



Perception of social support among family caregivers of vegetative patients: A qualitative study

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ABSTRACT

A vegetative state (VS) is the probable result after brain damage. After VS patients are discharged from the hospital, the responsibility of caring of them is transferred to their families, which impacts a caregiver's physical and psychological health. Social support as a valuable resource reduces the negative effects of stressful events. This study aimed to explore the perception of social support among family caregivers of VS patients.

This study is a part of a larger qualitative study which used the descriptive and qualitative method. Purposeful and theoretical sampling was done, and data was gathered through face-to-face, in-depth interviews. The four categories of "Family, a supporter in all aspects," "Beautiful emanation of the nurse's role," "Revitalization via empathy and companionship," and "Defects in support," were extracted. The primary concern of participants was receiving social support which can facilitate caregiving and coping with difficulties, but there are many shortcomings in supporting these caregivers.

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1. Introduction

A vegetative state is the probable result after severe brain damage. It is the result of dissociation between two parts of consciousness: awareness and wakefulness (Laureys, 2005). A patient in a VS is apparently awake, but has no sign of awareness of his own body or the environment, no purposeful or voluntary behaviors in response to stimuli, and is unable to communicate (Bernat, 2009; Giacino, Fins, Laureys, & Schiff, 2014). The number of VS patients in the world is increasing as a result of improvements in medical science and cardiac pulmonary resuscitation techniques. According to studies, the incidence of VS cases is 0.6–10 in 100,000 people (Zampolini, 2003); however, there are no statistics on the exact number of these patients in Iran.

Advanced medical interventions have prolonged the life of VS patients; the life expectancy of these patients has been estimated at 2–5 years, but it has also been reported to be more than 25 years (Chiambretto, Ferrario, & Zotti, 2001). VS patients are discharged from the hospital after passing the acute stage and reaching a stabilized medical condition (Beis et al., 2009). Afterward, the responsibility of patient care is vested to the patient's family. Even though the VS patient's condition is stabilized, he still require continuous medical and nursing care (Healy, 2010).

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Having someone in a vegetative state in the family is a complex and stressful experience, and caring for these patients creates many ethical, psychological, physical, and financial complications for family caregivers (Zarit, 2006). The patient's family suffers more than others (Chiambretto & Vanoli, 2006). Some of these caregivers leave their jobs, and most of them leave their interests, friends, or relatives and feel socially alone (Boss & Couden, 2002). Furthermore, the cost of caring for such a patient and leaving work cause financial, personal, social, and organizational problems (Dumont, Dumont, & Mongeau, 2008). In many studies, the burden and stress have been reported as side effects of caregiving (Chiambretto, Moroni, Guarniero, & Bertolotti, 2010; Chiambretto & Vanoli, 2006) which affect the caregiver's physical and psychological health (Giovannetti, Leonardi, Pagani, Sattin, & Raggi, 2013) and, as a result, the quality of patient care (Zarit, 2006).

Social support is defined as a subjective feeling of belonging, acceptance, recognition, and assistance in the required situation (Pehlivan, Ovaryolu, Ovaryolu, Sevinc, & Camci, 2011; Uchino, 2006), which can be provided by family members, friends, colleagues, professional groups, or the community (Uchino, 2006). Several studies have reported social support as a valuable resource which lightens the burden experienced by caregivers (Amendola, Oliveira, & Alvarenga, 2011; van der Voort, Goossens, & van der Bijl, 2009) and an emotion-oriented coping mechanism which improves the family caregiver's quality of life (Amendola et al., 2011), health behaviors (Yu & Petrini, 2010), and ability to cope with life events, thereby reducing the negative effects of stressful events (Shankar & Muthuswamy, 2007). In contrast, people with weak social support are vulnerable (Yu & Petrini, 2010) and experience high levels of stress (Shankar & Muthuswamy, 2007).

Many studies have emphasized the important role of social support in reducing the burden and improving mental well-being and physical health. Leonardi, Giovannetti, Pagani, Raggi, and Sattin (2012) assessed the burden and needs of caregivers of patients in vegetative states and minimally conscious states. The results showed a heavy burden related to providing care to these patients. The authors suggested planning comprehensive support strategies for caregivers in order to reduce the level of burden (Leonardi et al., 2012).

Study results obtained by Grant et al. (2006) indicated that higher levels of social support are associated with lower levels of caregiver depression symptoms and higher levels of well-being and general health (Grant et al., 2006). For example, Ryff, Radler, and Friedman (2015) reported that intervention and educational programs designed for improving the well-being of adults were followed by better physical health. Relieving a caregiver's mental problems increases his ability to cope with stressful situations. Grant et al. (2006) further stated that interventions that provide social support assist caregivers in developing adaptive abilities toward problem solving and coping with difficulties in caring. These kinds of support should be provided throughout the care delivery period. In their study, Giovannetti et al. (2013) expressed that support to the caregiver should be guaranteed throughout the duration of the relative's disease, because care-giving is a long-term commitment.

It is obvious that providing care to patients in a VS is oppressive, and the role of social support is pivotal in reducing care difficulties. Family caregivers receive support from different sources, including family and friends, HCPs, and community care organizations (Cameron, Naglie, Silver, & Gignac, 2013; Lilly, Robinson, Holtzman, & Bottorff, 2012). To the best of the authors' knowledge, only a few studies have focused on caregivers of VS patients, and most of them are quantitative assessments. Accordingly, there is a need for a detailed description which can illustrate the family caregivers' perception of social support. Therefore, the present study aimed to explore the perceptions of social support among family caregivers of patients in a vegetative state. Clarifying family caregivers' perceptions of social support can help in promoting caregivers' health and facilitating their coping with its challenges.

2. Method

This study is part of a larger study entitled "Exploring the coping process in family caregivers of vegetative state patients," which was conducted in the Kerman province in 2014. Since the study dealt with an unexplored area, it was important to choose a descriptive and qualitative method to obtain knowledge from the caregivers' own frames of reference. The study investigated perception of participants about types of social support they wanted and received, and perception about types of support they felt lack.

2.1. Informants

Purposeful sampling was used to recruit participants (Corbin & Strauss, 2008). Those who could best describe and enhance one's understanding of the phenomenon under study were recruited. Inclusion criteria were direct involvement in providing care and being responsible for care for at least 6 months. The criteria for patients being cared for by potential participants were the diagnostic criteria of the Royal College of Physicians (2013).

Because of its qualitative nature, this study did not determine sample size before data was gathered. The number of participants was determined based on information gathered. When additional interviews did not add new information about the targeted concept, the end point, or data saturation, was reached. Analysis occurred concurrently with data gathering in an iterative process, meaning that when no new information was observed after 10 interviews, two additional interviews were conducted to ensure data saturation had been reached.

Participants included 10 family caregivers and 2 nurses who helped families deliver care. Demographic characteristics are presented in Table 1.

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