

Prenatal counseling

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Clinical praxis



- Ms A, 23 1/7 weeks gestational age, impending birth with contractions and cervical dilation. She is expecting a girl, expected birth weight 400g.
- Ms B, 23 1/7 weeks gestational age, new diagnosis of trisomy 18. She is expecting a girl, expected birth weight 400g.

«Can you talk to the parents?»

Essential elements

- mutual recognition a decision has to be made
- understanding of risks and advantages of the different management options
- ensuring, the decision taken is based on facts presented by the medical staff as well as on parental values and preferences

Goals

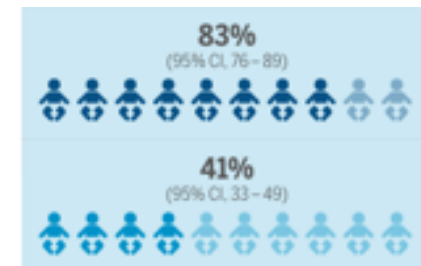
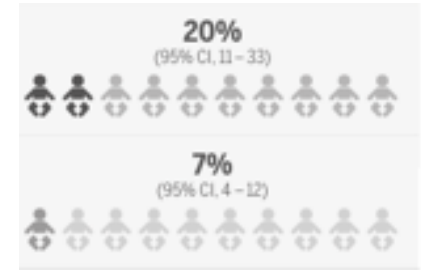
- multidisciplinary, multiprofessional approach
- to establish and maintain a trusting relationship between parents and healthcare professionals (compassion! time!)
- information should be precise, comprehensive and unbiased
- information should be presented using appropriate terms and understandable language

Outcome		
Survival rate (to hospital discharge for babies receiving survival-focused care)	↓ 83% (95% CI, 76–89) 	↓ 20% (95% CI, 11–33) 
Survival without severe morbidities¹ (to hospital discharge for babies receiving survival-focused care)	41% (95% CI, 33–49) 	7% (95% CI, 4–12) 

Swiss Recommendations for the Perinatal Care of Extremely Low Gestational Age Neonates. Berger et al. Acta Paediatr. 2026

Decision aids

- can facilitate understanding of prognostic information
- can improve the ability to recall and reproduce the provided information



«For parents, a 50% risk of mortality
does not mean much as their child will
be either 100% alive or 100% dead....»

(Haward and Janvier, 2015)

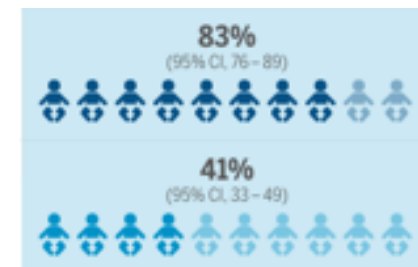
Decision aids



- can facilitate understanding of prognostic information
- can improve the ability to recall and reproduce the provided information

But:

- interpretation of data (especially survival rates) are dependent of the way the data are presented (framing) and collected (differences in reference population)
- individual, parental values are not addressed in decision aids



Effect of Neonatal Outcome Estimates on Decision-Making Preferences of Mothers Facing Preterm Birth: A Randomized Clinical Trial.

Kidszun et al. JAMA Pediatr. 2020.

- single-center, double-blinded, randomized clinical trial
- expectant mothers between a GA of 28^{0/7} weeks and 36^{6/7} weeks hospitalized because of impending premature birth
- randomly allocated to respond to either a case vignette of 60% or 30% survival rate (cases otherwise identical)
- mothers were asked to indicate a preference for life-sustaining treatment, palliative care, or no preference

Effect of Neonatal Outcome Estimates on Decision-Making Preferences of Mothers Facing Preterm Birth: A Randomized Clinical Trial.

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No differences between the 60% or 30% survival group with respect to the preference rates for life-sustaining treatments compared with palliative care

60% survival group 46.9% vs. 34.3%

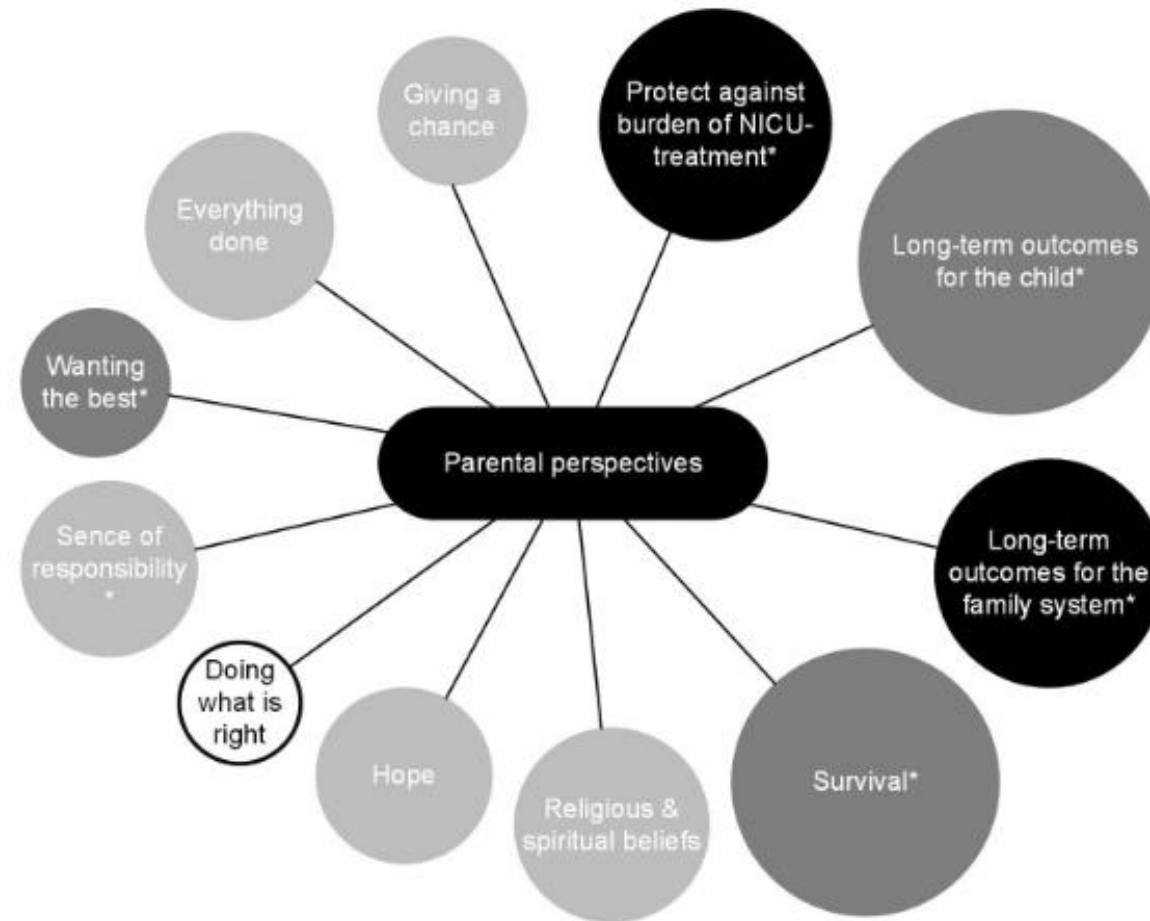
30% survival group 50.0% vs. 40.6%

odds ratio [OR], 0.90; 95% CI, 0.31–2.63

A scoping review of parental values during prenatal decisions about treatment options after extremely premature birth.

Angret de Boer, et al. Acta Paediatr. 2023.

- systematic literature search on parental decision making regarding treatment after birth at the limit of viability
- 15,159 papers examined, 17 included



A scoping review of parental values during prenatal decisions about treatment options after extremely premature birth.
De Boer et al. Acta Paediatr. 2023 May;112(5):911-918.

«Will my baby survive? When we do nothing, it will die for sure...»

«Will we be ok as a family, when my baby survives with disabilities?»

«Will I give birth today? Or later?»

Does the information we provide cover the questions the parents have?

«Will we be ok as a family, when my baby dies?»

«Will my baby suffer?»

«How can we predict happiness?»

Measuring and communicating meaningful outcomes in neonatology: A family perspective.

Annie Janvier et al. Semin Perinatol. 2016.

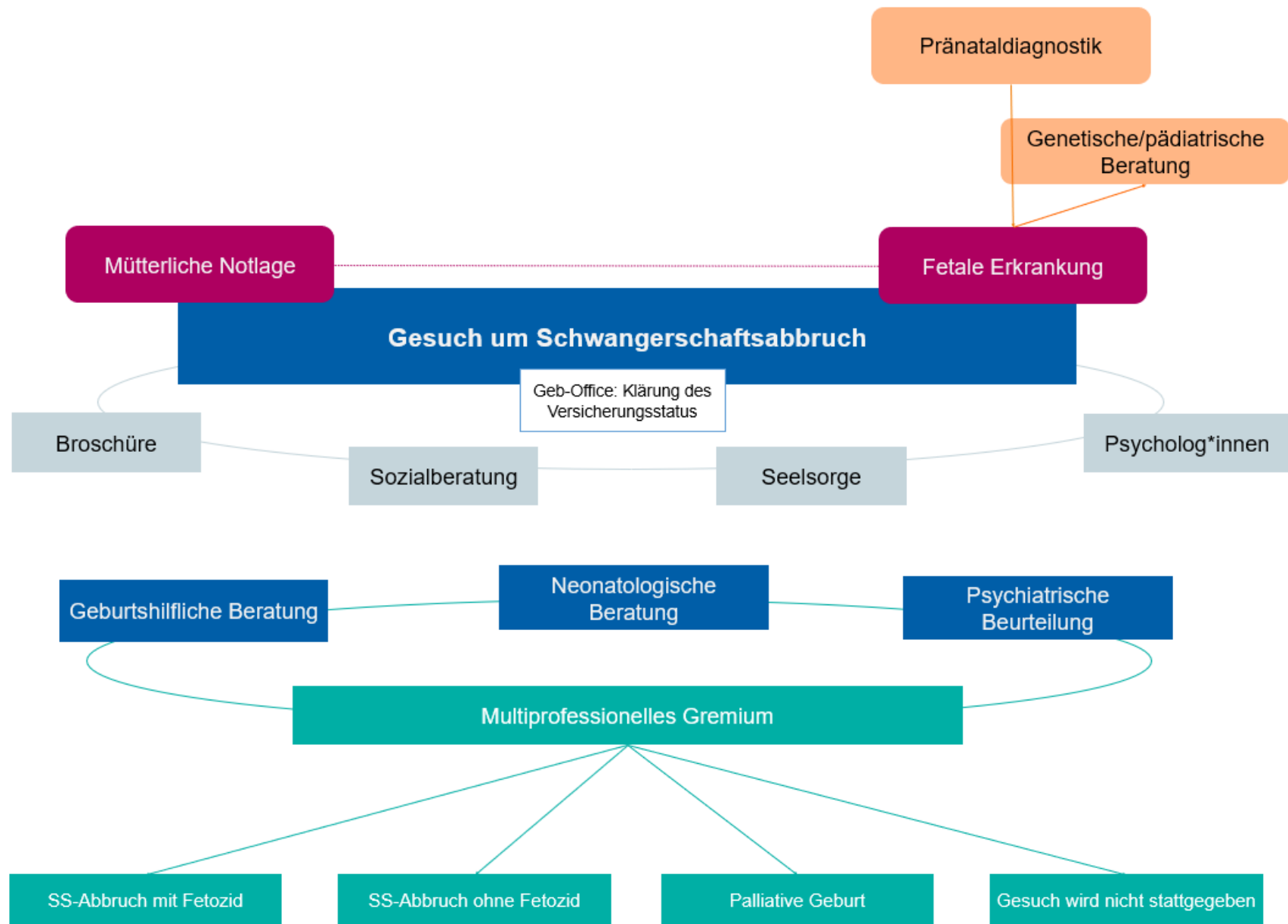
- information should be personalized, balanced (memory aids)
- discuss real-life outcomes
- wording is important
- provide information of parental support groups or associations
- empower

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Prenatal counseling and comfort care

- a process over time, rather than a onetime event
- talk about between nonresuscitation and not "doing nothing"
- interdisciplinary, interprofessional approach (think of early connection with the local PPC team)
- personalized information
- talk about expectations, wishes and fears

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