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Original Article

Dealing with parents' existential issues in neonatal intensive care

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ABSTRACT

Staff at neonatal intensive care units (NICU) are often confronted with existential questions brought up by the parents of sick newborns. This study explores how hospital staff approach parents' existential issues. Thirty-two interviews with physicians, nurses, counsellors, psychologists and priests at four NICUs were analysed using qualitative content analysis. Physicians and nurses found it difficult to deal with the existential issues of parents. Some considered that it was not their job and referred parents to a counsellor or psychologist. However, counsellors and psychologists noted that many parents would rather speak to a physician or a nurse whom they were already familiar with. Several of the priests felt that their job included providing support for the staff as much as for the parents. To adequately encounter parents' existential issues, physicians and nurses need training and guidelines concerning cooperation between the different professions.

Introduction

Seriously premature or otherwise ill newborns are treated at a neonatal intensive care unit (NICU). Most children recover, but a small group of children have more serious conditions, and it is uncertain whether they will survive or recover without permanent injury (SNQ, 2017). The situation for the parents of these children is particularly difficult. The majority of parents of children cared for at a NICU have never imagined that their newborn child would require treatment there. The way the staff handles parents' concerns is of great importance to parents (Stacey et al., 2015; Tandberg et al., 2013; Wigert et al., 2014).

In recent years, family-centred care has become an increasingly prominent healthcare model in neonatal care. Family centered care is characterised by close collaboration between staff and the child's family. The staff work actively to strengthen the parents' role as parents (Harrison, 2010) and to support them emotionally (Turner et al., 2014). Often they engage in conversations with parents in which the experiences and feelings of the parents can be brought up (Wigert et al., 2013).

When people are confronted with dramatic events, such as illness, existential issues to which there are no certain answers often arise (Mok et al., 2010). People's understanding of these issues is affected by their previous experiences and their current life situation (Puchalski et al., 2014). Previous research shows that existential issues and needs are seldom recognised in medical care (Ernecoff et al., 2015; Udo, 2014), although these issues affect the ethical approach of the staff towards the patient and his or her family and can thus have a significant impact on medical care (Sawatzky et al., 2005). Parents and relatives generally want staff to respond to their existential questions and give them the opportunity to discuss these issues (Strang et al., 2014), a goal which staff may also share (Balboni et al., 2014a).

Parents of children in the NICU often struggle with existential questions related to their child's severe illness (Wigert et al., 2014). The aim of this study was to describe staff members' experiences of dealing with parents' existential issues in neonatal intensive care.

Method

Design

A qualitative interview study was conducted with NICU hospital staff. The interviews were analysed according to Elos and Kyngäs' (2008) method of qualitative content analysis.

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Participants

Thirty-two physicians, nurses, counsellors, psychologists and priests who participated in the study were recruited from four NICUs in southwestern Sweden: one university hospital with a level III NICU and three level II NICUs. Ten physicians (female and male; six neonatologists and four neonatal fellows), ten nurses (all female; nine pediatric nurses and one midwife) were from the university hospital. Five counsellors (all female), four psychologists (all female) and three priests (one female and two male), of whom one priest worked at two hospitals, represented four different hospitals. The ages of the participants ranged from 31 to 65 years (mean 47.5) and their work experience ranged from 5 to 39 years (mean 19).

The neonatal units have a family-centred care policy (Harrison, 2010), and parents are welcome to spend as much time as they want at the unit with their child. Swedish parents can receive paid leave from work during their child's illness, allowing both parents to be with their child throughout the hospital stay (Försäkringskassan, 2017).

Interview

Open-ended interviews were conducted between October 2014 and May 2015 and recorded digitally. All interviews were performed in rooms at the hospitals and lasted between 26 min and 61 min (mean 44). One main guiding question addressed during the interviews was 'How do you experience encountering parents' existential issues when their children are cared for at NICU'? All participants were encouraged to speak openly about their experiences, and follow-up questions were used to strengthen the researcher's understanding of the narratives provided.

Analysis of the interviews

The interviews were transcribed verbatim and a qualitative content analysis (Elo and Kyngäs, 2008) was performed. Meaning units which reflected the ways medical and non-medical staff expressed when dealing with parents' existential issues were selected and grouped into categories. The categories and their content resulted in one main category.

Ethics

Ethical approval was obtained from the Regional Research Ethics Committee in Gothenburg, Sweden (Dnr 696-13), and the World Medical Association Declaration of Helsinki (WMA, 2013) was adhered to. All participants gave written informed consent and were informed about guaranteed confidentiality and their right to discontinue the interview at any time.

Result

The content analysis resulted in the main category: "Unclear how existential issues should be addressed at the NICU". The results are presented in text and the quotations are numbered 1–32.

Physicians and nurses confronted with parents' existential issues

Lack of training and time

Some physicians and nurses did not feel comfortable when confronted with existential questions. They felt that they lacked education and knowledge in these questions, as they were only trained in caring for child's illness. Others tried to be responsive to the parents' existential issues and considered it their responsibility as staff to give parents the chance to ask questions. It was unclear to them what responsibility they had to respond to existential issues and what was expected of them. Most physicians and nurses would have liked to have more training in facing existential issues.

> "*I'll think, what are my limits, not sure I have the training … these are definitely very difficult conversations*". (Nurse 8)

Another factor that made it difficult to respond to parents' existential issues was the pressured work situation in the NICU and lack of time. According to nurses, the physical environment with several beds per room also made it more difficult to respond to parents' existential issues.

Encountering different values

Through the existential issues of the parents, physicians and nurses were faced with other values than their own, which could be provocative and challenging: for example, the parents' wish that their children not receive any medical treatment, based on religious beliefs. Although they listened to the wishes of the parents, the doctors and nurses always put the child's interests first, as they considered themselves to represent the child's legal right to care and treatment.

> "*There were parents who were very religious and had very strong opinions about how the child should be treated, and especially that treatment shouldn't be stopped, for religious reasons. It was hard to deal with*". (Physician 17)

The physicians and nurses rarely asked the parents which religion they belonged to, as this was considered too private. They were uncomfortable bringing the subject up, as there were no guidelines as to how it should be addressed. Those of the physicians and nurses who chose to ask the parents about their religious affiliation felt confident in doing so and believed that parents might find comfort in their religious beliefs and receive support from their community.

> "*It's easier to deliver bad news to deeply religious people. Whether they're Muslim or Christian, they have an easier time dealing with that kind of pain because they have a deep faith to help them cope*". (Physician 19)

Both physicians and nurses asked parents about their religious affiliation to a higher extent when the parent wore religious symbols. Most of these parents were foreign-born.

> "*When you know that the parents are from another country, you ask, because it matters when it comes to how they think about existential issues, about life and death. You don't ask ordinary Swedes because you expect them to be like society in general, some people are religious and others aren't and you don't talk that much about it*". (Physician 17)

Ways of responding

Many nurses and physicians were unused to responding to existential issues in their work. One way to respond was to mainly listen and not talk much. Another way was to keep a certain distance from the parents, which made it easier to cope with the situation. They described how they could protect themselves by avoiding

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