



## Lay Summary

**Attitudes and values among health care providers, parents and society regarding end-of-life decision-making in extremely preterm infants in Switzerland**

### Project Team

#### *Project Leader*

Prof. Dr. med. Jean-Claude Fauchère

#### *Other project team members*

Prof. Dr. med. em. Hans Ulrich Bucher  
Dr. theol. Ruth Baumann-Hölzle  
Prof. Dr. med. Thomas M. Berger

### Contact address

Prof. Dr. med. Jean-Claude Fauchère  
Department of Neonatology Perinatal  
Centre, University Hospital  
Frauenklinikstrasse 10  
CH – 8091 ZURICH  
Phone: 0041 44 255 35 84  
E-Mail: [jean-claude.fauchere@usz.ch](mailto:jean-claude.fauchere@usz.ch)

April 10, 2017

In Switzerland, 0.3-0.4% of all babies are born extremely preterm, meaning that they are born between 22 and 27 weeks of gestation. Due to medical progresses, survival rates of infants born at the limit of viability have substantially increased over the last 2 decades. The average survival rate in Switzerland (2005-2009) ranges from 4% at 23 weeks to 88% at 27 weeks of gestation.

When a difficult medical decision must be made for an extremely preterm infant, physicians and parents tend to consider not only the best interest of the child as the only decisional factor. Other factors, such as personal attitudes and values, and aspects of familial autonomy also play an important role in decision-making at the end of life. These in turn are influenced by age, professional experience, culture and religious attitudes. The question this larger project aims to answer is “What factors play a role in the decision-making, and what differences are there between involved neonatal health-care providers (HCPs), parents and society at large?”

This project aims to examine attitudes and values that play a role in end-of-life decisions for infants born extremely preterm. It involves three parts. First and using a questionnaire, we surveyed the Swiss population in order to find out what associations Swiss people have with extreme prematurity and what they think about medical decision-making, quality of life aspects, intensive care measures and societal support in the context of taking care of extreme preterm infants. Second, we asked physicians and nurses working in Swiss neonatal intensive care units (NICUs) about their attitudes and values towards extreme preterm infants. Third, we asked parents whose infant born extremely premature had died to share their stories. These three parts are outlined in the next few paragraphs.

## **A. Survey of the Swiss Population**

### **1. Background**

Over the last decades, new treatment options have resulted into better survival chances for children born extremely premature. However, long-term disabilities have not decreased accordingly. In fact, it is often quite difficult to predict which infants will die, and which will survive with long-term disabilities. This uncertainty can complicate decision-making between parents and health care providers.

End-of-life decision-making – whether to continue, to limit, to withhold or to withdraw intensive care (IC) treatment for infants born extremely premature – can be influenced by the attitudes and values of healthcare professionals, parents, and society at large. Such diverging attitudes have led to differences in the way extreme preterm infants are treated, this mainly depends on someone’s (parent and/or physician) personal beliefs or which cultural background they come from (cultural differences). Also, the level in which parents are involved in the treatment decisions of their extremely premature child can depend on the cultural and social practice. For example, the degree of parental involvement in the decision-making process may vary substantially between France, the United States and Canada.

Additionally, high individual costs, cost-effectiveness aspects and resource allocation could play a complex role in decision-making for extreme preterm infants. Besides immediate care, parents may also take into consideration the society’s acceptance and assistance much later in life when formerly

extreme preterm infants surviving with a moderate or severe disability may need continuous treatment and financial support. Such a social cohesion as perceived by parents may influence their choices about life-sustaining treatment. However, this depends highly on the given circumstances of a country and their solidarity towards people with a disability.

## **2. Goals of the project**

Knowing what attitudes and values play a role in decision-making can be important in understanding the opinions and views put forward by parents and neonatal staff when having to embark in end-of-life decision-making. The attitudes and values within the Swiss population can explain whether social and cultural factors (age, gender or income) lead to different opinions on decisions for extreme preterm infants.

## **3. Methods**

We assessed these aspects by a telephone survey in which we called people and asked questions about extreme prematurity. At the beginning, we explained that an extremely preterm infant is born before 28 weeks of gestation (before the 7<sup>th</sup> month of pregnancy) with a birth weight ranging between 600 and 800 grams, and these infants always required intensive care treatment. In the end, we talked to 1210 adults of 18 years or older living in Switzerland. We asked people about decision-making, quality of life and their solidarity towards disabled people.

## **4. Results**

In our interviews we found out that, the majority of people stated that it is important that parents and the health care team take intensive care decisions together. People younger than 39 years were more likely to find this important than people who were 40-64 years old and 65 years or older. People from the Italian language region of Switzerland gave the physician and health care team more authority to decide on their own. In those cases where parents and doctors would not agree on the care of the infant, most people considered that the parents should have the final say in the decision. Again, the region and age of people shaped their opinions on decision-making. Older people over 65 years were less likely to say that the parents should be the final decision-makers. People from the French and Italian speaking region in Switzerland gave more final power to the physician to make the decision.

When asking people what they considered as the minimal criteria for an acceptable quality of life for infants born prematurely. The four most common answers to this question were: being able to have an independent life, being like others, living without medical assistance or living without a disability. Most people considered that the minimum criteria for a quality of life was the ability to show happiness and emotions and being able to communicate with others. People also mentioned (although less often) the importance of taking care of oneself, completing primary school and earning one's own living.

We also asked people to estimate their own personal solidarity, the solidarity of their friends/family/surrounding and the solidarity across Switzerland toward disabled persons. The Swiss population expressed a high overall solidarity toward disabled persons.

## **5. Significance of the results for science and practice**

An important finding of this study is that decisions should be made through a shared dialogue between the parents and the health care team. Neither the health care team, nor the parents should take these decisions alone. In those rare cases where parents and doctors do not agree, we found that people preferred that parents should have the last say in the decision. The differences in treatment choices were mostly caused by the language region. People from the German language region were more likely to see parents as the final decision-maker during disagreement, whereas in the French and Italian language region the physician was given more authority. These socio-cultural differences are particularly important when they influence life and death decisions in very premature infants. In a context fraught with clinical and prognostic uncertainty, different moral interpretations are bound to happen. Despite the aim of most national guidelines to set clear boundaries for appropriate care, studies in several European countries have shown that treatment decisions reflect local NICU cultures. The process of coming to a consensus in a shared approach within diverse societies can be a difficult yet important one. In future research, it is important to define a context where ethical trade-offs are accepted for decisions that cannot be considered medically beneficial or futile, but are somewhere in between. It is in this context where shared decision-making enables healthcare experts and parents to reflect on and reconcile with their underlying attitudes and values through continuous dialogue.

Our study indicates that solidarity does not only refer to the commitment of a group to carry the financial costs and elements of compassion may play a larger role. It is possible that the extreme vulnerability of extreme preterm infants and their acute need for intensive care promotes support. The Swiss health care system seems to have supported the right conditions for such a high level of solidarity. A high societal cohesion toward disabled persons may alleviate some pressure on parents in the decision-making process regarding their extremely premature infant in the NICU.

More importantly, meaningful support during end-of-life decisions requires optimal communication, which could limit the conflict and distress between the healthcare team and the family. Our findings provide valuable information that can be used to understand the societal attitudes, values and arguments put forward by the parents of extremely preterm infants being cared for in the NICU.

## **B. Survey among neonatal health care providers (HCPs) in Swiss tertiary NICUs**

### **1. Background**

Deciding to initiate, withhold or withdraw intensive care for infants born at the limit of viability remains one of the most difficult decisions in modern medicine. In high income countries, most extremely preterm infants who die in neonatal intensive care units (NICUs) do so after a decision to redirect treatment from intensive care to comfort care (i.e., withdrawal of life-sustaining therapies). Less commonly, a decision to withhold active treatment is taken before or immediately after birth.

It is generally accepted that end-of-life decisions in extremely preterm infants should be made in a process involving physicians, nurses and parents. End-of-life decisions are not only based on outcome statistics but are greatly influenced by the perceptions of the outcomes by the different parties involved in this process. Attitudes and values play an important role in end-of-life (EOL) decision-making. Factors such as age, professional experience, culture and the importance of religion fashion the health care provider's attitude and value scale. The same observation holds true for antenatal discussions between parents and obstetricians and neonatologists. The chronic exposure to difficult

situations and decisions in intensive care units represents a high level of work-related stress which has the potential to significantly impact on the caregivers' perceptions about the value of their work, feelings of success, satisfaction, performance and welfare (burnout syndrome). There is emerging evidence that this work-related stress may also well shape the attitudes of neonatal HCP, and thereby the treatment decisions for extremely preterm neonates. Accurate assessment of the individual fetus or infant and accurate prognostic and outcome data on which to base discussions and decisions within the caring team and with parents are required for sound ethical reasoning to reach a clinical decision.

The guiding principle when caring for newborns at the limits of viability seems to be more complex than simply being based on the principles of medical ethics. The respect for the autonomy of the family unit may in many cases outweigh the physician's assessment of the best interest of the individual infant. In the case of extreme prematurity, the perception of a negative impact on the family may have been viewed by clinicians as more important as the infant's chances to survive with or without impairment.

## **2. Goals of the project**

We were interested to explore the kind of problems that neonatologists and NICU nurses identify in end-of-life decision-making and how they perceive the role of parents in this process. For this reason an online survey was performed among all nine level III NICUS in Switzerland. We also aimed at investigating whether the answers were associated with professional status, years of experience or language region.

Moreover, we aimed at assessing the attitudes and values of neonatal doctors and nurses regarding intensive care of infants born at the border of viability, and its possible impact on the decision-making process regarding initiating, limiting, withholding or withdrawing treatment.

## **3. Methods**

The questionnaire consisted of 32 statements about end-of-life decision-making in infants born before 28 weeks' gestation, 9 statements about prenatal decision-making, five questions with several options, from which only one could be chosen in case of dissent between parents and HCPs and about the role of a Hospital's Ethics Committee. Four questions were about professional education and experience and importance of religion of the participants.

The goals of this study were presented to the staff of all nine Level III NICUS in Switzerland. All physicians and nurses who had been working for more than 12 months in a particular NICU (n=552) were invited per e-mail to participate in an online survey. Nonrespondents received two reminders. Data were analysed anonymously.

## **4. Results**

96 of 121 (79%) physicians and 302 of 431 (70%) nurses completed the online questionnaire. Compared to nurses, participating physicians were more frequently in a leading position and more often had children of their own.

### *Difficulties encountered in end-of-life decision-making*

A large majority of all HCPs found it difficult to foresee the patient's future quality of life and named the difficulty to make an accurate long-term prognosis. The following difficulties with end-of-life decision-making were reported more frequently by nurses than physicians: insufficient time for decision-making, legal constraints and lack of a consistent unit policy. Nurses also mentioned a lack of solidarity in our society and shortage of services for disabled more often than physicians. Lack of a consistent unit policy was more often indicated in the French speaking areas than in the German speaking areas.

#### *Acceptable approaches to limiting intensive care*

Administering sedatives and/or analgesics to suppress pain even if this might cause respiratory depression and death was acceptable to a majority of all respondents . Only a fourth accepted administering drugs with the explicit purpose to hasten death. Compared to physicians, nurses significantly less often indicated that withholding intensive care, refraining from increasing respiratory support and withholding full parenteral nutrition, tube feeding or antibiotics would be possible options.

#### *Parental involvement in decision making*

More than half of the respondents thought that parents should have the opportunity to take part in the decision-making process. Moreover, a minority thought that parents should always have the opportunity to decide the course of action for their infant. Nurses as compared to physicians, were more in favour of not directly involving parents in decision-making; they indicated that parental wishes and attitudes should be explored indirectly and considered by the decision-making health care team.

Neonatal HCPs gave several reasons for not directly involving parents in decisions on treatment limitations. Firstly, a majority considered that parents should not be involved because they might change their minds later and experience feelings of guilt. Secondly, they felt that parents should be spared the burden of such decisions. Thirdly, parents might not be in the right state of mind to take such decisions and finally, parents cannot fully understand the possible options and consequences.

#### *Disagreement between HCPs and parents*

In the event that parents would request limitation of intensive care, while HCPs recommend continuation of treatment, around half of respondents considered hospital ethics committees to be the ultimate decision-makers and a third felt that this would be the right of the parents. Another ten percent indicated the medical staff and only very few chose the court as ultimate decision-makers. In the opposite situation, namely if the parents request continuation of intensive care, while HCPs think that life-sustaining therapies should be withdrawn, a third of all respondents considered the ethics committee to be the ultimate decision-maker, around twenty percent named the parents, and few the medical staff.

#### *Hospital's ethics committee*

The roles of hospital ethics committees was seen as follows: 80% of respondents indicated to give advice in individual cases, 12% being responsible for ultimate decision-making in individual cases - the latter was favoured more often by nurses than by physicians.

### *Prenatal decision-making*

Most neonatologists argued that decisions to withhold life-sustaining therapies from infants born at the limit of viability should not be made prenatally because prognosis is not sufficiently accurate and individual assessments after birth allow a more nuanced approach. There was no consensus among physicians whether parental wishes and the child's best interest should be viewed differently before than after birth: a fourth of physicians agreed that, prenatally, parental wishes and values should be given more weight than the child's best interest, whereas this no longer is true after birth; half of the respondents disagreed with this statement.

### *Acceptability of setting limits to intensive care interventions (e.g. withholding/withdrawing treatment)*

Most neonatal HCPs agreed that setting limits to life-sustaining interventions (LSIs) was acceptable in situations where the condition or malformation is fatal. The same agreement between doctors and nurses was also seen in the presence of congenital malformation associated with expected severe disability and/or very poor quality of life or in presence of a severe congenital malformation and extreme prematurity. Significantly less nurses agreed on limiting LSIs when the expected neurological prognosis was poor, and HCPs in the German-speaking regions agreed significantly less often than in the French area. Professional experience and significance of religion did not play a significant role in the above situations. A third of doctors and two thirds of nurses felt that some babies are treated too intensively, and half of the HCPs in the German- vs. three quarters in the French-speaking region hold the same view.

### *Personal experience with decisions to set limits to intensive care interventions (e.g. withholding/withdrawing treatment)*

Neonatal physicians significantly more often decided by themselves or together with others to set limits to LSIs than nurses. With the exception of setting limits to LSIs when the neurological prognosis was poor, more HCPs in the German- than in the French-speaking area have taken that decision. The importance of religion did not influence these situations. Professional experience 6 to 15, and > 15 years was significantly associated with taking decisions to limit LSIs.

### *Minimal criteria for an acceptable quality of life*

Being able to communicate with other people was considered by a vast majority of HCPs as a minimal criteria (Swiss population 95.0%) with no difference between physicians and nurses. Being able to take care of oneself was a criterion for a sixth of physicians and nearly half of the nurses (nearly 80% of the Swiss population). 10.0% of doctors and 17% of nurses considered being able to finish primary school (Swiss population 75%).

### *Degree of agreement on questions regarding overall attitudes and values*

Nearly a fifth of HCPs agreed that limiting LSIs was a 'slippery slope' which will lead to abuses. On the contrary, two thirds of them stated that intensive care is a 'slippery slope' leading to therapeutic aggressiveness, with more nurses than physicians taking that view. A fourth of the HCPs shared the opinion that from an ethical point of view, there is no difference between withholding and withdrawing LSIs; with more doctors agreeing on that statement than nurses. and more HCPs in the German- compared to the French-speaking area. When asked if the same moral and ethical principles should apply to ethical decisions in extremely preterm infants as in other children or adults, a great majority of physicians and only half of the nurses approved. To the question, if the criteria for initiating LSIs in

extremely preterm infants, two thirds of the physicians and around 40% of nurses stated that they should be similar to those applied in older children (twice more HCPs in German- than in the French-speaking region).

#### *Infants best interest vs. familial autonomy*

50 % of neonatologists vs. 67% nurses hold the view that the child's best interest is the sole basis for decisions about initiating, withholding or withdrawing LSIs. When asked if the parents are the best judges of what is in the best interest of their child, only a fifth of physicians vs. 14% of the nurses agreed; with fewer HCPs in the German than in the French-speaking area. Around 70-80% of doctors and nurses approved that the parents' and family interests and values are as important as the child's best interest. The same holds true for a majority of neonatologists and nurses when a particularly negative impact on the family by the survival of a possibly severely disabled infant can be foreseen. Around a fourth of HCPs hold the view that parents' opinions should be given more weight.

#### *Setting financial limits to IC for extremely preterm infants (Tabl. 4)*

Around 80% of HCPs said no or rather no in comparison to a third of the Swiss population. There were no differences between physicians and nurses, German- vs. French-speaking area, professional experience, importance of religion.

## **5. Significance of the results for science and practice**

Physicians and nurses differ in many aspects of how and by whom end-of-life decisions should be made in extremely preterm infants. Acknowledging these differences is important to avoid potential conflicts in the process of end-of-life decision-making in preterm infants born at the limits of viability. Today, when difficult decisions in the care of extremely preterm infants have to be made, consensus regarding ethically justifiable treatment options among HCPs must be sought. The opinions of the nursing staff and the possibility to take part in decision-making processes must be given more importance and attention, given the large number of nurses involved in the care of an individual infant. Therefore, it is important to analyse, and once recognized, to address the reasons why nurses' opinion may differ from those of physicians and to include them in the whole decision-making process.

The Swiss Civil Code for the protection of adults and children, enacted in 2013, emphasises parental authority when a child is incapable of making his or her own decisions. Shared decision-making between neonatal HCPs and parents is proposed by many guidelines, however, there is no consensus, about what precisely "shared or collaborate decision-making" means. There also seems to be a contrast between the perceived best decision-making model, namely shared decision in this case, and the practice in a clinical setting. In this context, it is noteworthy, that in our study, HCPs give more weight to parental opinions in cases of disagreement if the parents request limitation of intensive care compared to situations where they ask for continuation of intensive care. In both cases, a large percentage of respondents think that a hospital ethics committee should be the ultimate decision-maker. This finding is in sharp contrast to the expectation of the society in such cases, where an overwhelming percentage gives parents the final word. Again, we recommend to translate the analysis of these findings into the teaching/curriculum of neonatal HCPs.



There is a clear gap between the legal and societal expectation regarding the weight given to parental opinions contrasting with the view of neonatal health care providers (only 23%). This finding is also reflected in the very low acceptance rate by HCPs that parents are the best judges of their infant's best interest. Moreover, the above findings are somewhat in contradiction to the view shared by two thirds of neonatal HCPs, namely that parents' and family interests and values are as important as the child's best interest. This could in our view constitute a hindrance to more actively involve parents in the decision-making process and to undergo a true shared-decision making model. This together with another gap found between the preferred model of a shared-decision as expressed by HCPs and the much less frequent practical application of a true shared-decision model need widespread recognition among neonatal professionals followed by teaching and sustained implementation into daily practice.

The results of these studies and related NRP 67 neonatal studies will need to be considered for the planned revision of the Swiss recommendations for perinatal care of infants born between 22 and 26 weeks (planned for 2017/18).

## **C. Parents Qualitative Interviews**

### **1. Background**

The birth of an extremely preterm infant often comes unexpectedly. Extreme prematurity represents not only a clinical challenge for neonatal doctors and nurses, but also a complex and stressful challenge for the parents of these babies. Decisions must often be made quickly and under circumstances that can be emotionally stressful or morally burdensome for parents and/or health care professionals. Because infants born at the borderline of viability have a wide range of outcomes, it is hard to predict, at birth, whether an infant will die or survive with or without impairment. This uncertainty makes decisions about life saving treatment particularly complex.

Parents of extremely preterm infants experience a range of stressors due to the immediate separation after birth, the alienating setting of the intensive care unit (NICU), the physical distance to the child, medical uncertainties, and upcoming decisions. Even though they are considered as the parents, they often cannot act as primary caregivers, at least not at the beginning.

Over the years, different decision-making approaches have aimed to guide parents through the uncertain context of prematurity. In the past, physicians considered it their professional authority with regard to taking decisions on initiating or withholding intensive care treatment. This was based on a number of reasons, e.g. their professional concern for the welfare and non-burdening of parents. In the last decades, however, the aims of caring for critically ill newborns have shifted its focus. Currently, most guidelines and policies advocate shared decision-making and promote parental involvement before and after birth. Decision-making should be a collaborative venture between HCPs and parents in making decisions about infant's care. However, despite this prevailing attitude, implementing a shared decision-making approach in practice has remained difficult.

### **2. Goals of the project**

Consequently, empirical data is important to provide further insight into how parents of extreme preterm infants' (1) experience parenthood; (2) consider communication with the health care team and; (3) how this affects the parental role towards end-of-life decision-making. Therefore, this study examined how parents reach coherent end-of-life decisions in the best interests of their extremely preterm infant. We sought to identify communication patterns between parents and neonatal HCPs leading either to an good or to a friction-laden decisional process in order to provide a critical assessment on the degree of parental involvement.

### **3. Methods**

We invited parents, whose child died in the delivery room or in the neonatal intensive care unit, to share their stories. We interviewed 20 parents (seven couples, five mothers and one father) whose extremely premature baby was born and died in a tertiary University Hospital with a perinatal centre in the years 2013–2014.

### **4. Results**

Parents shared their experiences of the birth and death of their extremely premature babies. For some parents their baby died in the delivery room after minutes or hours. For others their child was admitted to the neonatal intensive care unit and died there after several days. Several topics were raised by the parents such as parenthood and parent-child bonding despite the short lives of their children, communication with the health care team and parental roles in end-of-life decision-making.

Parents were affected by uncertainty, distress, inexperience, hopes, fears, and sometimes feelings of responsibility and guilt. They described that they were not emotionally prepared for the birth of their child, for the immediate separation (the children had to undergo intensive care treatment immediately, thereby leaving often no time for the parents to see or hold the infant immediately after birth), and the unknown NICU setting. This made parents perceive the situation as being 'dreamlike' and unreal.

Parents described how some elements favored and some others challenged communication between parents and the health care team. On the one hand, thorough medical explanation on what extreme prematurity entails, prepared parents for the process ahead. Parents also greatly appreciated health care professionals who were honest and showed empathy. On the other hand, some parents experienced poor communication. Some parents explained how they did not receive any information regarding the hospital's policy not to initiate care for infants born before 24 weeks of gestation.

Parents experienced their involvement in decision-making at the end of their premature baby's life in divergent ways. An overwhelming majority of parents did not feel truly involved in end-of-life decision-making and felt that everything was already decided. Parents felt comfortable with the decision to withhold care based on their trusting relationship with the attending physician. However, some parents criticized their level of involvement. They felt that the options and decisions presented by the health care team might have been biased and directive. A second group of parents reported that they experienced neither non-involvement nor involvement. Their minds felt clouded by all-consuming shock, which made it difficult – and for some parents impossible – to be actively involved

in the decision-making process. Finally, some parents recalled expressing their personal preferences and wishes to the health care team and subsequently being involved in decision-making.

After the decision of withdrawing further intensive care, parents were offered a private space to spend their last moments together with their child. For the parents under study this was the first time that they could be alone with their child. These were the first moments where they could hold their child and this was experienced as both a gift and a parental duty. In that moment, parents had the opportunity to spend time with their baby as a member of the family, without all the tubes and wires. Parents created a sense of family by spending time together and by photographically documenting and thus visibly representing themselves as a family. Parents either created memories themselves, were assisted by the health care staff with collecting memories, or the health care staff created memories of their own accord and gave the photographs to the parents at hospital discharge. Thinking back, parents highly appreciated these tangible memories.

In this final stage, they could do “things parents normally do” (e.g., have the baby close, give him or her some warmth during dying, hold him or her during and after death, and wash and dress their child). Along with these parenting activities, parents experienced closeness or guilt and felt deeply responsible for protecting their deceased baby from exposure or harm and for safeguarding his or her dignity. Thus, for the parents, the baby’s vulnerability and the duty of “caring” for and protecting him or her continued after death. This enabled parents to feel like parents after being observers and onlookers and to experience privacy after being observed and watched.

## **5. Significance of the results for science and practice**

Our study confirmed that parents of extremely preterm infants need specific support, in which high quality communication with the health care team plays a crucial role. Parental satisfaction with decision-making seems to rely on communication within the EOL process rather than on involvement. Treatment decisions are, thus, connected to and rely on the communication process. Therefore, a shared and collaborative decision-making process relies on the communication skills of caregivers. Despite parents’ wish to be involved in the decision-making and the increasing commitment of health care staff to the topic, our findings suggest that shared decision-making has remained difficult. Parental experiences of a frictional decisional process relate to problems of communication, which can hinder shared decision-making. Neonatologists and nurses, who are closest to parents, should aim to avoid this by enabling and encouraging parents’ relationship with their child. Directive counselling should be avoided and the physician should recommend all possible treatment options (when available) and discuss these with the parents. They should create a space where parental preferences for passive or active roles in decision-making can be assessed and considered a shared commitment. Open and honest communication strategies such as (1) sharing weighted information, (2) discussing a range of treatment options, (3) providing time to think and (4) building towards a trustful relationship through the continuation of care can enable parents to participate in decision-making based on their own preferred level of involvement.

Our study shows the importance of promoting bonding at all times, but specifically, at the end-of-life so that parents overcome feelings of “parental incompleteness”. Parents of extremely preterm babies suffered from unpreparedness of becoming parents. They were considered parents with the birth of their baby, but to actually feel like parents they needed to go through a process of biological and psychosocial bonding. Because of the child’s vulnerable condition, it was difficult and almost

impossible for parents to bond through holding, touching, smelling, caring and feeding. Caring for their dying and deceased child often enabled them to become parents. Even though this happens quickly, it is very important that parents receive the professional support needed to experience parenthood. The support of establishing parenthood and family construction after the baby's death calls for highly aware and sensitive verbal and non-verbal communication. It is important that the health care team uses a sensitive language when approaching bereaved parents, avoiding clinical terms, and instead talking about the baby in a person-like manner respecting his or her name and identity. Establishing parenthood in the NICU involves viewing and treating the deceased baby as a person and parents and the baby as a family.