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Psychological Outcomes in Parents of Critically Ill Hospitalized Children

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ABSTRACT

Parents of children in pediatric intensive care units (PICUs) are subjected to significant psychological stress. The purpose of this study was to determine the prevalence of, and factors associated with anxiety, depressive symptoms and decisional conflict in parents of children hospitalized in the PICU. The study employed a descriptive, cross-sectional design to investigate the psychological status of 118 parents of 91 children (74 mothers and 44 fathers) admitted to the PICU, using measures of anxiety (STAI), depression (CES-D), and decisional conflict (DCS). Using hospital data and self-administered questionnaires, information on child and parent characteristics and psychological outcomes were collected. Objective measures of parental sleep also were examined using actigraphy and sleep diaries. The research findings indicated that 24% of parents achieved scores characteristic of severe anxiety. Proportions of parents with symptoms indicative of major depression and significant decisional conflict were 51% and 26% respectively. For all psychological outcomes, higher levels of social support were protective. Inconsistency in sleep schedule and sleep location affected psychological outcomes and are possible targets for future interventions. Given evidence that parents of children admitted to the PICU are at risk for developing post-traumatic stress symptoms, future studies should examine the effects of hospitalization on long-term parental psychological outcomes. Screening for those at risk and implementing interventions to promote coping strategies and reduce decisional conflict may be beneficial. Pediatric nurses have a critical role in assessing parents' psychological distress and promoting family health during a child's hospitalization.

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Introduction

Having a child admitted to the Pediatric Intensive Care Unit (PICU) is a challenging life experience for parents that can evoke a myriad of emotional responses marked by considerable stress and feelings of uncertainty. Much of the research conducted on parents' experiences of a child's admission to the PICU has focused on identifying potential causes of stress. Common parental stressors identified include the hospital environment, inconsistent communication, alterations in a child's appearance and parental role, and uncertainty relating to a child's illness and future prognosis (Board & Ryan-Wenger, 2003; Colville et al., 2009; Jee et al., 2012). A PICU admission warrants ongoing monitoring, along with numerous diagnostic and invasive procedures to help a child overcome an acute health change. As such, parents of children admitted to

the PICU have higher levels of stress than parents of children admitted to general pediatric wards, both during their child's hospitalization (Board & Ryan-Wenger, 2002; Board, 2004), and following discharge (Rees, Gledhill, Garralda, & Nadel, 2004).

A number of studies have examined the long-term impact of a child's PICU admission on parents, reporting high levels of distress, anxiety, and depressive symptoms that persisted for months following hospital discharge (Board & Ryan-Wenger, 2002; Colville et al., 2009; Rees et al., 2004). Longitudinal studies examining parents at two (Balluffi et al., 2004) and eight months post PICU discharge (Colville et al., 2009) found that parents' level of distress during a PICU admission – and not a child's illness severity – was positively correlated with the extent of subsequent posttraumatic stress symptoms. These findings signify the importance of identifying predictors of adequate coping and addressing parents' psychological distress early during the PICU hospitalization.

Despite the clinical and social importance of assessing parents' psychological status during a child's PICU admission, research in this area remains limited. Fauman et al. (2011) measured depressive symptoms in 61 parents of chronically ill children in the first 48 h following PICU admission and found rates of mild to moderate depression of 28% and severe depression of 8%. Higher depression scores occurred in parents

Abbreviations: Center for Epidemiological Studies – Depression scale, (CES-D); Decisional Conflict Scale, (DCS); Multidimensional Scale of Perceived Social Support, (MSPSS); Paediatric Logistic Organ Dysfunction, (PELOD); Pediatric Intensive Care Unit, (PICU); Spielberger State-Trait Anxiety Inventory – state anxiety subscale, (STAI).

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of children with planned PICU postoperative admissions, and an inverse correlation between time since a child's diagnosis and parents' depressive symptoms was observed. However, the study's examination of depression solely in parents of children with chronic illnesses (Fauman et al., 2011) provides little clarification of clinical implications for the wider PICU patient population.

Anxiety and depressive symptoms are thought to negatively affect comprehension of medical information and decision-making. Nonetheless, the last few decades have seen an increased focus on improving family members' participation in shared decision-making, given the widespread recommendations for enhanced patient and family-centered care practices (Davidson et al., 2007; Heyland et al., 2003). Research on family members' decision-making in both adult (Heyland et al., 2003) and pediatric intensive care settings (Madrigal et al., 2012) suggests that the majority of families do prefer some degree of shared decision-making with the medical team. However, family members also report difficulty with making decisions on behalf of loved ones and are often asked to make choices under considerable stress and uncertainty (Cohen, 2004; Hickman, Daly, & Lee, 2012), which has the potential to contribute to further psychological distress (Davidson, Jones, & Bienvenu, 2012).

Several studies indicate parents of hospitalized children experience reduced sleep duration, increased nighttime awakening and difficulty falling asleep (Matthews, Neu, Cook, & King, 2014; McCann, 2008; McLoone, Wakefield, Yoong, & Cohn, 2013). In the general population, nighttime sleep deprivation has been shown to significantly impact cognitive and psychological function, with reports of an increase in mood disorders such as anxiety and depression (Dinges et al., 1997; Nilsson et al., 2005; Pilcher & Huffcutt, 1996). Even one night of sleep deprivation has been found to compromise advanced cognitive thinking and decision-making ability (Harrison & Horne, 1999). During their child's hospitalization, parents are required to understand complex medical information and participate in decision-making. The consequences of poor sleep quality on parents' psychological well-being and decision-making are not well-understood. However, reports of poor sleep quality in hospital suggest that parents may experience negative mood and difficulty in making decisions under such circumstances.

In summary, little is known about the prevalence of clinically important psychological difficulties such as anxiety and depression, the degree to which parents struggle with decision-making, or factors that may influence psychological distress and decision-making experiences of parents while their child is hospitalized in the PICU. Insight into which parent (e.g. gender, race, marital status, social support, sleep quantity), child (e.g. age, severity of illness, reason for admission) and environmental (e.g. distance from home, parental sleep location) factors are associated with psychological difficulty is essential for identification of parents in need of targeted intervention. Furthermore, the majority of available studies of parents with critically-ill children overlook fathers' experiences, focusing exclusively or disproportionately on mothers (Board & Ryan-Wenger, 2003; Noyes, 1999; Rees et al., 2004; Tomlinson, Harbaugh, Kotchevar, & Swanson, 1995).

Without an understanding of how psychological distress and decisional conflict differ across family demographics and characteristics of both expected and unexpected PICU admissions, it is difficult for health care providers to identify parents at risk for undesirable psychological consequences. Nurses' close contact with families is central to their ability to assess parents' psychological status and tailor specific interventions for effective family-centered care and support. Knowledge of various influential factors can be used when identifying supportive nursing practices aimed at promoting family health and parents' decision-making ability during a child's hospitalization.

The primary aims of this exploratory study were 1) to ascertain the prevalence of anxiety, depressive symptoms and decisional conflict in parents; and 2) to identify factors associated with parental anxiety, depressive symptoms and decisional conflict during their child's hospitalization in the PICU.

Methods

This paper reports on psychological outcomes which were measured as part of a larger study of sleep quantity and quality (Stremler et al., 2014) and a qualitative examination of parents' experiences while their child was hospitalized in the PICU (Stremler, Dhukai, Wong, & Parshuram, 2011).

Participants and Recruitment

The study was conducted in a 36-bed quaternary-level PICU in an urban, research-intensive pediatric hospital. Parents of admitted children were recruited to a maximum of two parents per child by convenience sampling. Eligibility criteria included English-speaking parents who had a child expected to remain in the PICU for at least two nights following enrollment. If a parent had a diagnosed sleep disorder or if their child was receiving end-of-life care, they were excluded from the study.

Procedures

Institutional research ethics board approval was obtained. Unit staff identified eligible patients and referred interested parents to a study research assistant (RA) to learn more about the purpose of the study. Following written consent, participating parents completed a baseline demographic data questionnaire at the time of enrollment. Data regarding the current hospitalization were collected from the child's medical records. Participating parents were provided an actigraph to wear on their non-dominant wrist for objective measurement of sleep over five consecutive days and nights. The RA met with parents to explain the use of the actigraph and gave instructions on completing the corresponding sleep diary. The RA visited each parent in the unit or telephoned the parent at home each morning to ensure no difficulties had been encountered with actigraphy or sleep diary. Following the fifth night of actigraphy, the RA visited parents to collect the actigraph and sleep diary data. At this time, the RA had parents complete a final questionnaire, aimed at examining psychological outcomes (e.g. anxiety, depressive symptoms, decisional conflict, social support). The final questionnaire was self-administered and parents sealed their questionnaires in envelopes marked only with a study identification number, reducing social desirability bias and providing confidentiality. If completion of the questionnaire uncovered a participant's high score of anxiety on the State-Trait Anxiety Inventory (STAI) (>59) or depression on the Center for Epidemiologic Studies Depression Scale (CES-D) (>14), the primary investigator notified the participant and a visit to a family physician or health professional specializing in mental health was recommended. A referral to a PICU social worker was arranged if the parent was willing. Each parent received a \$10 gift certificate following completion of data collection in thanks for their participation in the study.

Measures

Psychological Outcomes

Anxiety. The State-Trait Anxiety Inventory (STAI) incorporates two subscales that measure state anxiety and trait anxiety (Spielberger, 1983). The 20-item self-report State-Trait Anxiety Inventory, state-anxiety subscale (STAI) was completed by parents to assess levels of relatively transient, situation-related (state) anxiety. Items are rated on a 4-point Likert-type scale to produce a total score ranging from 20 to 80. Higher scores indicate higher levels of state anxiety, such that a score of 40–59 indicates moderate anxiety and a score ≥ 60 , severe anxiety. The STAI-State questionnaire has demonstrated acceptable reliability (0.86 to 0.92) and good discriminant validity (Spielberger, 1983).

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