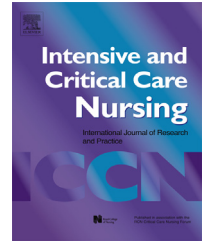




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Parents' experiences of family functioning, health and social support provided by nurses – A pilot study in paediatric intensive care



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KEYWORDS

Child;
Family-centred care;
Family functioning;
Family health;
Intensive care;
Social support

Summary

Objectives: The objective of this study was to describe parents' experiences of family functioning, health and social support provided by nursing personnel, while their child was in intensive care, and to determine how social support was associated with family functioning and family health.

Design: Cross-sectional study.

Setting: The data were collected by a self-administered questionnaire from 31 parents of critically ill children from 2010 to 2011. The data were analysed statistically.

Main Outcome Measures: The parents considered their family functioning, health and social support provided by the nursing personnel to be good.

Results: The sub-area of family functioning that rated the lowest was strengths of family, whereas the lowest rated sub-area of family health was ill-being. Child's previous hospital treatments were associated with family health. Parents, whose child had already been in hospital care, reported more well-being and less ill-being than parents with children hospitalised for the first time. Parents' education was associated with family functioning, family health and social support given by the nurses. Weak positive correlation was also found between social support given by nurses and family health experienced by parents.

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Conclusion: There is a need to discuss how nursing care can further support parental resources.
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Implications for Clinical Practice

- It is necessary to consider how parents' resources could be reinforced and the negative feelings alleviated through nursing.
- The area of concrete aid could be improved as the parents felt they received it less compared to the affirmation and affect.
- Affect could be increased by paying more attention to continuity of care after an intensive care period.

Background

The purpose of paediatric intensive care is to support children and young people with imminent or existing organ failure due to acute disease, trauma or elective treatment like surgery, and assumed to be curable (Barry et al., 2010). The role of family is highlighted in the paediatric intensive care; family is the primary source of strength and support for ill children and parents feel responsible for the child even if he/she is hospitalised. Family members are important information and perspective providers for the clinical decision making. That is why the family-centred philosophy of care should be integrated in paediatric nursing practice and study (American Academy of Pediatrics, 2003).

There are previous qualitative studies about parents' paediatric intensive care unit (PICU) experiences (Colville et al., 2008; Haines, 2005; Latour et al., 2011b). There are also a few validated instruments, such as the Critical Care Family Needs Inventory (CCFNI) and Parental Stressor Scale: Paediatric Intensive Care (PSS: PICU), are available to study either parental needs in PICU or parents' stress during or after the PICU experience. However, an instrument that could be used for assessing family functioning and family health from the client's perspective during their PICU experience has not been presented before. Such an instrument would contribute to family nursing knowledge and the development of family-centred nursing care in PICU context. The instrument could also be used for assessing the association between social support received by families and family functioning and family health.

Family functioning is one of the main aspects of family study. According to Paavilainen et al. (2006) family functioning consists of family relationships, structural factors of family, strengths of family and relationships outside family (Paavilainen et al., 2006). The intensive care of a family member, e.g. child, affects everyday life and family functioning in many ways. It causes stress manifesting as eating and sleeping disorders as well as irritability. Furthermore, a family member in the intensive care unit influences daily routines of the rest of the family. The family must adapt to changes in the condition of the patient. (Koponen et al., 2008.) Family members' perceptions of family functioning may vary. Doucette and Pinelli (2004) studied the

relationship of family coping, resources and strains of family adjustment following the neonatal intensive care unit experience. After 1.5–2 years the mothers reported improved family functioning, whereas fathers reported the opposite.

The illness of a family member is reflected in the health of the whole family, and sometimes family members must compromise on their own well-being to promote the health of the whole family. This is the case especially in families with children. (Åstedt-Kurki et al., 1999.) Severe illness in a child affects the family health. It changes familiar daily routines and roles of the family members (Knapp et al., 2010). Parents experience stress about their child's intensive care (Board, 2004; Bronner et al., 2010; Colville and Cream, 2009). The sources of stress experienced by the parents are parental role alteration, alterations in the child's appearance, tubes and needles in the child and monitor alarm sounds (Shudy et al., 2006). Other identified stressors include nursing procedures and communication difficulties with intensive care unit staff (Board and Ryan-Wenger, 2003; Shudy et al., 2006). Siblings of a critically ill child may also show physical and psychological symptoms, and therefore should not be forgotten (Houtzager et al., 2005). Åstedt-Kurki et al. (2004) define family health through five sub-areas: values, well-being, ill-being, knowledge and activities (Houtzager et al., 2005). Values mean freedom, security and relationship to the natural environment. Well-being means effortless coping, no pain or symptoms and carefree existence. Ill-being, on the other hand, means feelings of discomfort like pain and bad feelings. Knowledge refers to knowing that one is healthy, whereas activities mean promoting one's health for example via exercising (Åstedt-Kurki et al., 2004).

Social support means human interaction that involves one or more of the following elements: affection (referring appreciation, admiration, respect or love or creating a sense of security), affirmation (referring reinforcement, feedback, influencing the individual's way of making decisions) and concrete aid (referring objects or money, spending time in helping someone) (Kahn, 1979; Tarkka et al., 2003). The need for social support grows when people are in an unexpected situation or confronted with a change or stressful experience such as a child's admission to intensive care. Earlier studies show that parents of critically ill children often rate their informational needs higher than

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