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RESEARCH

End-of-Life Decision Making for Parents of Extremely Preterm Infants

Manya J. Hendriks and Andrea Abraham

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Correspondence
Manya J. Hendriks, MSc,
Department of Neonatology,
Perinatal Center, University
Hospital Zurich, University
of Zurich,
Frauenklinikstrasse 10,
Zurich CH-8091,
Switzerland.
manya.hendriks@usz.ch

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ABSTRACT

Objective: To explore parental attitudes and values in the end-of-life decision-making process of extremely preterm infants (gestational age $<$ 28 weeks).

Design: Hermeneutically oriented qualitative research design with in-depth interviews.

Setting: Level III NICU in Switzerland.

Participants: Purposive sample of seven couples, five mothers, and one father (20 parents).

Methods: Qualitative content analysis was used to categorize and interpret themes from parents' narratives.

Results: Parents described factors that affected the decision-making process in satisfactory or unsatisfactory ways. Transparent information, empathy, and honesty enhanced communication between parents and the health care team. Lack of transparent information and continuous support decreased satisfaction. The level of involvement in decisions differed by setting. Most parents made decisions regarding lung maturation and/or initiation of care in the delivery room. Parent participation in the NICU was experienced differently. Contrary to the hospital's ethical model, few parents recalled being involved in the decision-making process. Some parents experienced a dissociative state of mind that hindered their involvement, whereas others felt actively involved.

Conclusions: Our results suggest the need for careful and continuous professional evaluation of parents' wishes about involvement in the decision-making process, along with descriptions of medical facts and treatment options. A lack of attentive listening and dialogue may cause paternalistic decision trajectories.

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Manya J. Hendriks, MSc, is a research associate in the Department of Neonatology, Perinatal Center, University Hospital Zurich, University of Zurich, Zurich, Switzerland, and a PhD candidate in the Institute of Biomedical Ethics and History of Medicine, University of Zurich, Zurich, Switzerland.

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The birth of an extremely preterm infant (gestational age $<$ 28 weeks) often comes unexpectedly. Therefore, decisions must often be made under circumstances that can be emotionally stressful or morally burdensome for parents and/or health care professionals (HCPs; Provenzi et al., 2016). Because neonates born at the borderline of viability have a wide range of outcomes, it is hard to predict before or after birth whether they will die or survive with or without impairment. Prognostic uncertainty makes decisions about life-saving treatment particularly complex (Leuthner, 2014).

Over the years, different decision-making approaches have been developed to guide parents through the uncertain context of prematurity. In the past, HCPs considered it their professional prerogative to make decisions about initiating or withholding intensive care treatment. This concept is known as paternalism. In recent decades, however, the focus of decision making has shifted to include concepts such as informed decision making, informed shared decision making, partnership, patient involvement, patient-centered care, and evidence-based patient choice (Moumjid, Gafni, Bremond, & Carrere, 2007). Currently, most guidelines and policies advocate shared decision making and promote parental involvement before and after birth. They are based on the premise that decision making should be a collaborative venture between neonatal HCPs and parents (American College of Obstetricians and Gynecologists et al., 2015). In fact, it has been shown that parents want to participate in life-support decisions about their infants' care (Moro et al., 2011; Provenzi et al., 2016; Weiss, Barg, Cook, Black, & Joffe, 2016). Moreover, parental involvement in combination with compassionate communication, consistent information, and support from HCPs contributed to parental satisfaction with decisions (Brosig, Pierucci, Kupst, & Leuthner, 2007; Obeidat, Bond, & Callister, 2009). Hence, the relationships and communications between HCPs and

More emphasis has been placed on parental involvement in decision making in the NICU, but this shared approach is understudied and difficult to implement in practice.

parents are key in establishing parental involvement (McHaffie, Laing, Parker, & McMillan, 2001; Moro et al., 2011), whereas nurses play important roles in supporting parents in making decisions (Kavanaugh, Moro, & Savage, 2010).

However, despite the prevalence of this perspective, implementation of shared decision making in practice has remained difficult (de Vos et al., 2015; Stiggelbout et al., 2012). Consequently, empirical data are important to provide further insight into how parents of extremely preterm infants experience communication with the health care team and how this affects involvement in end-of-life (EOL) decision making. Therefore, we examined how parents reach medical decisions for their extremely preterm infants in our perinatal center in Switzerland. We sought to identify communication patterns between parents and neonatal HCPs that lead to the perception of a satisfactory or unsatisfactory decision process. We further assessed the degree of parental involvement within the ethical decision-making model applied in our perinatal center between 1994 and 2015. This study was part of a larger research project on EOL decisions for extremely preterm infants in Switzerland. In this qualitative study we aimed to shed light on the perspectives of parents, whereas the quantitative part of our project focused on the perspectives of society and of HCPs who work in Level III NICUs (Hendriks, Bucher, et al., 2017; Hendriks, Klein, et al., 2017).

Methods

Sample and Setting

Out of 42 potential cases, 20 parents of 13 extremely preterm infants (7 couples, 1 father, and 5 mothers) were recruited by purposive sampling. Potential participants who met the following inclusion criteria were recruited: parents of newborns who were born alive at younger than 28 weeks gestation and died in the delivery room or in the NICU from 2013 through 2015. Parents with various linguistic backgrounds were invited to participate by means of a translator. A timeframe of 1 to 2 years between the infant's death and the interview was chosen in recognition of the mourning process and of parents' vulnerability (Caeymaex et al., 2011; Rosenblatt, 1995). To reach a homogenous sample, participants were excluded if they gave birth to two or more infants (i.e., multiple births) or if their infants were stillborn. Participants received a letter (written in German and English) from an attending neonatologist and the former director of the neonatology department to solicit participation in the study. Interested participants were asked to contact the interviewers directly by e-mail, phone, fax, or letter. The Ethics Committee of the Canton Zurich (Switzerland) approved the study protocol. Participants gave informed written consent for the research use of the collected data.

Data Collection

Data were collected through narrative interviews with semistructured follow-up questions to clarify specific themes (see Table 1). The interviews were used to explore participants' experiences of prematurity, communication with the health care staff, and the EOL process. In developing the interview guide, the literature on EOL decision making for parents of extremely preterm infants was taken into account (Leuthner, 2014; Rosenthal & Nolan, 2013). Additionally, this was complemented by our field notes from observations in the NICU, informal interviews with various staff members (i.e., neonatologists, a physiotherapist, a psychologist, a pastor, and a music therapist), and chat forums used by affected parents. The interviews started with a narration of participants' experiences, that is, they were invited to share their stories starting with the pregnancy until after the death of the newborns. Some participants showed photographs, diaries, and other memories of their newborns. The interviews were conducted in a place selected by the participants. The interviews were audio-recorded, lasted approximately 60 to 160 minutes (97 minutes on average), and were transcribed by a professional transcriptionist.

Data Analysis

Data analysis followed hermeneutically oriented qualitative content analysis, which takes into account previously defined research questions outlined by the literature and allows categories to emerge out of the data. This deductive–inductive procedure was guided by Kuckartz's approach of content analysis, which integrates elements from grounded theory such as theoretical memos and iteration to generate not only descriptive results but also conceptual models of the topics under study (Kuckartz, 2014). Hence, this approach is focused on the importance of context in determining meaning that is data driven and iterative. Our analysis included the following steps:

Andrea Abraham, PhD, is a research associate in the Department of Neonatology, Perinatal Center, University Hospital Zurich, University of Zurich, Zurich, Switzerland; the Head of Research in Dialog Ethics, Interdisciplinary Institute of Ethics in Health Care, Zurich, Switzerland; and a research associate in the Institute of Social Anthropology, University of Bern, Bern, Switzerland.