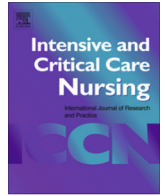




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The experience of Greek families of critically ill patients: Exploring their needs and coping strategies

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ABSTRACT

Objectives: To explore the experiences, needs and coping strategies of families of patients admitted to adult intensive care units.

Design and setting: A descriptive qualitative research design was chosen using an inductive thematic content analysis approach. Semi-structured interviews were conducted with fourteen family members in three hospitals of Crete.

Findings: Four main themes were derived from data analysis. Our results showed that family members were in turmoil having to deal with intense and alternating feelings. The protection of patient's dignity and well-being was of utmost importance mainly by maintaining proximity. Getting comprehensible information and building communication with the healthcare providers was often problematic. Three coping strategies were used: optimism, family support and spirituality.

Conclusion: This study is a contribution to the understanding of Greek family's experiences and psychosocial needs during critical illness. A family-inclusive framework should be promoted and implemented in intensive care recognising and supporting family's role in the patient's illness and recovery.

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Implications for Clinical Practice

- Planning appropriate interventions to detect early and reduce the stress of families related to the vast changes of the critically ill experience.
- Meeting family's need to be near the patient and be reassured that he/she is being cared for with dignity and respect by applying flexible visiting practices.
- Assessing and addressing factors impeding health professionals' communication with family members. Effective communication should be promoted as this is a source of empowerment, reassurance, and hope for the family members.
- Implementing a family-centred philosophy in the intensive care unit by acknowledging particular family vulnerabilities and issues of spirituality and optimism as important coping mechanisms.

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Introduction

The admission to an Intensive Care Unit (ICU) is a stressful and traumatic experience for family members causing a disruption in their life and requiring continuous adjustments on their part as the patient's condition changes (Davidson, 2009). As it frequently occurs without warning, patient's family is overwhelmed by the circumstances and needs to find new coping mechanisms to deal with the situation (McClowry, 1992; Chui and Chan, 2007). It was found that even a planned admission can be particularly stressful for family members (Norheim, 1989).

The family constitutes an important component of caring during critical illness, as, most frequently, the patients are not able to take decisions concerning their care or develop a therapeutic relationship with the healthcare team. Families can help the staff to effectively interact with the patient, and facilitate staff's understanding of patient's preferences (Al-Mutair et al., 2013a; Engström, 2007; Wong et al., 2015). Family members' needs, their experiences and coping strategies have received significant attention in the previous years. However a better understanding of these issues in various cultural contexts is required to better meet those needs and provide culturally relevant care. Particularly in Greece perceived needs and coping strategies of patient's family during critical illness remain underexplored.

Background

Since Hampe's (1975) pioneering work on the needs of the grieving spouses of critically ill patients in a hospital setting, many studies have been conducted to understand the family needs of persons hospitalised in ICUs. Most of these studies adopted a quantitative approach using the Critical Care Family Needs Inventory (CCFNI), a self-report instrument developed by Molter (1979) and later modified by Leske (1986). Molter's conceptual framework was based on both family systems theory (Olsen, 1970; Bowen, 1985) and crisis theory (Lindemann, 1944; Caplan, 1964). According to the family systems theory family is a unit with interconnected and interdependent members in a dynamic relationship. The hospitalisation of the critically ill adult constitutes a crisis situation according to Caplan's definition of situational crises (Caplan, 1964), as it impacts the equilibrium and the functioning of family system as a whole and cannot be resolved by the customary problem-solving resources (McClowry, 1992). Understanding family needs during crisis and meeting those needs are also beneficial for the therapeutic outcome (Davidson, 2009; Frosch and Kaplan, 1999).

According to studies using the CCFNI questionnaire the family members' most important needs are those for information and hope, and the need for support from hospital staff (see for a review Al-Mutair et al., 2013a,b; Holden et al., 2002; Paul and Rattray, 2008; Verhaeghe et al., 2005). The ranking of these needs diversified through the years. For instance while initially emotional support ranked first, it was replaced the next decades by the need for information and reassurance of the quality of care being delivered (Khalaila, 2013; Molter, 1979).

It is well established that families of a critically ill feel strongly the need to be near him/her and desire direct, accurate and detailed information from the healthcare personnel (Al-Mutair et al., 2013a,b). Research has shown that family members express a strong need to be heard, to feel connected to nurses and physicians and to have frequent contact with the patient (Adams et al., 2014). Therefore adequate information, effective communication, understanding of the diagnosis, prognosis and treatment are important parameters to enable family members to adequately comprehend the nature of the disease, consider the possibility of imminent

death and have an integrated picture of the patient's condition (Adams et al., 2014; Davidson, 2009).

The admission of a family member to the ICU due to a life threatening condition can cause significant changes and continuous tension in the family, reinforced by the constant state of uncertainty associated with the health condition of the patient (Eggenberger and Nelms, 2007). Psychological distress under these circumstances may lead family members to post-traumatic stress disorder (PTSD), anxiety, lack of sleep, depression, fatigue, changes in eating habits and despair (Carlson et al., 2015; Day et al., 2013; Rusinova et al., 2014; Schmidt and Azoulay, 2013; Van Horn and Tesh, 2000). These might impact negatively on the relationship between the family and the intensive care staff as well (Davidson and Jones, 2012; Molter, 1979).

The implementation of holistic care, a comprehensive model of caring acknowledging a person as a whole and attributing equal importance to psychosocial factors to the treatment process is very significant for the critically ill. Furthermore including in this model a family-centred approach by creating a caring environment to meet both the needs of the individual and the family is a great challenge for a critical care unit (Eggenberger and Nelms, 2007; Henneman and Cardin, 2002). Nevertheless research findings indicate that healthcare professionals are not paying enough attention to meet the psychosocial needs of the family, i.e. communication, information, emotional support, more flexible visiting hours and the need of the family to feel accepted and discuss the possibility of imminent death (Browning and Warren, 2006; Carlson et al., 2015; Khalaila, 2013; Van Horn and Tesh, 2000).

Although qualitative studies add a more in-depth understanding of family needs, a limited number of studies were found, coming predominantly from Anglo-Saxon countries (e.g. Burr, 1998; Coulter, 1989; Fulbrook et al., 1999; Jamerson et al., 1996; Wilkinson, 1995). Albeit local or cultural factors should also be considered, as they may affect differently family members' needs, there is restricted qualitative research from other cultural contexts (Al-Mutair et al., 2012b; Chui and Chan, 2007; Engström, 2007; Wong et al., 2015). In the Greek context research on family needs is scarce mainly based on quantitative data (e.g. Chatzaki et al., 2012; Paparrigopoulos et al., 2006), while fewer studies focused on these needs from a qualitative perspective (Plakas et al., 2009).

Aim

This study aimed to explore the experiences, needs and coping strategies of families of patients admitted to Adult Intensive Care Units of three hospitals in the island of Crete, Greece.

Method

Design

A descriptive qualitative design was used in the present study. Qualitative designs are considered the most appropriate approach for exploring human experiences and interpreting phenomena under investigation (Berg, 1989; Burns and Grove, 2001). This methodological approach may provide in-depth understanding and specific knowledge on how family members experience their patient's hospitalisation in ICU, an area that is not explicitly researched in Greece.

Context and participants

The study was conducted in the Adult Intensive Care Units of three public hospitals, all three located in the island of Crete (Greece). The first hospital (site 1) is a general hospital with 412

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