

Review Article

Spirituality of the Relatives of Patients with Disorders of Consciousness

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Keywords

- Spirituality
- Family
- Intensive Care Units
- Consciousness Disorders

Abstract

Researchers have perceived religion, prayer, hope and faith to be needs of family members throughout the illness process. Family members of patients with disorders of consciousness experience suffering and anguish, due to the length of time waiting and uncertainty involved in the recovery process, with spirituality being an important source of emotional aid and relief from tensions. Spirituality has no power to immediately resolve the situation; however, it can renew the energy of the family through identification of resources and learning to cope with the situation. This is an important part of life for many families and cannot be neglected in the context of illness.

INTRODUCTION

This review article brings together concepts and considerations regarding the spirituality of relatives of patients with disorders of consciousness arising from single moments that occurred in studies by authors on the subject. Religion, prayer, hope and faith are needs of family members that have been perceived by researchers to be present throughout the illness process [1-4]. Spirituality is a search for the meaning of life, with possible routes being through religions, philosophies, ethics, morals and ideologies [5]. Spirituality is more individualistic and self-determined, while religion typically involves connections with the community, beliefs and shared rituals [6]. Spirituality can be conceptualized as a search for the Sacred, the most central function of religion, relating to the way in which people think, feel, act or interrelate in their efforts to find, preserve and transform the Sacred in their lives [7]. Spirituality in health institutions primarily refers to life. This means to consider the human being in its entirety and in all its dimensions: physical, intellectual, emotional and spiritual; to create a corporate culture sustained by principles, in which ethics and spiritual and human values are used to direct decisions, strategies, policies and organizational relationships [5]. The improvement of individuals in relation to ethics is essential, particularly in care, and is closely related to the development of the individual's spirituality. The human being is born neither ethical nor unethical, but born amoral. Such conditions are acquired with biological, psychological and social development. Ethics depend on moral values and presuppose an individual construction of values and truths [8]. The meaning of life is important and related to human spirituality, with it often being affected by situations of suffering and illness. In this, individuals find strength and motivation to overcome adversity

and continue living, to have hoped for better times [9]. Therefore, beliefs and religious practices, such as prayer, help individuals to cope and to reduce the level of stress, with these activities being related to physical health, considering what is known about the effects of psychological stress and depression on the body [7]. Spirituality used as a coping mechanism can be observed in patients or relatives through gestures, words or religious accessories, such as a posture of prayer, prayer beads and bibles in the hospital. The coping process can be described as a situational process, a set of strategies used by people to adapt to adverse or stressful circumstances [10]. The use of religion and spirituality as a coping strategy can be defined as the use of religious beliefs and behavior seeking to facilitate the solution of problems and to prevent or alleviate the negative emotional consequences experienced in an emotionally critical situation [6,11]. Health professionals are being asked to inquire about spiritual support for patients as this constitutes part of an integral healthcare system. Medical treatment or a diagnosis, without considering the person in his/her totality, it is no longer acceptable. Patients are individuals with life stories, emotional reactions, family and social relationships that affect and are affected by the disease, with their own meanings and purpose to their lives. For many patients and their families, experiences with diseases are influenced by existential issues and spiritual concerns that may have a direct impact on the acceptance of the diagnosis, treatment and recovery process [6]. After identifying how the family members support each other regarding spirituality and the implications for the emotional state of the individual, nurses can (re)think the nursing care to the family and target the care towards an ethical and holistic view, seeking to include spirituality as an important element of the care [1]. Due to the length of time

waiting and the uncertainty common in the recovery process, the family members of patients with disorders of consciousness experience suffering and anguish, with spirituality being an important source of emotional aid and relief from tensions. Coping strategies based on the spirituality expressed by relatives of patients with disorders of consciousness can include believing in the strong influence of the Divine power upon the outcome, prayer as a comforting strategy to better cope with the situation, having faith as something necessary for healing, thanking God, asking for spiritual intervention in the patient's recovery, asking for a blessing and giving spiritual comfort to the patient. When the families delegate the power of the "cure" to God, they achieve a better emotional state, feeling more relaxed and calm because they believe there is someone to enlighten the doctors, nurses and caregivers, assigning the responsibility to the Divine in the entire process. Religion allows the family, through the exercise of faith, the gratification of healing. Spirituality provides an important role of social support, allowing an understanding of psychological distress, as the therapeutic relationship imposed by medicine does not allow clarification of the condition presented by the patient [12]. Hope is something unique in relatives of patients with disorders of consciousness due to the severity and misunderstanding of the disease. Disorders of consciousness are clinical situations where there is diffuse psychological loss, often accompanied by generalized reduction or change in the content of consciousness, added to deficiencies in the awakening [13]. Hope is an important element in coping strategies, even though there is some fantasy in the recovery of patients with disorders of consciousness, with false hopes sometimes being influenced by the media dissemination of miraculous and sudden recoveries. To work respectfully with this issue is an important intervention by the healthcare professional. Coma, the vegetative state and sedation are disorders of consciousness with important clinical and prognostic differences. In a vegetative state, patients "awake" from a coma (opening their eyes spontaneously or after stimulation), however, remain unconscious of themselves or the environment (only presenting reflex motor responses) [14]. In these situations, the family can create many expectations, which can be negatively stimulated by the media. For instance, how the media can negatively influence hope was reported in a study that compared the probability of recovery of comatose patients in American soap operas with data from a meta-analysis. Mortality for non-traumatic and traumatic coma was significantly lower than predicted by the data from the meta-analysis (non-traumatic 4% versus 53%; traumatic 6% versus 67%; $p < .001$). On the day that the patients regained consciousness, most presented no evidence of limited function, cognitive impairment or residual disability. Compared with data from the meta-analysis, the patients of the soap operas had a much better chance than expected of returning to normal cognitive motor function (non-traumatic 91% versus 1%; traumatic 89% versus 7%, $p < .001$). The picture of coma in soap operas was overly optimistic and, although these programs are presented as fiction, they can contribute to false hopes for recovery [15].

In addition to hope, prayer is one of the main spiritual coping strategies of relatives of patients with disorders of consciousness. Prayer can be defined as a set of words that expresses a complete thought, elevation of the soul to God, which is done only with the

thought, through meditation [16]. Prayer can be a way to approach the Divine and an active way to wait for the outcome, constituting concrete actions at a time when there are few possibilities for direct action by the relatives. Spirituality is an important resource for family members in coping with diseases, especially when presented with threatening prognoses. Even when their prayers do not fully meet their expectations, family members are grateful for the benevolence granted by God and believe that God can heal the sick and protect them from medical complications. A strong relationship with God helps the family to continue to fight for the recovery of the patient. The disease brings moments of reflection and new values [17]. Spiritual practices are related to the search for giving meaning to suffering and finding answers to existential questions related to illness in the family life. In the difficult moments of suffering, in which the affliction seems unbearable, the family relies on significant practices related to their beliefs [18]. Faith, as a necessary element for healing, becomes a coping strategy for the relatives of patients with disorders of consciousness. Faith can be defined as belief in the doctrines of a particular religion, the belief in the existence of any fact or truth of any assertion, this being the first of the three theological virtues [16]. Family members encourage patients to have faith, talking to the patient, emphasizing the need for mutual faith, in both the family members and the patient, so there is recovery. The faith of relatives of patients with disorders of consciousness can be strengthened or reborn in this serious situation. Especially in longer and most stable disorders of consciousness, such as the vegetative state, with the only possibility of family action, beyond physical comfort and basic patient care, being the waiting, with the waiting sometimes continuing for a very long period. In this context, faith can assume an important role, providing the family with the opportunity to experience the situation with more strength, courage and fortitude. With spirituality there is a singular acceptance of suffering by the family, which happens to be active, in as much as it has the possibility of heal through faith [16]. Requests for spiritual intercession in the recovery of patients with disorders of consciousness by the family, when expressed, are intense and appear almost like supplication and may demonstrate a certain degree of despair. Praying to God is one way to approach spirituality. Spirituality is an integral part of the individual, it is what allows individuals to find meaning and purpose in life, motivating and giving them reason to live. Spirituality can have an impact on the recovery process of patients when it is experienced by the nursing team and by the family, both needing to be involved in a convergent way [19]. Spirituality has no power to immediately resolve the situation; however, it can renew the energy of the family through the identification of resources and learning to cope with situations. This is an important part of life for many families and cannot be neglected in the context of illness [20].

CONCLUSION

The spirituality of the relatives of patients with disorders of consciousness constitutes a coping strategy during difficult situation. In this respect, to believe in the influence of the divine power over the outcome, to pray for support, to see faith as necessary for healing, to thank God or ask for spiritual intercession in the recovery of the patient and to ask for blessing or give spiritual comfort to the patient are actions that can

provide well-being to the family members, therefore, nurses should be aware of these needs.

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