



CASE HISTORY

Losing one twin in the NICU - A case study of the parental experience



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KEYWORDS

Active parents; Attachment; Bereavement; Consistency; Discourse; Loss; NICU; Parent experience; Twin **Abstract** The aim of this case study was to generate a deeper understanding of parents' experiences of losing one twin in the NICU.

In an in-depth interview the parents told their story of giving birth to twins born extremely preterm and shortly after losing one of them.

A thematic analysis was conducted and revealed tree overall themes. These themes indicate that besides struggling with grief related to the loss of one infant, the parents were challenged by the medical discourse, the lack of staff continuity and space to develop parenthood. This case study emphasizes how the loss of a premature twin reinforced the parents' need of an understandable dialogue with a team of nurses. Furthermore the nurses have to offer a close partnership and create the necessary space for parents to develop parenthood while simultaneously dealing with the unexpected and traumatising circumstances related to the loss of an infant.

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Introduction

Over the last decades there has been a dramatic increase in the proportion of multiple births throughout the western world (Martin et al., 2013). This development is caused by an increasing incidence of fertility treatment as well as a continuous

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rise in maternal age at time of pregnancy (Ingerslev et al., 2012). Simultaneously, there has been a rise in the rate of preterm births in twin pregnancies. With an average gestational age below 35 weeks, twins have a higher rate of morbidity and are more than four times as likely to die in infancy compared to singletons (Blondel et al., 2002; Martin et al., 2013; Biggio and Anderson 2015). The overall development emphasizes the need to explore the parental perspective on having premature twins and being admitted to a neonatal intensive care unit (NICU), especially in the event that one of the infants die.

Literature review

Pector & Smith-Levin found that the majority of parents of premature twins have undergone in vitro fertilization (Pector and Smith-Levitin 2002). Thus, these parents have invested both physically and emotionally in the privilege of parenthood, making them feel more stressed during pregnancy and more anxious than parents of singletons when being admitted to the NICU (Pector and Smith-Levitin 2002). Furthermore, parents who lose one twin or their entire set of multiples experience a more intensive grief and have a higher risk of developing a subsequent depression (Pector and Smith-Levitin 2002). According to Pector & Smith-Levin, this experience can impair their attachment to the surviving infant due to fear of losing this child as well (Pector and Smith-Levitin 2002). The parents have ambivalent emotions, wanting to open up to a close relation with the surviving infant but at the same time having difficulties diverting their attention from the mourning of the lost twin.

McGrath, Butt & Samra explored the ambivalence of experiencing new life and death simultaneously, and how parents cope with the complexity of emotions (McGrath et al., 2011). They found that balancing the mourning process with the needs of the surviving infant could be overwhelming and lead to one or both parents delaying their grief process. Another study showed that especially fathers postponed their grief with a mean of 25 months after the death of an infant, while mothers grieve actively and feel more depressed at the time of their loss (Swanson et al., 2009).

Kendall and Guo described that some parents are still emotionally affected months and even years after the loss, quite often putting a strain on the parents' partnership (Kendall and Guo 2008). This study emphasizes that early

intervention and support from the NICU nursing staff can facilitate parents coping with the death of their infant, thereby minimizing the long term impact of their loss and encouraging the interaction with the surviving child (Kendall and Guo 2008).

In a critical literature review of how parents cope with the loss of one premature twin, Lee discussed the difficult challenge parents face in going through a mourning process while still trying to focus on the survivor (Lee, 2012). The study found that a healthy attachment to the surviving twin requires parents to mourn or to have mourned the lost child (Lee, 2012). A number of studies indicate that the nursing staff in the NICU can accommodate the mourning process by rebuilding the parents' faith that they have the capacity to overcome the loss of an infant (Lee, 2012). Furthermore, nursing staff must also respect the parents' different emotions by acknowledging the existence of the lost infant and encourage the parents to discuss the death of their child whenever they wish. However, Pector found that the health professionals' response to death did not meet the needs of the parents, leaving them feeling distressed, guilty and denied permission to grieve (Pector, 2004).

Little is known on how to guide clinical practice and accommodate the unique caring needs of parents who experience the loss of one twin while caring for the other (Pector and Smith-Levitin 2002, Pector, 2004; Lee, 2012). The aim of this case study was to explore the parental experiences in the NICU when losing one premature twin, and to gain a deeper understanding of how the nursing staff can support the parents.

Method

A qualitative case study is defined as an empirical exploration of a chosen contemporary phenomenon in its natural context (Robson, 2002; Flyvbjerg, 2006; Ramian, 2008). This article presents a specific clinical case consisting of an interview with a couple who experienced the loss of one twin while being admitted to the NICU; the couple wished to be interviewed to share their experiences with others.

To gain an in-depth understanding of the parental experience it is necessary to unfold the unique context in which the case occurred (Flyvbjerg, 2006; Ramian, 2008). In addition to obtaining approval from the ethics committee, a number of specific ethical considerations were

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