which the patient demonstrates behavioural evidence of self or the environment with a reduced consciousness) (3,4). More in

detail, coma is a state of complete unconsciousness from which the patient cannot be aroused. The eyes remain closed, there are no sleep-wake cycles on Electroencephalography (EEG), and there is no evidence of purposeful behaviour or intelligible communication. When coma is caused by acquired brain injury (i.e., trauma, hypoxic-ischemic events, metabolic disorders), it usually evolves into VS or a conscious state within 2 to 4 weeks. In VS, the patient shows spontaneous eye opening, evidences of sleep-wake cycles, but no sign of environmental or self-awareness, and no ability to interact with others. VS may persist unchanged (i.e. a permanent state of unconsciousness), or it may evolve in higher levels of consciousness, such as MCS (4). Evidence of awareness may be a sustained visual pursuit

and gestural yes/no responses to simple commands, or movements and affective behaviours occurring in relation to specific environmental events (i.e. smiling for a family photo). Differential diagnosis has to be made with the locked-in syndrome, where patients are awake and completely conscious but ocular movements are the only way to communicate with these patients (5). In Italy, the Italian Ministry of Health technical report on patients with DOC reported rates of incidence and prevalence of 0.5–4/100.000 and 0.6–10/100.000, respectively, although these numbers seem to underestimate the real increasing incidence of VS and MCS in Italy as reported in the same document (6).

The most successful scales to assess coma and outcome are respectively the Glasgow Coma Scale (GCS) and Glasgow Outcome Scale (GOS) for their easiness and rapidity of administration (7). Another important scale is the Brief Post-Coma Scale (BPCS) (8), an easy diagnostic tool for individuals with DOC that could distinguish patients in the minimally conscious state (MCS) from those in unresponsive wakefulness syndrome (UWS) (9), formerly defined as vegetative state (VS). However, according to the recent review of behavioral assessment scales for DOC, the Coma Recovery Scale-Revised (CRSR) has excellent content validity and is the only scale to address all Aspen Workgroup criteria (9). Recently a new scale has been developed, the Music Therapy Assessment Tool for Awareness in Disorders of Consciousness (MATADOC), a sensitive assessment of auditory responsiveness (10). The MATADOC is a 14-item measure that provides a rigorous and detailed assessment of auditory responsiveness that uses several musical stimuli: *isolated single auditory stimuli* (i.e., a single pitch on a single instrumental timbre), *complex musical sounds* (e.g., singing a familiar song), and *musical activities* to measure a number of functional behaviours across the motor, communication, visual, and auditory domains (11).

Development of interventions for treatment and rehabilitation of patients with DOC is a crucial challenge for current and future generations of neuroscientists. The management of these patients is an extremely difficult task for relatives and society in general, and these cases are usually considered hopeless. Although current treatments promoting recovery in such cases are extraordinarily limited, the findings of the Cuban

Group for Study of DOC, suggest new medical, ethical and practical implications for the diagnosis and management of VS patients (12). Indeed, the aforementioned Group is developing several research protocols to search for preserved residual brain and autonomic functions in VS and MCS cases (12).

In addition, due to the difficulties in diagnosis and attitude to treat DOC, only few studies (4 out of a total of more than 299 articles) about rehabilitative techniques are available (13).

In the rehabilitation setting, the primary goals of the assessment in patients with DOC are to establish an accurate diagnosis, to develop a valid prognosis, and to design an appropriate treatment plan. The rehabilitation of patients with DOC is laced with challenge and uncertainty. Over the last 10 years, specific recommendations for the assessment and rehabilitation of patients with DOC have been promulgated by neurology and neurorehabilitation organizations to provide some guidelines for care (14). However, standards of care have not been established to guide rehabilitative treatment in patients with DOC. Pharmacologic interventions, sensory stimulation, physical management procedures, hyperbaric oxygen therapy, and deep brain stimulation have all been utilized for rehabilitative purposes. No treatment has been empirically shown to be clinically effective in restoring consciousness, cognition, or functional capacity (15). There is, however, supportive evidence that some interventions may promote recovery, particularly in patients with MCS (15).

Therefore, rehabilitative management of patients with DOC continues to be plagued by many unanswered questions. In the absence of clear-cut guidelines, it is critical that clinicians adopt a systematic approach from the assessment to the rehabilitative treatment. In this field, it should be interesting to consider and to develop these stimulation interventions as integral part of a multidisciplinary management of patients with DOC. Nurses and caregivers are fundamental figures in the management of DOC patients.

Aim

This scoping sought to depict the complex, but fundamental role of DOC patients' caregivers in the

multidisciplinary approach of these frail individuals, as well as the importance of nursing in managing and supporting both patients and caregivers.

Methods

Search Strategy

Studies published in the last 20 years (from January 2000 to June 2020) were identified by searching on PubMed, Web of Science and Cochrane databases. The search combined the terms disorder of consciousness (EC) AND/OR caregivers AND/OR nursing AND psychological support AND/OR vegetative state/minimally conscious state. All results of each database were evaluated for possible inclusion. After the removal of the duplicates, all the articles were evaluated based on the titles and abstracts.

Study selection

The inclusion criteria were: (i) patients with DOC; (ii) DOC management; (iii) English language; and (iv) published in a peer-reviewed journal. The exclusion criteria were: (i) patients with coma or locked-in syndrome; (ii) animal studies; and (iii) conference proceedings, or case studies. Data extraction was performed on 70 articles, based on the following data: authors, year, and type of publication (for example, conference proceedings, clinical case); characteristics of the participants involved in the study; and purpose of the study.

Data Charting

After an accurate revision of full manuscripts, 13 articles satisfied the inclusion/exclusion criteria and were reviewed (see main findings in table 1).

Results

Caregivers' psychological profile

Caregiver is a complex and difficult figure to manage and support in the long route of management

of DOC patients. They act a kind of assistance that is not strictly related to curing, but gives psychological, affective and practical support to the patient. Actually, the term caregiver (or informal caregiver) refers to all the people who voluntary and without payment take care of a patient and are not healthcare professionals, like relatives and friends (16). In the 80's, Finch and Groves identified two distinct dimensions of caregiving: one is material and related to physical needs of the patient who is totally dependent, the other one concerns the aspects of care involving affection and attention to psychological needs of the patient (17). Moreover, caregiving may be also differentiated by the intensity of caregiving responsibilities and the duration of the caregiving relationship in: *primary* caregiver, defined as an individual who spends most of the time with the patient, and the *secondary* caregiver who provides additional support (e.g., siblings, neighbors, or friends) and intensive personal care (i.e., eating, dressing, and toileting) or instrumental tasks (e.g., using the telephone, shopping, and taking medications) and emotional support (18-21).

Caregiver's risk factors

Caregiving requires the ability to perform a repetitive and painstaking work; it requires at the same time continuous organization and redefinition of an ever-changing situation. The onset of DOC can be a trauma that perturbs the structure of a family unit and the entire life of the relatives. In fact, they have to cope with the emotional paradox of the loss of the person as he/she usually was, even though he/she is not dead. The clinical course of every single DOC patient, especially VS patients, is the story of a "life into the death". This doubtful situation between life and death prevents the relatives of patients with DOC from mourning and elaborate the loss. Moreover, the conflict between the representation of the person as familiar and the impossibility of recognizing him/her as he/she was generating, according to Freud, a "familiar estrangement" (22). The situation requires radical changes of the relationship with the patient: communication is not reciprocal anymore and become mostly non-verbal, therefore the caregiver has to develop great empathy and sensitiveness. Instead, he/she has to assume the function of keeping a "double memory": both the experiences

Table 1.

	Authors	Type of Studies	Patients/Subjects	Major findings
<p>Caregiver's profile and support</p>	Ohman et al. ²⁴	Qualitative study/ Observational study	14 Close relatives of serious chronic illness patients	The aim of this study was to elucidate the meaning of close relatives' experiences of living with a person with serious, chronic illness. The authors interpret the findings in the light of the works of philosophers who have described ethical demands and natural love between people.
	Tzidkiahu et al. ²⁸	Observational study	PCU patient's family, unspecified	The authors highlighted some of the main reactions of the immediate family of the PCU patient in the case of PCU patients' families, they tend to recur. Attacks of grief and guilt, and so forth, can beset a family that has already begun to adjust.
	Giovannetti et al. ³⁰	Observational multicentre cross-sectional study	487 Caregivers of VS-MCS patients	The results showed that burden and distress were high for all caregivers of VS and MCS patients. They suggested that support to the caregiver should be guaranteed throughout the duration of the relative's disease despite the patient's diagnosis.
	Cipolletta et al. ³¹	Observational study	24 caregivers of VS patients	The results highlighted the importance for vegetative state caregivers in considering new possibilities of life that go beyond the assistance of vegetative state patients.
	Chiambretto et al. ³²	Longitudinal	30 family members of patients in VS	The authors observed the experience of family members of those who, following acute brain injury, traumatic or otherwise, find themselves in a vegetative state, in particular how families cope, year after year, with care of the patient in hospital and home-based.
	Giovannetti et al. ³⁴	Longitudinal study	53 MS patients	The authors observed that patients accurately perceive some changes in their level of cognitive dysfunction, although they are insensitive to the degree of their current dysfunction.
	Imanigoghary et al. ³⁶	Qualitative study/ Observational study	14 caregivers of VS patients	The study evidenced role of the nurse in helping the family caregivers of vegetative patients, to meet their needs and cope with difficulties. Nurses can improve the caregivers' well-being by considering the importance of training and support them during care process.

Nursing Role	Puggina et al. ²	Explorative study	Unspecified	The study explored the aspects of nursing care in patients recovering from coma such as difficulty of diagnosis, residual perception, clinical assessment, care and management, and communication with the patient and the family.
	Sato et al. ³⁸	Observational study	15 Patients VS	The study aimed to identify physical responses to nursing interventions among patients in a PVS. The authors observed an improvement in consciousness level and the accumulation of benefits after each successive week of nursing interventions.
	Wright et al. ⁴¹	Descriptive study	Unspecified	The study showed management of the Care of the long-term tracheostomy patient is changing. The reintegration of patient into a productive life is dependent upon the collaborative care of several disciplines directed by the specialist and of the importance of new caregiving role.
	Fife et al. ⁴⁴	Prospective cohort study	186 Patients	The objectives of the study are to determine risk factors for pressure ulceration in an intensive care setting, to evaluate the Braden scale as a predictor of pressure ulcer risk in critically ill patients.
	Por et al. ⁴⁷	Lecturer\	Unspecified	The paper showed the importance of advancing nursing practice and the future roles of advanced nurse practitioners both in the UK and elsewhere.
	Donald et al. ⁴⁸	Quantitative systematic review	Unspecified	The study reported quantitative evidence of the effectiveness of advanced practice nursing roles, clinical nurse specialists and nurse practitioners, in meeting the healthcare needs of older adults living in long-term care residential settings.
	Gosseries et al. ⁴⁹	Observational study	523 Healthcare workers	The authors on this study observed the presence of burnout among professional caregivers managing patients with severe brain injury recovering from coma and working in Neurorehabilitation centres or nursing homes.
	Wong et al. ⁵⁰	Qualitative systematic review	Unspecified	The authors described findings of a systematic review of studies that examine the relationship between nursing leadership and patient outcomes. The findings suggest that an emphasis on nursing leadership is an important organizational strategy to improve patient outcomes.

he/she lived with the patient during their relationship and the memories of the patient, for example what he/she enjoyed and the way he thought. The trauma affects even the perception of time of the caregiver: he/she cannot use his/her time freely and his/her mind is limited in the present, made of simple actions organized in a routine. Caregivers focalize their life to the patient modifying their habits or ignoring leisure activities leading to a barely compulsive attention to every clinical event of the patient daily life and putting themselves second to provide intensive support to the relative and, especially when the illness is in the critical phase, their whole existence is entirely focused on the patient, feeling a limitation on their personal freedom (23,24). They can feel guilty about dedicating time to themselves instead of their loved ones (25). They retired from their jobs, and barely live their life waiting the visit to their own relative. Therefore, usually caregivers report adverse and long-standing difficulties in emotional health, social activities and family relationships (26). Consequently, they increase the likelihood of developing stress-related disorders (physical, psychosocial and financial) and live every situation as a burden (27,28). Quantification of changes in time for family and social activities, emotional well-being and ability to cope with stress could be quantified by the revised 15-item Bakas Caregiving Outcomes Scale (29). Several caregivers showed some difficulties in taking care of their relatives, likely due to the situation that is particularly stressful or have some difficulties in finding their role in the process of caring with the result of avoiding that situation or reducing their care time to less than 3 hours per day (30). Therefore, individuals who were caregivers for <2.3 years reported negative outcomes in mental health and higher state of anxiety, having higher levels of burden than caregivers of patients with long-term care facilities who complained problems and expressed to be in great need for social involvement (30). Marsh et al. showed that adverse effects may still be present several years (5 years for VS and MCS caregivers) after the acute event (31). However, after a period between 6 months and 1 year of adaptation, long-term care facility caregivers were able to maintain stable levels of anxiety, depression and emotional burden, as well as to adopt situation-focused rather than emotion-focused coping

strategies (acquisition of social support and resources, positive appraisal, and family tension management: e.g., sharing problems with other family members and taking a break from the care of patient) (32).

Actions to support caregivers

Given that caregivers' needs and lifestyles change over time, it is very important to adjust the psychological intervention on the basis of the specific caregiver situation. Sattin et al. reported that 42% of caregivers referred that communication with professionals and the answer to the need of information were the most critical points in the acute phase, and evidenced the lack of availability of psychologists for caregivers during long-term care (33). In the complexity of caregiver's daily life, it is not important how long do they have to wait to come into assist their family and how tired they are, they have to be present and routinely have to take care of the patient. Hours of care-giving is the only significant factor that has been associated with the overall level of burden perceived by DOC caregiver. Moreover, it has been shown that positive coping strategies are fundamental to deal with DOC, and therefore there is a need to develop such effective coping strategies aimed to reduce psychological distress and improve caregiver's well-being (34). Considering the burden of caregivers, it is necessary a support in their caring process. Assessing needs, coping strategies and adopting emotion-focused rather than problem-focused strategies seems to help caregivers to manage anxiety (35). About coping strategies, caregivers try to invest on other people, as suggested by the high use of social support, but at the same time they feel isolated, maybe because they have difficulties with other family members, and they have little time for leisure activities and relaxation, because of the amount of time devoted to care-giving. For caregivers, the future become a harassing thought that they deny and cannot face up. Thus, it is important that the healthcare professionals support the caregivers and monitor the stress of the family to prevent an emotional breakdown. The nurse is a helpful and distinctive figure to support family care. Nurse's competence and experience for the care of the DOC patients is necessary to adequate their assessment to the level of awareness in which the patients are. As a consequence of the

difficulty in getting the right differential diagnosis of DOC, an interaction between a multidisciplinary team and families is crucial to guarantee a respectable daily life. A single new reflex, every little different event in facial expression or involuntary movement could be a “light in the long dark route” of awakening. In this description, caregivers play a fundamental role in clinical assistance of DOC patients reporting any clinical variation. Nonetheless, at the same time, they live in the expectation and obsessive daily research of new signals. Moreover, it is also very important to keep the family fully informed of the prognosis and any developments to avoid false positive expectancies.

The growing importance of Nursing in managing DOC

Nurses' role

As defined by Puggina et al. in their review, management of DOC patients is “challenging” due to the widespread concerns that have to be accomplished in daily care of acute and chronic phases (2). As consequence, role of nurses is fundamental to improve this condition and prevent complications and provide comfort. As Imanigoghary et al. reported in their study, nurses are an integral part of the health system and act as mediators between the VS patients' families and the health system. In the handling of DOC families' nurses has been divided in three different roles by caregivers, especially of VS patients, in an educational and supportive manner. In particular, the first category is “nurse as a pursuer teacher” (“teach to accept care” and “teach to provide safe care”) due to the needs of family to be trained in order to prevent complication in patients (36). As consequence of an inadequate training, physical and psychological complications for both family caregivers and patients would appear. The second role is “nurse as a compassionate caregiver”, as a figure taking care of the whole life of the patients and, at the same time, paying attention to the family. The last category is the “nurse as a supporter” because of the capacity of assisting caregivers in providing necessary facilities and obtaining supportive aid in the health system bureaucracy (36).

The Royal College of Physicians Guidance on DOC, especially for VS patients, describes several fundamental steps that should be taken into account in the care of patients: i) adequate nutrition (usually via a percutaneous endoscopic gastrostomy tube); ii) good skin care; iii) suction to avoid inhalation pneumonia associated with naso-gastric tube feeding, tracheostomy decannulation management; iv) supervision of bladder and bowel incontinence; and v) care for dental and oral hygiene (37). Sato et al. sought to evaluate the effects of nursing interventions on consciousness levels of VS patients, as compared to elderly bedridden subjects with consciousness. They used three different interventions: sitting the patient in an upright position, footbath care, and oral care and evaluated the patients' responses using the Kohnan Score and the General Well-Being Schedule score, as well as detecting plasma cortisol and adrenaline levels, and facial expression. They found that only Kohnan scores improves significantly in VS patients, showing an increase in levels of consciousness. These findings indicate the importance of assessing the quality of each intervention and treatment (38).

Nursing risk in the patient management

The main complications in DOC patients, requiring a nurse careful monitoring, as well as appropriate preventive and treatment programs are: increased muscle tone leading to contractures and permanent deformities, bladder and renal tract complications (infections, bladder stone and contracted bladder), bowel complications (constipation or diarrhea), under nutrition, respiratory infections, stress ulceration, deep vein thrombophlebitis, decubitus ulceration, heterotopic ossification, family dynamics and complications of medications. It is a good medical practice to initiate the artificial provision of fluids and nutrition when the patient's prognosis is uncertain, and to allow for the termination of treatment at a later date, when the patient's condition becomes hopeless. Moreover, patients with DOC have an increase of caloric and proteic requirements. Therefore, appropriate and timely nutritional intervention can play a vital role in the prevention of malnutrition (39). Moreover, good management of dysphagia avoids complications, such

as aspiration pneumonia, malnutrition, and dehydration, frequently under recognized and neglected conditions. Several interventions, from parenteral and enteral feedings to modifying bolus consistencies in recovering patients, are indispensable for patients who cannot achieve full supply of energy and substrate demand. Therefore, enteral feeding requires an entire nutrition support team. When upper airway obstruction is present, to maintain a correct oxygenation, artificial airway devices are needed, such as an oral or nasopharyngeal airway, or more complex airway support as placement of either an endotracheal or tracheostomy tube is required (40). Tracheostomy tubes could be structured with an inner cannula, cuff, and fenestration. Tracheostomy complications could be divided into short-term (bleeding, wound infectious, pneumothorax, tube obstructions) and late complications (tracheal stenosis, fistula, granulation tissue, tracheomalacia, tracheocutaneous fistula). In order to avoid these complications and to maintain a good care of the tube, an accurate management should be done (41-43). However, artificial airways can be used for both short- and long-term airway management. A critical point in nursing care is the development of pressure injuries. A study showed that 23 of 186 patients, interned in a neurological intensive care unit, developed at least one pressure ulcer (incidence of 12%) after an average stay of 6 days (44). The top 5 non-modifiable risk factors potentially associated with unavoidable pressure injury are: impaired tissue perfusion and oxygenation, immobility, spinal cord injury, and unstable pelvic fractures compromising tissue tolerance due to arterial insufficiency (45). Further risk factors are nutritional depletion, malnutrition or cachexia, septic shock, and impaired cardiopulmonary status. Education on the risk factors can affect prevention and early identification of critically ill patients at high risk for pressure injury and can affect the nurses' attitudes and behaviours.

Interprofessional Approach

Collaborations with physicians and nurse practitioners are essential to create a multidimensional plan of care within the context of each patient's illness (2). Other interdisciplinary collaborations should

include physical and occupational therapists to assist with the management of mobility restrictions and optimize the use of alternative positioning strategies. About patient's immobility, another consequence is the developing of articular alterations and spasticity. The decerebrated or decortized posture lead to difficulty in maintaining appropriate positioning and could be the source of physical deformations and pain during mobility. To this end, a strict interaction between nurses and physical therapist is needed. In order to reduce risk of impaired tissue perfusion and to preserve metabolic equilibrium, administration of chronic intravenous fluids for hydration, certain antibiotics and continuous intravenous medication infusion could be managed correctly with the insertion of venous access device hospitals. Standard peripheral intravenous catheters, "midline catheter" insertion, and central venous cannulation or peripherally inserted central catheter, are the main devices used for either short or long-term infusion therapy (46). Physicians should be constantly advised by the nurses who constantly take care of DOC patients, so to adapt medications, intravenous idration and enteral nutrition to the patient's needs and clinical picture.

The systematic education of all healthcare professionals and the development and practice of catheter removal protocols could contribute to the prevention of catheter-associated urinary tract infections. Finally, the evaluation of the vital signs is extremely important to supervise neurological status because, in proportion to the increase of the cerebral compression, the vital signs tend to be reverted: tachypnea, hypotension, and bradycardia (2,45). This further supports a close collaboration between nurses and doctors. Due to the complexity of DOC patients' assistance, nurses are expanding further knowledge to improve the outcomes of these frail patients. Nurses must be familiar with all aspects of support and counselling to safely provide care. Moreover, education of caregivers in long-term care facilities is an important goal to obtain for a better management of the patient. Appropriate care includes identifying high-risk patients, observing for new symptoms, assessing for possible complications. The management of all these clinical aspects, strengthen the definition of a nurse as an "advancing nurse practitioner" (ANP) defined as "An ongoing process using

expanded knowledge, clinical expertise and research to further the scope of practice” (47). It is an ‘expert’, arising from either a specialist or generalist approach, an “educator”, “researcher” and “consultant”.

However, within the arena of chronic disease, evaluation of the effectiveness of ANP roles is revealing. Donald et al. demonstrated both quality and cost-effectiveness of care where ANPs were involved (48). In fact, there was an improvement or reduced decline in health status indicators, including depression, incontinence, pressure sores, aggressive behavior, but also in the achievement of personal goals. The strength of this well-designed study is that it examined not only the clinical role of the ANP, but also some of the sub-roles, particularly innovation and leadership. Indeed, ANP influence has been observed to make a significantly positive impact on patient outcomes (38,49). It is noteworthy that a significant percentage of nurses taking care of patients with DOC may suffer from burnout (50). Indeed, prevention of burnout symptoms among these healthcare professionals is fundamental to promote more efficient medical care of such challenging patients.

Conclusions

The care of patients with DOC is an emerging concern that is raising several important ethical, social and medical issues. As the allocation of healthcare resources is an important issue because DOC patients are maintained alive artificially and require prolonged care, it is evident that a uniform ethical framework needs to guide clinicians and caregivers in terms of clinical outcome, prognosis, and medical management. This review highlights the important role of DOC caregivers in the complex management of these frail patients; at the same time, the need for a specific support and counselling of caregivers was evidenced, as they often present with stress-related disorders negatively affecting their quality of life. This support may be given by nurses, given that they are the healthcare professionals more involved in DOC care and cure. Unfortunately, this review has some limitations related to the poor quality and the small sample size of the published papers, so the results are not generalizable

and no clear indications emerge on the best nursing/counselling approach to both patients and caregivers.

As the prevalence of DOC patients is increasing, the healthcare management plan should aim to improve the clinical state of the patient and reduce the burden of caregivers. In this context, it is fundamental the presence of a multidisciplinary clinical team for preventing secondary complications and for providing a proper clinical and psycho-physical environment for DOC patients’ optimal recovery.

Compliance with ethical standards: This article does not contain any studies with human participants or animals performed by any of the authors.

Conflicts of interest: Each author declares that he or she has no commercial associations (e.g. consultancies, stock ownership, equity interest, patent/licensing arrangement etc.) that might pose a conflict of interest in connection with the submitted article.

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