

# Extreme prematurity in Switzerland: the silent suffering of parents whose children do not survive

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## Abstract

This viewpoint focuses on the suffering of parents whose extremely preterm infant died after spending some days or weeks in the neonatal intensive care unit (NICU) of an urban Swiss University hospital. These reflections are based on our in-depth qualitative study during which we have conducted participant observations in a NICU, narrative interviews with 20 parents, and five interviews with health care professionals. We discuss these empirical results by illustrating the various dimensions of parental suffering regarding parenthood, withdrawal of care and the dying and death of the child. We then relate our findings to the conceptualizations of suffering as proposed by the physician Eric Cassell and the bioethicist Howard Brody. The last section highlights the implications of parental suffering for palliative and bereavement care that aims to move beyond the hospital setting.

In Switzerland, around 300 newborn infants each year (0.3–0.4%) are born extremely premature, i.e. before the 28<sup>th</sup> week of gestation [1]. Common causes of such a premature birth can include multiple pregnancies, infections, and chronic conditions, however, the cause is often not known [2]. Over the past several decades, technological improvements in the field of neonatology have led to an increase in survival numbers for infants born at the margin of human viability [3]. However, increased survival rates for extremely premature infants are not an unmitigated success. Some survivors are left with lifelong medical problems, cognitive or developmental delays, or neurologic impairments [4]. And some infants born extremely premature do not survive. Although there is a lot of (inter-)national variation in survival rates for reasons that go beyond this viewpoint article [5], the average survival rate in Switzerland ranges from 4% at 23 weeks to 88% at 27 weeks of gestation [6]. More importantly, it is hard to predict before and after birth which babies will die and which babies will live with or without long-term impairments [3]. The following viewpoint will focus on the suffering of parents whose extremely preterm infant died after spending some days or weeks in the neonatal intensive care unit (NICU) of an urban Swiss University hospital.

These reflections are based on our in-depth qualitative study<sup>1</sup> during which we have conducted participant observations in a NICU, narrative interviews with 20 parents, and five interviews with health care professionals [7, 8]. We will discuss these empirical results by illustrating the various dimensions of parental suffering regarding parenthood, withdrawal of care and the dying and death of the child. We will then relate our findings to the conceptualizations of suffering as proposed by the physician Eric Cassell and the bioethicist Howard Brody. The last section will highlight the implications of parental suffering for palliative and bereavement care that aims to move beyond the hospital setting.

## Parenting from a distance

A premature birth often comes unexpectedly and represents not only a clinical challenge but also a complex and stressful experience for the parents concerned [9, 10]. The uncertainty of the baby's survival, possible medical complications and future disabilities evoke a diverse range of emotional reactions ranging from confusion, disappointment, distress, shame, failure, guilt, and helplessness [11–13]. When the extremely preterm infant is transferred to the NICU, this is the onset of a period during which health care professionals are the primary care givers and parents are dependent on instructions and support to care for their infants. The foreign technical environment, lack of intimacy and privacy, and the frailty of the child's health condition create a context in which parenting is experienced as a stressful oscillation between hope and fear. Even though they are considered parents, they can only enact this role from a distance. After delivery, extremely preterm infants are immediately separated from their mothers in order to provide them with neonatal intensive care. Efforts to subsequently facilitate parent-child encounters, i.e. physical contact such as feeling, touching, smelling, and holding, in the NICU can be limited due to the medical circumstances [14]. Without such physical contact it can be challenging for parents to

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grasp their baby's existence in the highly alienating setting of the NICU. Many parents when facing their baby in the incubator express disbelief that this is "their" baby. Parental bonding, as a physical, social, and emotional relationship-building interaction between parents and baby, is experienced as challenging for parents of extreme preterm infants [8].

### Dying in the NICU

After a period of distant parenting it was only when the infants' situation deteriorated and death was approaching that intense child-parent bonding could occur in our sample. Withdrawal of neonatal intensive care meant that parents could now hold their babies for the first and last time, feel them, experience intimacy and privacy as a family and accompany their baby throughout the process of dying [8]. Furthermore, the emotional nature of a decision to withdraw neonatal intensive care represented an act of parental responsibility [7]. By having the opportunity to spend time together, parents could co-create memories as a family unit. Such intensive child-parent bonding was encouraged for the well-being of the dying infant as well as the current and future well-being of parents [15].

After the dying process, all parents felt the need to spend some time with their deceased baby even though this varied from a few hours to a week. With professional support, parents washed and dressed their child for the first time and created moments of memories as a family. It was thus only in these moments of dying and death that parents could experience *embodied* parenthood (i.e. biopsychosocial experience of being a parent) [8, 16]. When the time came to take leave of the deceased child, parents entered the intense and long-lasting phase of mourning, and the onset of an everyday life without their child.

### Dimensions of suffering

According to the physician Eric Cassell, "[s]uffering is an affliction of persons, not bodies, and can occur in relation to any aspect of a person: physical, psychological, social, or spiritual" [17]. He conceptualises suffering as the fragmentation of personhood, involving a past, presence, anticipated future, the private life and roles. Parents, who have lost their extremely preterm child, experience a fragmentation not only of personhood but also of parent- and familyhood. Suffering, in their case, implies that past visions for their anticipated future as parents and as a family are disrupted and may be gone forever. This biographical caesura is what medical ethicist Howard Brody many years ago called a "broken story" [18]. The death of a child does not only imply a physical disappearance but also an immediate

alteration of visions for the future, of social roles and relationships, and of everyday life [19]. For instance, the very short biography of extremely premature babies often creates a status of non-existence for the parents' social environment. The loss of a newborn child, in contrast to the death of an older child, is a socially less recognized death. As a result, parents are often left alone with their grief and feel socially and emotionally isolated [20].

### Caring for suffering parents in and outside of the hospital

While all the interviewed parents received intensive professional support during the NICU stay of their child, they all recounted the transition from hospital to their home environment as very demanding and burdensome. Whereas in the inpatient setting care was offered and sometimes even imposed on parents, after hospital discharge they had to actively search for professional and private support. Parental bereavement support depends on a multitude of factors, namely their emotional strength, their capacity to search for help, and the availability of (professional) support in their environment. While in the hospital setting parental support is institutionalised, it becomes a purely individual matter after hospital discharge. This is problematic because long-term suffering of parents consist of antenatal fear, feelings of ambiguity in the NICU (or "liminality", i.e. a transitional in-between process), the eventual death of their child and continues after hospital discharge in the home environment. Thus, the process of bereavement calls for long-term support in and outside of the hospital [8].

Perinatal palliative care (PC) is a holistic approach, which starts at the moment of recognition of a potential palliative condition, and provides physical care for the infant and supportive care for the family. The aim is not to prolong life at any cost, rather to ease the suffering of the infant, enhance his or her quality of life, and facilitate informed decision-making with parents. Furthermore, psycho-social and bereavement support is offered to parents, their partners and other family members and care coordination between clinicians across sites of care is provided [21]. Hence, perinatal PC extends from the prenatal phase to the time after the child has died.

However, as of yet, perinatal PC has remained rather underdeveloped in Switzerland [22]. While there is a body of existing (inter-)national knowledge about key elements of perinatal PC and specific guidelines for its provision, evidence shows the inconsistency in the application of palliative care principles in this group [23, 24]. Recently, a Swiss study illustrated how only a small minority of parents of neonates received specialized palliative care services [25]. We hold that long-term palliative care would support parents in coping with

the manifold manifestations of suffering during pregnancy, and during and after the lives of their children. Hence, there is a need in Switzerland to further identify best practice, outcome measures and an evidence base for future practice. Although – or because – the beginning and the end of the lives of extremely premature babies are so close, we should support palliative and bereavement care endeavours that enable “quality care” for babies, “grief support” for parents and recognize the existence of a family no matter how short lived [8].

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#### References

- Berger TM, Steurer MA, Bucher HU, Fauchere JC, Adams M, Pfister RE, et al. Retrospective cohort study of all deaths among infants born between 22–27 completed weeks of gestation in Switzerland over a three-year period. *BMJ Open*. 2017; Forthcoming.
- WHO. Preterm birth 2016. Available at: [www.who.int/mediacentre/factsheets/fs363/en/](http://www.who.int/mediacentre/factsheets/fs363/en/) (accessed 6/7/2018).
- Verhagen E, Janvier A. *Ethical Dilemmas for Critically Ill Babies*. Dordrecht: Springer; 2016.
- Jarjour IT. Neurodevelopmental Outcome After Extreme Prematurity: A Review of the Literature. *Pediatr Neurol*. 2015;52:143-52.
- Guillen U, Weiss EM, Munson D, Maton P, Jefferies A, Norman M, et al. Guidelines for the Management of Extremely Premature Deliveries: A Systematic Review. *Pediatrics*. 2015;136(2):343-50.
- Berger TM, Steurer MA, Woerner A, Meyer-Schiffer P, Adams M, Swiss Neonatal Network. Trends and centre-to-centre variability in survival rates of very preterm infants (<32 weeks) over a 10-year-period in Switzerland. *Archives of Disease in Childhood – Fetal and Neonatal Edition*. 2012;98:e1-e.
- Hendriks MJ, Abraham A. End-of-Life Decision Making for Parents of Extremely Preterm Infants. *Journal of Obstetric, Gynecologic & Neonatal Nursing*. 2017;46(5):727-36.
- Abraham A, Hendriks MJ. “You Can Only Give Warmth to Your Baby When It’s Too Late”: Parents’ Bonding With Their Extremely Preterm and Dying Child. *Qualitative health research*. 2017;27(14):2100-15.
- Aagaard H, Hall EO. Mothers’ experiences of having a preterm infant in the neonatal care unit: a meta-synthesis. *Journal of pediatric nursing*. 2008;23(3):e26-e36.
- Petteys AR, Goebel JR, Wallace JD, Singh-Carlson S. Palliative care in neonatal intensive care, effects on parent stress and satisfaction: a feasibility study. *American Journal of Hospice and Palliative Medicine*. 2015;32(8):869-75.
- Fortney CA, Steward DK. Medical record documentation and symptom management at the end-of-life in the NICU. *Advances in neonatal care: official journal of the National Association of Neonatal Nurses*. 2015;15(1):48.
- Hoffenkamp HN, Braeken J, Hall RA, Tooten A, Vingerhoets AJ, van Bakel HJ. Parenting in complex conditions: Does preterm birth provide a context for the development of less optimal parental behavior? *Journal of pediatric psychology*. 2015;40(6):559-71.
- Schappin R, Wijnroks L, Venema MMU, Jongmans MJ. Rethinking stress in parents of preterm infants: a meta-analysis. *PloS one*. 2013;8(2):e54992.
- Hutchinson SW, Spillett MA, Cronin M. Parents’ experiences during their infant’s transition from neonatal intensive care unit to home: a qualitative study. *The Qualitative Report*. 2012;17(12):1.
- Kymre IG, Bondas T. Skin-to-skin care for dying preterm newborns and their parents – a phenomenological study from the perspective of NICU nurses. *Scandinavian journal of caring sciences*. 2013;27(3):669-76.
- Guillaume S, Michelin N, Amrani E, Benier B, Durrmeyer X, Lescure S, et al. Parents’ expectations of staff in the early bonding process with their premature babies in the intensive care setting: a qualitative multicenter study with 60 parents. *BMC pediatrics*. 2013;13(1):18.
- Cassell EJ. Teaching the Fundamentals of Primary Care: A Point of View. *The Milbank Quarterly*. 1995;73(3):373-405.
- Brody H. “My story is broken; can you help me fix it?”: Medical ethics and the joint construction of narrative. *Literature and Medicine*. 1994;13(1):79-92.
- Arnold J, Gemma PB. The Continuing Process of Parental Grief. *Death Studies*. 2008;32(7):658-73.
- Janvier A, Bauer KL, Lantos JD. Are newborns morally different from older children? *Theor Med Bioeth*. 2007;28(5):413-25.
- Leuthner S, Jones EL. Fetal Concerns Program: a model for perinatal palliative care. *MCN Am J Matern Child Nurs*. 2007;32(5):272-8.
- Bergstraesser E, Zimmermann K, Eskola K, Luck P, Ramelet AS, Cignacco E. Paediatric end-of-life care needs in Switzerland: current practices, and perspectives from parents and professionals. A study protocol. *J Adv Nurs*. 2015;71(8):1940-7.
- Cignacco E, Stoffel L, Raio L, Schneider H. Empfehlungen zur Palliativpflege von sterbenden Neugeborenen. *Z Geburtshilfe Neonatol*. 2004;208:155-60.
- SAMW. *Medizin-Ethische Richtlinien und Empfehlungen: Palliative Care*. 2013.
- Zimmermann K, Bergstraesser E, Engberg S, Ramelet A-S, Marfurt-Russenberger K, Von der Weid N, et al. When parents face the death of their child: A nationwide cross-sectional survey of parental perspectives on their child’s end-of life care. *BMC Palliative Care*. 2016;15(1):30.