

Communication with families of critically ill newborns: New ways of research

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Families of critically ill fetuses, newborns or infants

Despite major diagnostic and medical advances in perinatal medicine, nearly 40% of all paediatric deaths in Switzerland occur in the first four weeks of life, making neonates the largest subgroup¹

- Deaths after live birth occur in delivery room (59%) or following admission in NICU (41%)²
- In the NICU, most patients die after discontinuation of therapy in the hospital (90-96%)^{3,4}
- Very few fetuses/newborns receive specific/specialized palliative care at the end of their lives^{2,3}
- Newborns can benefit from palliative care at the end of life^{6,7}

1. BAG 2018
2. Berger et al. 2017
3. Zimmerman et al. 2018
4. Craig&Mancini 2013
5. Samsel & Lechner 2014
6. Young et al. 2015

Families of critically ill fetuses, newborns or infants

Many families face difficult conversations in which health care professionals (HCPs) touch upon the possibility of withholding or withdrawing intensive care measures

Consultations arise with:

- the prenatal diagnosis of a life-limiting fetal anomaly or an expected extreme prematurity
- after the diagnosis of a neonatal life-limiting condition at birth
- after the failure of cure-directed treatment to reverse severe medical problems



Families of critically ill fetuses, newborns or infants

These circumstances can be extremely distressing for (expecting) parents

- Worry and uncertainty about the outcome
- Parents need to make crucial decisions before *feeling* like parents
- Might require (grief) counselling before the patient is born
- Bonding and relationship building might take place simultaneously with the mourning process
- Families rarely live together or can take the baby home

Can create feelings of powerlessness in (expecting) parents

(Hoffenkamp et al. 2015; Schappin et al. 2013; Abraham et al. 2017; Fleming et al. 2016)

Perinatal Palliative Care

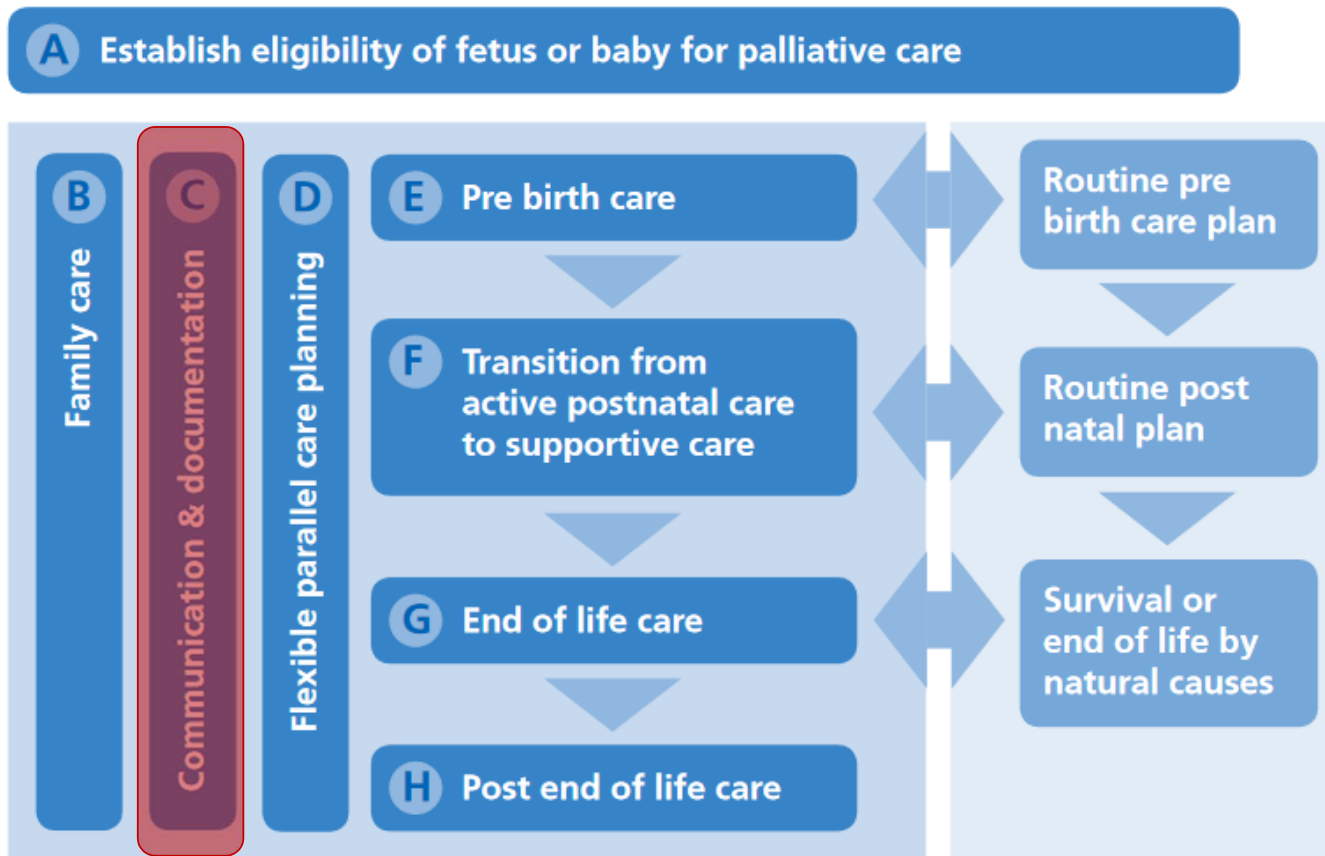
Importance for HCPs to meet the requirements of competent perinatal palliative care (PC):

Perinatal PC as *“an active and total approach to care, from the point of diagnosis or recognition, throughout the child’s life, death and beyond. It is the holistic management of supportive end-of-life care following multidisciplinary agreement on eligibility.”*



Perinatal Palliative Care

Stages of palliative care planning



(BAPM 2019)

How do we initiate conversations in the context of perinatal palliative care?

Clinical guidelines and recommendations

Reports from parents and healthcare professionals

Clinical guidelines and recommendations



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text

Perinatal care at the limit of viability between 22 and 26 completed weeks of gestation in Switzerland

2011 Revision of the Swiss recommendations

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The decisions that must be taken with the pregnant women and on behalf of the preterm infant in this context are complex and have far-reaching consequences. When counselling pregnant women and their partners, neonatologists and obstetricians should provide them with comprehensive information in a sensitive and supportive way to build a basis of trust. The decisions are developed in a continuing dialogue between all parties involved (physicians, midwives, nursing staff and parents) with the principal aim to find solutions that are in the infant's and pregnant woman's best interest.

Communication

Prenatal ethical decision making regarding maternal and foetal interventions at the limit of viability is rationally and emotionally challenging both for parents and physicians. To communicate complex issues in an appropriate way and adapted to the parent's level of understanding requires competence and experience. Therefore, these discussions must be led by experienced and appropriately trained obstetricians and neonatologists. The goal of these conversations is to establish a trusting relationship between the parents and the health care team. The parents should be provided with adequate information so that they can actively participate in the decision making regarding pre- and postnatal maternal and infant care.

Communication among members of the perinatal team

The perinatal care of a foetus or a preterm infant at the limit of viability must follow a multidisciplinary approach and requires close cooperation among obstetricians, neonatologists, midwives, nurses and other involved parties. Frequently, decisions have to be made within a short period of time. It is therefore necessary that the members of the perinatal team have previously discussed and agreed upon a standard approach in such situations.

Communication with the parents

Obstetricians and neonatologists should inform both parents about the situation of the unborn child and his/her likely short- and long-term prognosis. This information should be precise, comprehensive and unbiased and should be presented using appropriate expressions and understandable language. It has been shown that the way messages

Clinical guidelines and recommendations

Leitsätze für Palliativversorgung und
Trauerbegleitung in der Peri- und Neonatologie



The relationship between family and treatment team is rooted in partnership and professionalism. **The communication should be professional, ongoing, honest, empathetic and transparent.** Parents should be confident that they are being **listened to carefully** and that **no information is being withheld** from them. Especially in critical or dynamic situations, discussions should be timely and not delayed.

Parents report;

- Less optimal involvement in decision-making^{1,2}
- Communication with doctors could be improved³
 - Parental involvement
 - Detail provided
- Being distressed by insensitive communication^{3,5}
- Overwhelmed by conflicting information²
- Interaction with Drs. their least positive experience⁴
- 46% involved in decisions about their baby only «sometimes or not at all»⁵

1. Zimmerman et al. 2016
2. Hendriks et al. 2017
3. Abraham et al. 2017
4. Poppy 2008
5. NNAP 2012



Consistency

“When the doctor told us about the bleed in the brain, he should have been a bit more specific... that day was really traumatic for us, we were crying our eyes out.. Then at night.. There’s another doctor, and he told us no no, its not a bleed, it’s a tiny bruise, and it doesn’t need anything”

Continuity of care

“One would inform us well and would start telling us everything on her own, with others you had to drag the information out of them.”

Involvement

“We are her parents and we should make this decision. And we should decide what is best for our baby. Now in retrospect, I regard that as a great act of love. But in those hours – I thought I would die.”

Trust

“We relied on the staff and their advice. They have more experience, when they say it does not make any sense, then that was the decision. There was not really something to decide.”

Healthcare professionals report;

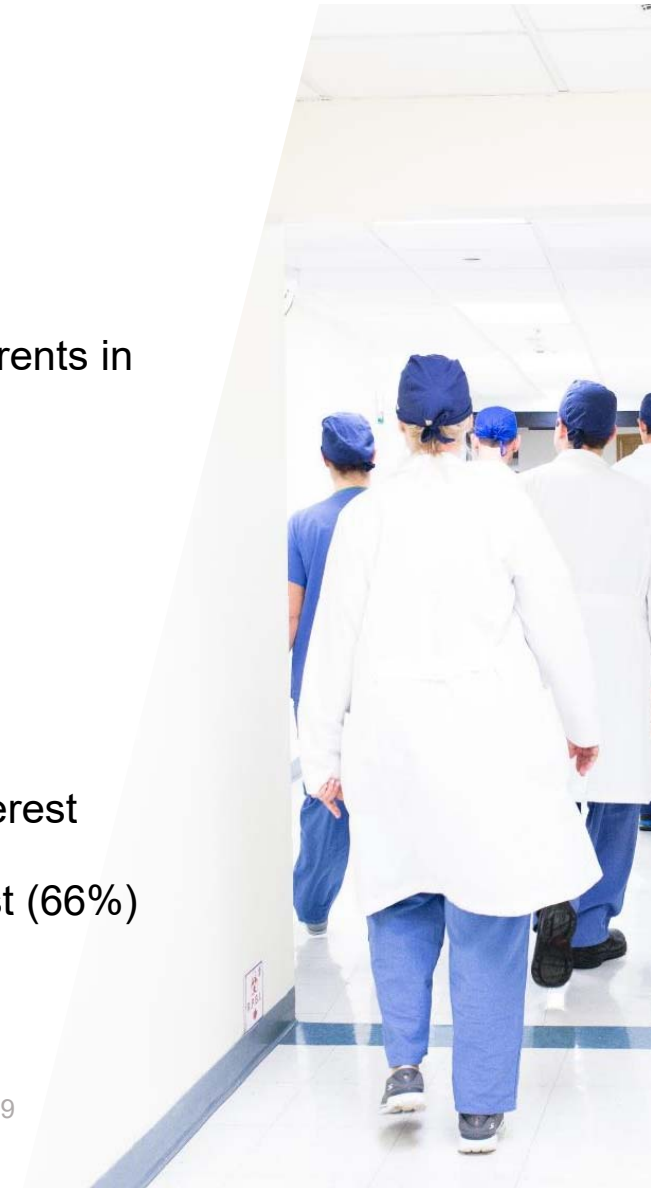
Despite (inter)national recommendations and guidelines

National differences regarding Swiss HCPs attitude towards involving parents in the decision-making process (64% in D-CH vs. 49% in F-CH) ¹

- Parents might change their minds (93%)
- Parents should be spared the burden (71%)
- Parents might not be in the right state of mind (50%)

Best interest of child is difficult ²

- The child's best interest is the basis for decisions about withholding/withdrawing IC measures (59%)
- Family interests and values are as important as the child's best interest (67%)
- Parents are not the best judges of what is in the child's best interest (66%)



How do we initiate conversations with families of critically ill newborns?

Evidence-based?

- Family or clinician recollections of conversations occurred hours, months, or even years in the past
- Clinician characterization of their “usual” counseling behaviors or response to hypothetical scenarios

→ Lack of observational data & Recall bias ←

“data derived from post hoc interviews are filtered through the lens of the listener and thereby provide an incomplete view of the communication that transpired.” (Kaye et al. 2019)

FamKom Study: A Mixed Methods Study on Perinatal Palliative Care Services in Switzerland



SAMW «Palliative Care Research» Project Nr. 11/18

Main Applicant : Hendriks Manya

Co-Applicants: Gubler Deborah, Krones Tanja, Fauchère Jean-Claude

Staff: Boan Pion Antonio

Collaboration partners: Local coordinators Swiss NICUs (Swiss Neonatal End-of-Life Study Group), Hauff Marianne, Dinten-Schmid Barbara, De Vos Mirjam, Marlow Neil

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USZ neonatal
department



FamKom Study: A Mixed Methods Study on Perinatal Palliative Care Services in Switzerland

The goal of this nationwide study is:

Part 1:
Survey

to assess the context of perinatal palliative care practices of healthcare professionals working in Swiss level III neonatal intensive care units (NICUs) (N=428)

Part 2:
Audio-
recording

to prospectively analyze perinatal PC consultations (i.e. HCPs-parent interactions) in clinical practice (N=45)

Part 3:
Focus
groups

to develop communication strategies with HCPs for perinatal palliative care (N=16)



Research questions

Audio recording of consultations in the perinatal setting in which palliative/comfort care measures are considered

Research questions;

- How do clinicians and parents navigate difficult conversations during perinatal palliative care consultations?
 - In which ways do clinicians provide information to parents?
 - What happens when clinicians and parents talk about decisions?
 - What does 'involvement' actually mean and how is it achieved during consultations?

Methods

Multicenter Study (2019-2021)

- 9 level III NICUs
 - 3 level III NICUs recruited
- 5 consultations per unit (N=45)
- Audio-recordings
- Coding instrument & Conversation analysis
- *Ongoing data collection*



Methods – Coding instrument & Conversation analysis

Coding instrument

- De Vos et al. 2015
- Conceptual framework
 - Decision-making in the medical encounter¹
 - Physician communication behaviors in relation to shared decision-making²
- Coding instrument
 - Describing physician and parents' communication behaviors
 - Qualitatively and quantitatively analysis
- Iterative process

Conversation analysis

- Harvey Sacks & colleagues 1960s
- An approach to the study of social interaction and talk-in-interaction
- Draws on naturalistic interactions
- Describe stable practices using
 - Close study of single interactions
 - Identification of patterns across interactions
- In particular
 - Turn taking, repair, action formulation and ascription, and action sequencing

Collaboration – Netherlands

Pilot Study (2008-2015)

- 2 PICUS
 - 31 family members
 - 21 clinicians
 - 19 consultations
- Audio recorded
- Coding instrument
- *Publication: De Vos et al. 2015*

Multicenter Study (2017-2021)

- 8 University Medical Centers
- 4 NICU's, 4 PICU's and 4 ICUs throughout the country
- 4 consultations per NICU (N=32)
- Audio-recordings
- Coding instrument & Conversation analysis
- *Ongoing data collection*

Collaboration – United Kingdom

Pilot Study (2013-2015)

- 1 NICU
 - 9 family members
 - 6 clinicians
 - 16 consultations
- Audio recorded
- Conversation Analysis
- *Publication: Shaw et al. 2016*

Multicenter Study (2018-2020)

- 3 NICUs
 - 30 family members
 - 39 consultations
- Audio or Video-recordings
- Conversation analysis
- *Ongoing data collection*

Relevance

- ↑ Better understanding of palliative care consultations (quantitative and qualitative aspects of interactions)
- ↑ Develop best practices that is evidence-based
- ↑ Enables reflective practice
- ↑ Generates explicit descriptions of communication practices and their outcomes
- ↑ Scientific evidence for training clinicians key communication skills
- ↑ Avoiding problems with recall bias
- ↓ Logistical and ethical challenges
- ↓ Conducting research with families in the midst of stressful, chaotic, and urgent clinical events
- ↓ Bias in recruitment (willingness to participate)
- ↓ Audio or video?

Conclusions

- Conversations with parents demand
 - Sensitivity
 - Respect
 - Listening
- Support decision-making is challenging
- Conversations often not inclusive
- Real conversations useful
 - Put into perspective parental and HCPs «retrospective or hypothetical» reports
 - Training resource



Thank you for your attention!
Questions?

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References

- Abraham, A. and M. J. Hendriks (2017). "“You Can Only Give Warmth to Your Baby When It’s Too Late”: Parents’ Bonding With Their Extremely Preterm and Dying Child." Qual Health Res.
- BAPM (2010). Palliative Care (Supportive and End of Life Care) A Framework for Clinical Practice in Perinatal Medicine.
- Berger, T. M., et al. (2011). "Perinatal care at the limit of viability between 22 and 26 completed weeks of gestation in Switzerland: 2011 Revision of the Swiss recommendations." Swiss Medical Weekly **141**: w13280.
- Bucher, H. U., et al. (2018). "Decision-making at the limit of viability: Differing perceptions and opinions between neonatal physicians and nurses." BMC Pediatr **18**(81): 1-9.
- (BAG), B. f. S. (2018). Säuglingssterblichkeit, Totgeburten
- Bundesverband „Das frühgeborene Kind“ e.V. (2018). Leitsätze für Palliativversorgung und Trauerbegleitung in der Peri- und Neonatologie. A. PaluTiN.
- Craig, F. Mancini, A. (2013) Sem Fetal Neonat Med
- de Vos, M. A., et al. (2015). "Talking with parents about end-of-life decisions for their children." Pediatrics **135**(2): e465-476.
- Feudtner, C., et al. (2011). "Pediatric palliative care patients: a prospective multicenter cohort study." Pediatrics **127**(6): 1094-1101
- Feudtner, C., et al. (2007). "Shifting place of death among children with complex chronic conditions in the United States, 1989-2003." Jama **297**(24): 2725-2732.
- Fleming, V., et al. (2016). "Dying at life’s beginning: Experiences of parents and health professionals in Switzerland when an ‘in utero’ diagnosis incompatible with life is made." Midwifery **34**: 23-29.
- Gallagher, K., et al. (2018). "Parental experience of interaction with healthcare professionals during their infant’s stay in the neonatal intensive care unit." Arch Dis Child Fetal Neonatal Ed **103**(4): F343-F348.
- Hoffenkamp, H. N., et al. (2015). "Parenting in complex conditions: Does preterm birth provide a context for the development of less optimal parental behavior?" Journal of pediatric psychology **40**(6): 559-571.
- Janvier, A., K. Barrington and B. Farlow (2014). "Communication with parents concerning withholding or withdrawing of life-sustaining interventions in neonatology." Seminars in Perinatology **38**: 38-46.
- Kaye EC, Gattas M, Bluebond-Langner M, Baker JN. Longitudinal investigation of prognostic communication: Feasibility and acceptability of studying serial disease reevaluation conversations in children with high-risk cancer. Cancer 2019.
- Keele, L., et al. (2013). "Differences in characteristics of dying children who receive and do not receive palliative care." Pediatrics **132**(1): 72-78.
- POPPY Steering Group (2009) Family-centred Care in Neonatal Units. A Summary of Research Results and Recommendations from the POPPY Project. London: NCT.
- Samsel, C. and B. Lechner (2014). "End-of-life care in a regional level IV neonatal intensive care unit after implementation of a palliative care initiative." Journal of perinatology : official journal of the California Perinatal Association **35**(3): 223-228.
- Schappin, R., et al. (2013). "Rethinking stress in parents of preterm infants: a meta-analysis." PLoS One **8**(2): e54992.
- Shaw, C., et al. (2016). "Parental involvement in neonatal critical care decision-making." Sociol Health Illn **38**(8): 1217-1242.
- Younge, N., et al. (2015). "Impact of a palliative care program on end-of-life care in a neonatal intensive care unit." Journal of perinatology : official journal of the California Perinatal Association **35**(3): 218-222.