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EDUCATING FAMILY CAREGIVERS OF VEGETATIVE PATIENTS AS A VERY IMPORTANT NECESSITY: A QUALITATIVE STUDY

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Introduction: Patients in a permanent vegetative state are living human beings, thus providing dignified and humanized care for them is very important. The mean survival predicted for these patients is 2-5 years, but there have been reported some patients with survivals of more than 10 years. It is worth noting that, because of their special self-care state, these patients need continual medical and social interventions and should also receive extensive care related to keeping their airways clear, immunity, liquid and electrolyte balance, nutrition, skin and corneal integrity, defecation and urination, giving them sensory stimulation, etc. On the other hand, the mentioned care should be provided by professionals, but in many countries such as Iran, because of the prolonged care period of these patients, they are discharged after their situation gets stabilized, and then they are cared for by family caregivers at home. So, continued education for family caregivers of these patients is very important but is unfortunately neglected because although home care is a very important part of the health system, it has not been adequately implemented or has been mis-implemented in the primary health care of Iran. Therefore, the present study was conducted to explain the process of vegetative patients' care performed at home by home caregivers, one of the dimensions of this process being their educational needs and how to receive them.

Materials & Methods: The present qualitative study was conducted from 2013 to 2015 in some provinces of Iran. Purposive sampling was used and 22 informants, including 17 family caregivers and 5 professional caregivers and hospital nurses, participated in this study. Ethical considerations were respected in the sampling process. Unstructured face-to-face interviews, observation, and field notes were used for data gathering. Data collection continued until data saturation was achieved and major themes became apparent. Content analysis was performed using the Lundman

and Graneheim approach and the constant comparative technique. Guba and Lincoln's criteria were followed to ensure rigor in this qualitative study.

Findings: As a result of data analysis, the main theme of seeking opening education emerged, and its' three sub-themes included: the necessity of education, avid seeking of education and effective education. These three sub-themes had 8 subcategories. These subcategories revealed that incomplete discharge education and the patients' need to receive multiple cares result in much fear in family caregivers. In response to this scary lack of knowledge, caregivers sought information from all sources, including professional and unprofessional sources. However, the result of the efforts of family caregivers in searching for information was accessing effective education that resulted in providing effective care for their patients.

Conclusion: Patients in a vegetative state need a variety of professional care and lack of optimized education to the family caregivers and families results in much psychological stress for them. So creating a process and a system for continuous and desirable education in the health system is very necessary. To achieve this goal, the proper intervention is to add home care to Iran's health system.

Biography

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