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Bothersome care: The family caregivers' experiences of caring at home for a patient with vegetative state

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Background: Vegetative state (VS) occurs through re-turn of the brain stem after coma state. After hospital discharge, responsibility of caring of VS patients is transferred to their families, which causes high burden to them.

Objectives: To explore the family caregivers' experiences of caring at home for a patient with vegetative state.

Method: This study is a part of a larger qualitative study which was performed in Kerman province, Iran during 2014-2015. Purposive and theoretical sampling was used. 16 caregivers participated in the study. Data were gathered by using face-to-face in-depth interviews and were managed by MAXQDA 10 software. Analysis was done through constant Comparative Method.

Results: The main theme "Bothersome care" was derived from analysis. The categories include "high burden of caring", "silent but alive patient", "defect of support" and "caregiver social isolation". These theme and categories represent caregiving burden which family caregivers experience during the care process of vegetative patients.

Conclusion: Family caregivers of VS patients due to the nature of disease, experience high physical, emotional and financial burden during caring process, they face with an alive but completely depended patient and an unmet need for social support and caregivers limit their social interactions due to society's attitude.

Biography

Zahra Imani-goghary is a PHD candidate in Nursing with a 10 year work experience in ICU ward and providing care to VS patients. Due to transferring the patient care to family caregivers in Iran, she decided to do some studies about their experiences, coping process and needs.

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