SWISS RECOMMENDATIONS FOR THE PERINATAL CARE OF EXTREMELY LOW GESTATIONAL AGE NEONATES (ELGANs)

Revision of the 2011 Swiss guidelines

Authors (in alphabetical order):
Adams M,
Berger TM,
Diebold C,
Dinten B,
Fauchère JC,
Gubler D,
Hendriks M,
Hodel M,
Kind C,
Martinez de Tejada B,
Natalucci G,
Pfister RE,
Schulzke S,
Surbek D,
Truttmann AC

Consultation

- Swiss Society of Neonatology (SSN) (contact: Meyer, P)
- Swiss Society of Gynaecology and Obstetrics (SSGO) represented by the Swiss Academy for Feotomaternal Medicine (AFMM) (contact: Hodel, M)
- Swiss Society of Paediatrics (SSP) (contact: Bachmann, I)
- Swiss Society for Developmental Paediatrics (SSDP) (contact: Natalucci, G)
- Paediatric Palliative Care Network Switzerland (PPCN CH) (contact: Gubler, D)
- Swiss Federation of Midwives (contacts: Steiner A, Diebold C)
- Parent representatives from Né Trop Tôt (contact: Nguyen, L) and Frühchen Schweiz (contact: Hediger, D)

Editorial responsibility:
Berger TM, Fauchère JC

Overview

Abbreviations

DR:	delivery room
CTG:	cardiotocography
ELGANs:	extremely low gestational age neonates
HCPs:	health care professionals
NICU:	neonatal intensive care unit
PPROM:	prolonged premature rupture of membranes
SDM:	shared decision-making

1. Summary

Perinatal care of pregnant women at high risk for extremely preterm delivery and of preterm infants born at an extremely low gestational age (< 28 weeks of gestation) requires a multidisciplinary approach by an experienced perinatal team. Knowledge of current gestational age-specific mortality and morbidity rates and how they are modified by prenatally known prognostic factors (e.g., estimated foetal weight, gender, treatment with antenatal corticosteroids for foetal maturation, single or multiple births), as well as accepted ethical principles form the basis for responsible decision-making.

While women at risk for preterm delivery should be transferred to a level III perinatal centre as early as 22 0/7 weeks of gestation, such in utero transfers do not automatically mandate survival-focused perinatal care but allow for detailed interdisciplinary counselling of the parents for shared decision-making (SDM) and optimizing perinatal care.

The care of preterm infants with a gestational age below 23 0/7 (as confirmed by first trimester ultrasound scan) should be limited to comfort-focused palliative care. Obstetric interventions for foetal indications such as foetal surveillance by cardiotocography and Caesarean section delivery are not indicated.

In preterm infants with a gestational age ≥ 23 0/7 weeks, risk assessment must be individualized by considering additional non-modifiable and modifiable risk factors; decision-making based on gestational age alone must be abandoned. The management options that will have to be discussed with the parents fall into three different trajectories.

First, if experienced members of the perinatal team conclude that survival-focused care is not in the best interest of the infant because the burden clearly outweighs the benefit, parents should be informed that obstetric interventions for foetal indications are not recommended, and preference should be given to comfort-focused palliative care for the infant.

Second, if survival-focused care clearly is in the best interest of the patient, parents should be informed that obstetric interventions for foetal indications are recommended, and survival-focused care should and will be provided for the infant.

Third, if the perinatal team concludes that both survival-focused and comfort-focused palliative care can be considered because the best interest of the infant is uncertain, parental preferences must be explored, respected, and supported. While parental decisional authority is limited when the best interest of the infant is obvious, SDM becomes of paramount importance when the best interest of the infant is uncertain.

As a general principle, any obstetric interventions for foetal or maternal indications must be discussed with the pregnant woman and must follow SDM principles.

As pregnancy advances, risk must be re-evaluated frequently, sometimes on a daily basis. In doubtful situations, it can be reasonable to initiate survival-focused care in the delivery room (DR), and to admit the preterm infant to a neonatal intensive care unit (NICU). The infant's clinical course and additional discussions with the parents will help to clarify whether survival-focused care should be continued or redirected towards comfort-focused palliative care.

Life support is continued as long as there is reasonable hope for survival and the burden imposed by intensive care is acceptable. If, on the other hand, the health care professionals (HCPs) and the parents have to recognise that the burden of currently used therapies has become disproportionate given a very poor prognosis, intensive care measures are no longer justified, redirection of care is appropriate, and comfort-focused palliative care becomes the new prioritiy. If a decision is made to withhold or withdraw life-sustaining therapies, the neonatal HCPs should focus on comfort care for the dying infant and support for the parents.

2. What is new?

The revised Swiss recommendations attempt to describe a medically and ethically sound approach to women and infants confronted with the risk of birth at an extremely low gestational age (< 28 0/7 weeks). They differ from the previous guidelines in several key aspects:

- They emphasize the limited value of risk assessment based on gestational age alone.

- The concept of a gestational age-based grey zone has been replaced by a structured and individualized risk assessment, which considers updated national and international information on mortality and morbidity rates of extremely low gestational age neonates (ELGANs).

- They explain the central role of SDM and, of particular importance, the active involvement of the parents in this process with appropriate consideration of their decisional authority and the women's autonomy regarding obstetric interventions.

- They define the relevant elements of both survival- and comfort-focused perinatal care.

- They emphasise that the care of women at high risk of preterm delivery and preterm infants with an extremely low gestational age must be provided by an experienced interdisciplinary and interprofessional perinatal team who can support parents with compassionate guidance.

3. Introduction

These recommendations refer to the perinatal care of women at high risk of preterm delivery and preterm infants with an extremely low gestational age. They have been written for physicians, midwives, nurses, and other professionals who are involved in the care of this high-risk population.

The first recommendations for the care of infants born at the limit of viability in Switzerland were published in 2002(1) and revised in 2011(2). The fact that revised recommendations from North America and Europe(3-9) and new mortality and morbidity data, including results from Switzerland(10), have become available, has prompted the Swiss Society of Neonatology to commission the revision of the Swiss recommendations. National recommendations are necessary because ethical decision-making is not only based on widely accepted ethical principles but is also strongly influenced by societal, economic, and legal considerations(11-13). High quality outcome research is important, and results from such studies vary considerably between different countries(14,15). Therefore, the adoption of similar guidelines from other countries would be unlikely to gain wide acceptance in Switzerland. Such nationwide acceptance, however, is important to minimize potentially problematic centre-to-centre variability in the care of women at high risk of preterm delivery and their infants.

While the revised recommendations continue to define a gestational age limit below which survival-focused care is not recommended (23 0/7 weeks), they no longer describe an upper gestational age limit beyond which life-sustaining therapies should always be offered. Rather than defining limits that emphasize gestational age, they highlight the importance of a structured and individualized risk assessment and decision-making process that considers all aspects that can impact on a particular infant's prognosis. The recommendations also recognize the difficulty of dichotomizing decision-making (survival-focused care versus comfort-focused palliative care) when faced with continuous and dynamic variables, such as gestational age and estimated foetal weight.

The principles of ethical decision-making are re-emphasised. The guidelines again highlight the importance of an interdisciplinary approach and SDM. They discuss parental authority and strengthen the role of parents in situations where the assessment of burden and benefit of survival-focused care can reasonably be described as equivocal.

The new guidelines describe appropriate and coherent obstetrical and neonatal approaches to both survival- and comfort-focused palliative care based on current evidence. Importantly, they provide up-to-date information on mortality and morbidity rates of ELGANs cared for in Switzerland(10). They emphasize that decision-making must be based on mortality and morbidity rates for infants who have received survival-focused care; whereas infants who have received *a priori* comfort-focused palliative care must be excluded since all these infants will inevitably have died, leading to underestimation of true chances of survival.

Relevant demographic, diagnostic and outcome information of ELGANs is routinely collected by the Swiss Neonatal Network (SwissNeoNet, Swiss Society of Neonatology), and data from the most recent 5-year-period is used for overall risk assessment. All level III perinatal centres have access to the Swiss Outcome Calculator for very low gestational age neonates. Where possible, these figures are put into a broader context by comparison with outcome data from other high-income countries.

In addition, visual aids have been developed to be used in counselling *(see Appendix II)*. They standardize outcome information presented by the HCPs and may be useful to help parents to understand the consequences of extremely preterm birth.

The new recommendations were elaborated by a group of experienced specialists from different perinatal centres in Switzerland. The current literature was reviewed, and representatives of each specialty contributed to the respective chapters of the new recommendations. Valuable input from parents of former ELGAN infants was also sought regarding SDM and communication. The final version of the new recommendations was approved by all members of the working group as well as the Swiss Society of Neonatology, the Swiss Society of Gynaecology and Obstetrics (represented by the Swiss Academy for Foetal and Maternal Medicine), the Swiss Society of Paediatrics, the Swiss Society of Developmental Paediatrics, the Paediatric Palliative Care Network Switzerland, and the Swiss Federation of Midwives.

Finally, the authors of these recommendations acknowledge that, globally, the availability of resources and, therefore, the quality of neonatal care continue to differ enormously, leading to wide gaps regarding the definition of what is considered to be the limit of viability. The authors agree that privileged countries should recognize these inequalities and support efforts to diminish the existing gaps.

4. Importance and limitations of gestational age assessment

The *International Classification of Disease* (11th revision) defines the gestational age as the postmenstrual age in weeks and days(16). The period between 25 weeks and 0 days (25 0/7 weeks) and 25 weeks and 6 days (25 6/7 weeks), for example, corresponds to 175 to 181 days and is termed 25 completed weeks of gestation; the foetus is in the 26th week of gestation.

Gestational age continues to be a strong predictor of risk and must be taken into consideration when overall risk assessment is performed. However, even the best methods to estimate gestational age are not precise. Early foetal ultrasound examination of the crown-rump length at 11 to 14 weeks of gestation can only determine gestational age within +/- 4days. This means that a foetus estimated to be at 24 0/7 weeks might in fact have a gestational age between 23 3/7 and 24 3/7 weeks(17,18). A much wider range of uncertainty of gestational age (-6 to +14 days) must be accepted when the history of the last menstrual period is used.

It is important to realize that even though outcome data are stratified into segments of weeks, outcomes at either end may be closer to those of the adjacent week than those at the other end of the same week (e.g., outcomes at 23 6/7 weeks are likely more comparable to those at 24 0/7 weeks than those at 23 0/7 weeks). Defining outcomes based on completed weeks arbitrarily eliminates the differences between a foetus at 23 0/7 weeks and one at 23 6/7 weeks of gestation, as well as the similarities between a foetus at 23 6/7 weeks and 24 0/7 weeks of gestation.

In addition, there is considerable variability in maturity at any given gestational age; preterm infants of identical gestational age may exhibit significantly different biological maturity, which in turn may influence their therapeutic requirements and even affect individual mortality and morbidity risks.

5. Additional risk factors

Apart from gestational age, several additional risk factors that can be determined prior to delivery have been found to be associated with short- and long-term outcomes. *Non-modifiable perinatal risk factors* include estimated foetal weight, infant gender, ethnicity, and plurality (single versus multiple gestation). Less well explored and therefore less quantifiable, but likely to be of significance, are early (i.e., second trimester) premature rupture of membranes, anhydramnios, clinical evidence of amnion infection syndrome, placental insufficiency, complications of monochorionic twin pregnancies, as well as severe congenital malformations (e.g., congenital heart disease requiring early interventions, abdominal wall defects, congenital diaphragmatic hernia, etc.).

In addition, there are *potentially modifiable perinatal factors* that can have a significant impact on the prognosis of ELGANs. Modifiable obstetric practices include antenatal interventions (e.g., antenatal corticosteroids for foetal maturation, tocolysis, antibiotics for (P)PROM, magnesium sulphate ($MgSO_4$) for neuroprotection, delayed cord clamping), as well as the site and mode of delivery. Following delivery, the site of neonatal care, initial neonatal resuscitation in the DR, subsequent care in the NICU and approaches to redirection of care are potentially modifiable neonatal practices.

The Swiss Neonatal Network has developed a *risk calculator* that, in addition to gestational age, considers estimated foetal weight, gender, plurality and antenatal corticosteroids for foetal maturation (*see Figures 1, 2*). The calculations are based on prospectively collected data from all infants born with a gestational age < 32 0/7 weeks and/or a birth weight of 400 to 1500 g. The calculations are updated annually, and the displayed results are based on data from the last five years. All level III perinatal centres have access to their own centre-specific outcome data and can compare their data to the Swiss national average (see *Outcome Calculator*).

6. Decision-making process

(see Appendices I-III)

6.1. Ethical considerations

High mortality and morbidity rates of ELGANs as a group *(see Appendix I, Tables 1-3)* and prognostic uncertainty in individual cases create moral dilemmas for both caregivers and parents, thus rendering ethical decision-making difficult. Situations where neonatal HCPs and parents feel that survival-focused care is not justified are influenced by the cultural and personal background of the decision-makers(11-13,19-28). There is, however, consensus regarding the importance of the relevant ethical principles proposed by Beauchamp and Childress(29). It is widely accepted that beneficence, non-maleficence, autonomy and justice must be considered, but several conflicts arise when these principles are applied to ELGANs(30).

One major conflict arises from the question of how the physician's duty to preserve life could be modified by thoughts about the achievable quality of life. If it is not permissible to take the quality of life into account, and human life must be supported with all available means, there is a risk of inappropriate or even excessive therapy. On the other hand, to only accept life-sustaining therapies if a certain quality of life can be guaranteed, could be regarded as discrimination toward the disabled. A possible compromise between these two extreme positions might be to ask the question if the burden imposed on the patient by the various interventions can be ethically justified when confronted with a very unfavourable prognosis(31,32). In such situations, the decision to withhold or withdraw life-sustaining therapies is motivated by the desire to protect the patient from undue suffering.

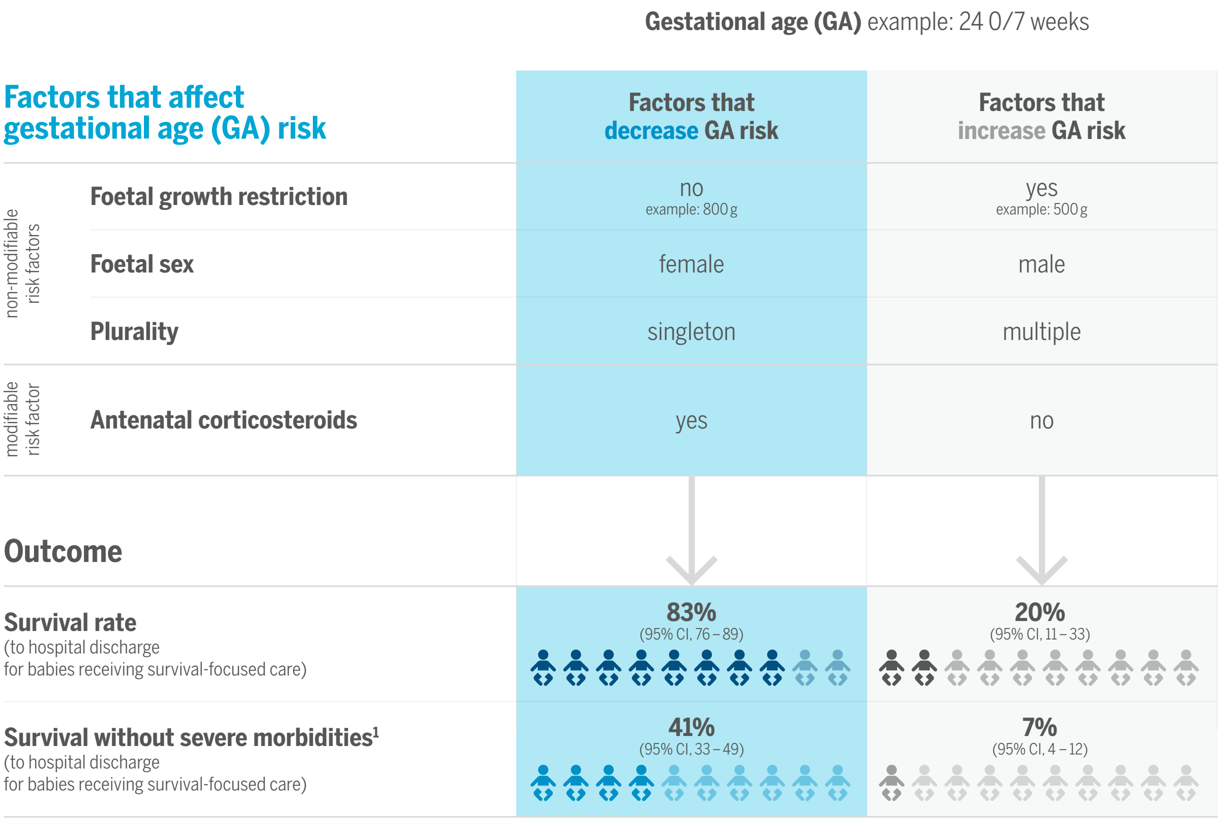
6.2. Decision-makers

Since the preterm infant whose life is directly affected by the treatment decisions cannot communicate his/her preferences, decisions must be made by proxy. This surrogate role may be played by the HCPs, the parents of the infant or by a societal body, such as an ethics committee or, in some rare cases, a court of law. Ideally, such decisions should not be made by a single party at a particular point in time but should rather be developed in an ongoing dialogue between

Individualised risk assessment
by interdisciplinary team considering all factors known to affect prognosis

Factors known to affect prognosis	**Positive impact on prognosis**	**Negative impact on prognosis**
A) Continuous variables		
— Gestational age	higher gestational age	lower gestational age
— Estimated foetal weight	higher foetal weight	lower foetal weight
B) Binary variables		
— Sex	female	male
— Plurality	singleton pregnancy	multiple pregnancy
— Antenatal corticosteroids	yes	no
— Neuroprotection ($MgSO_4$)	yes	no
C) Other factors		
— Severe foetal malformations	no	yes
— Chorioamnionitis	no	yes
— Foetal compromise	no	yes

Fig. 1. *Individualised risk assessment for the perinatal management of ELGANs with a gestational age ≥ 23 0/7 weeks.*



Gestational age (GA) example: 24 0/7 weeks

Factors that affect gestational age (GA) risk		**Factors that decrease GA risk**	**Factors that increase GA risk**
non-modifiable risk factors	**Foetal growth restriction**	no example: 800 g	yes example: 500 g
	Foetal sex	female	male
	Plurality	singleton	multiple
modifiable risk factor	**Antenatal corticosteroids**	yes	no
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 morbidities[1] (to hospital discharge for babies receiving survival-focused care)		**41%** (95% CI, 33 – 49)	**7%** (95% CI, 4 – 12)

Fig. 2. *Prognostic impact of prenatally known risk factors on gestational age-specific outcomes: example of extremely preterm delivery at 24 0/7 weeks of gestation.*

Note: estimates are based on prospectively collected data (2018-2022) from the Swiss Neonatal Network (see Outcome Calculator), including all infants born with a gestational age < 32 0/7 weeks and/or a birth weight of 400 to 1500 g

1 necrotizing enterocolitis Bell's stages 2-3, intra/periventricular haemorrhage grade 3-4, moderate to severe bronchopulmonary dysplasia, retinopathy of prematurity stages 3-4 all parties involved, namely physicians, midwives, nursing staff and parents within a SDM process(33-38).

At the same time, the decisional autonomy of the pregnant woman must be respected. From a legal standpoint, all decisions regarding obstetric interventions are made by the woman (not by the obstetric HCPs, and not by the partner). Therefore, any obstetric interventions, such as foetal surveillance or Caesarean section, always require her explicit informed consent.

6.3. Individualised risk assessment for decision-making

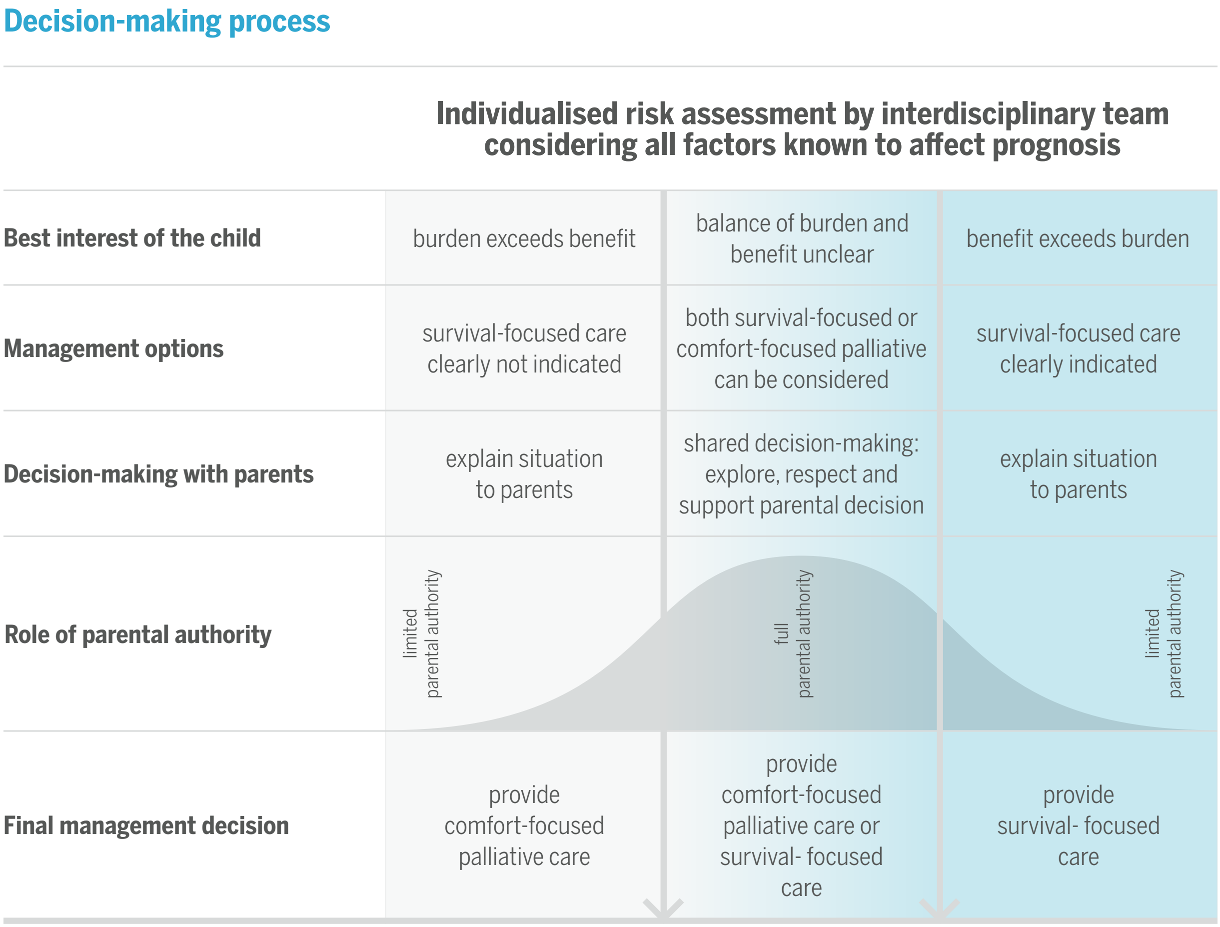
Mortality and morbidity rates of preterm infants correlate with gestational age. However, additional risk factors significantly affect prognosis and, therefore, must be considered. Nevertheless, given an extremely high risk of adverse outcome (see *Appendix I*), these recommendations do not recommend initiating life-sustaining therapies at less than 23 0/7 weeks of gestation. In contrast, non-initiation of life-sustaining therapies when individual risk assessment is favourable would not be ethically justifiable. In between, individual risk assessment can be equivocal. In those situations, values and preferences of the parents play a central role in the decision-making process. It is imperative to explore their attitudes, to respect their authority, and to support their final decision *(see Figure 3)*.

6.4. Prenatal communication among decision-makers

Prenatal ethical decision-making regarding maternal, foetal, and neonatal interventions at the margin of viability is rationally and emotionally challenging for both parents and HCPs(33). Communicating complex issues in an appropriate way, which is adapted to the parent's current level of understanding, requires competence and experience. Therefore, these discussions must always be led by experienced and appropriately trained senior obstetricians/foetomaternal medicine specialists and neonatologists. The goal of these conversations is to establish and maintain a trusting relationship between parents and HCPs. 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 (ethical deliberation)

Perinatal care of a foetus or a preterm infant at an extremely low gestational age must follow a multi-



Decision-making process

Individualised risk assessment by interdisciplinary team considering all factors known to affect prognosis

Best interest of the child	burden exceeds benefit	balance of burden and benefit unclear	benefit exceeds burden
Management options	survival-focused care clearly not indicated	both survival-focused or comfort-focused palliative can be considered	survival-focused care clearly indicated
Decision-making with parents	explain situation to parents	shared decision-making: explore, respect and support parental decision	explain situation to parents
Role of parental authority	limited parental authority	full parental authority	limited parental authority
Final management decision	provide comfort-focused palliative care	provide comfort-focused palliative care or survival- focused care	provide survival- focused care

Fig. 3. *Decision-making process for the perinatal management of ELGANs with a gestational age ≥ 23 0/7 weeks.*

disciplinary approach and requires close cooperation between obstetricians/foetomaternal specialists, neonatologists, midwives, neonatal nurses, and other parties involved. Frequently, decisions must be made within a short period of time. In a first step, an individualised risk assessment must be made conjointly by the responsible senior staff members of the perinatal team. Following individualised risk assessment, the specific management trajectory is explained and discussed with the parents. Importantly, this first consultation must be conducted by experienced obstetricians and neonatologists *together* to avoid unnecessary dissonance and parental confusion.

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; it should be presented using appropriate terms and understandable language. It has been shown that the way messages are relayed significantly influences the parent's perception of their child's condition and their treatment decisions(39-45). Therefore, information should not only focus on the rates of mortality and severe impairment but also mention the chances for survival without severe impairment to avoid inappropriately influencing the decision-making process. Great care must be taken that the parent's cultural background, their religious/spiritual beliefs, and their ability to understand complex issues are adequately considered. The services of professional translators or cultural mediators should be used liberally. Parental expectations and hopes should be carefully explored and compared to the published prognostic data. Frequently, parents have unrealistic expectations not only of what is medically feasible but also of the prognosis of their child, irrespective of which therapeutic options are discussed. For parents, it is important to realise that outcome data describe probabilities of a cohort of infants; therefore, it is crucial that they understand that there is always some degree of uncertainty regarding the estimated prognosis of an individual child.

The perinatal team is obliged to support parents in their role as their child's proxy. Parents should be given sufficient time to ask questions, to address unclear issues of the conversation or to weigh risks and benefits of the discussed therapeutic strategies. Further conversations among family members or support by members of hospital clergy can be helpful. Parents should also be informed that because of the imprecision of prenatal estimates of gestational age and foetal weight, it may occasionally be necessary to revise prenatal agreements immediately after birth.

Quite often, there is a need for several prenatal conversations, particularly when pregnancy continues and the infant's prognosis changes. Additional discussions should ideally be led by the same physicians as continuity and emotional relations are important to parents.

Parents should be informed that even if no life-sustaining efforts will be made, the infant will likely be born alive and possibly live for several hours. The infant will stay with the parents. Privacy will be maximised while the parents are supported by the HCPs. This will also apply if survival-focused resuscitative efforts are not successful. Parents should understand that their presence is very important, and human warmth must be provided. In addition, if non-pharmacological comfort measures are considered insufficient, the infant will receive analgo-sedative medication to relieve any suffering.

6.5. SDM

(for more in-depth information, see Appendix III)

Perinatal HCPs and parents face increasingly complex choices in pre- and postnatal treatment decisions. Whenever uncertainty exists regarding the potential benefits of a given treatment or approach, and when no clear best strategy can be formulated, SDM is the recommended decisional approach.

In a SDM process, HCPs respect parental authority and competence. Parents must be given the opportunity to actively engage in decision-making. A trusting partnership between parents and perinatal professionals may encourage parents to take part in the decision-making process. This requires open and compassionate bi-directional exchange of essential information. SDM emphasizes the importance of exploring parental values, perspectives, goals, and beliefs. The common goal is to make optimal medical decisions that are in the infant's best interest and respect parental preferences(11,38).

7. Survival-focused care

7.1. Obstetrical aspects

Consultation at a level III perinatal centre at < 22 0/7 weeks of gestation

Caring for high-risk pregnant women with preterm labour, a short or partially open cervix, continuous vaginal bleeding, or prolonged premature rupture of membranes (PPROM) before 22 weeks is challenging. Consultation at a level III perinatal centre for outpatient specialized risk assessment can support the referring obstetric team in their care of the pregnant woman. Furthermore, and if appropriate, risks and benefits of potential future perinatal interventions can be discussed with the parents. The goal of these discussions is to establish a trusting relationship between the parents and the team at the level III perinatal centre. This will facilitate timely transfer to the perinatal centre should this become necessary at a later point in time.

Referral to a level III perinatal centre at ≥ 22 0/7 weeks of gestation

Parents must be told that the prognosis regarding mortality and morbidity of an ELGAN is better if referral to a level III perinatal centre occurs prior to delivery. Ideally, following discussion with the referral centre, women who are at high risk for extremely preterm delivery should be transferred to such a centre as early as 22 0/7 weeks of gestation. Such *in utero* transfers do not automatically mandate survival-focused perinatal care but allow for detailed counselling of the parents for SDM and optimizing perinatal care.

When it has been agreed that potentially life-sustaining care for the baby is appropriate, active obstetric interventions are indicated to ensure the baby is born in the best condition.

Antenatal corticosteroids to enhance foetal maturation(46)

Timely administration of antenatal corticosteroids has a significant impact on prognosis and will therefore have a marked impact on risk assessment when delivery becomes imminent. It does, however, not automatically imply that survival-focused perinatal care must always follow. A second course (rescue foetal maturation) can be administrated if the first corticosteroid doses have been given very early and preterm delivery again becomes imminent.

Tocolysis(47,48)

There is no clear evidence for the effectiveness of tocolysis prior to 24 0/7 weeks of gestation. However, on an individual basis, and after discussion with the parents, tocolysis can be used earlier, and might allow for effective foetal maturation.

Antibiotics following PPROM(49)

While there is no conclusive data to support the administration of antibiotics after PPROM prior to 24 0/7 weeks of gestation, they can be given at an earlier stage in case of a relevant risk of maternal sepsis. For later gestational ages, there is strong evidence for improved maternal and foetal outcomes. The optimal regimen of antibiotics after PPROM is unknown, but amoxicillin/clavulanic acid is not recommended in this context(50).

Cervical cerclage(51)

Pregnant women with a single pregnancy without previous spontaneous preterm labour or late abortion presenting with a cervical length of < 10 mm at an extremely low gestational age can be considered for cervical cerclage. Similarly, when the cervix is dilated to more than 1 cm, a rescue cerclage can be performed if there is no evidence of chorioamnionitis. Women with previous preterm delivery before 34 weeks of gestation should be offered a cerclage if the cervical length is shortened to less than 25 to 30 mm before 24 weeks of gestation.

Neuroprotection with magnesium sulphate ($MgSO_4$)(52,53)

Antenatal administration of $MgSO_4$ improves long-term neurological outcome in ELGANs. This intervention can be repeated once if delivery occurs at a later stage.

Foetal ultrasound examination and foetal monitoring

An extended ultrasound examination should be performed to assess foetal weight, gender, and wellbeing. In addition, this examination can exclude severe malformations which could potentially alter perinatal management. Serial follow-up ultrasound examinations will allow to assess foetal growth and placental function. Even though there is scarce evidence for its usefulness, cardiotocography (CTG) monitoring should be considered once survival-focused care has become an option.

Mode of delivery(54)

Caesarean sections should not be performed routinely to deliver ELGANs. If the foetus is in a cephalic position and there are no maternal and/or foetal contraindications, vaginal delivery under continuous CTG surveillance can be considered, depending on the overall clinical situation (e.g., vaginal bleeding, PPROM, foetal presentation, multiple gestation, etc.) and maternal preference.

Delayed cord clamping(55-57)

There is robust evidence that placental-neonatal transfusion through delayed cord clamping is associated with improved haemodynamic stability, decreased need for blood transfusions and a lower incidence of intraventricular haemorrhage. In addition, delayed cord clamping lowers the mortality rates of preterm infants.

7.2. Neonatal aspects

Initial resuscitation in the delivery room (DR)

Once a decision has been made that survival-focused neonatal care should be pursued, delivery of ELGANs must be attended by an experienced neonatology team. Initial stabilisation should not be compromised by *a priori* exclusion of interventions that are considered effective in more mature infants with lower risks. It has been demonstrated that the clinical condition of the infant after birth and the response to resuscitative measures are not reliable prognostic factors (58). Except for extreme situations (i.e., asystole), it should not deter from the agreed upon survival-focused care.

Generally, such infants will benefit from interventions that include, but are not limited to, prevention of hypothermia by meticulous control of the thermal environment (e.g., designated resuscitation area with a high ambient temperature, plastic wraps), lung protective respiratory support (often including endotracheal intubation and surfactant administration) and establishing vascular access (usually by placing umbilical venous and arterial catheters) to draw blood, continuously monitor blood pressure, and administer fluids and drugs.

Provisional intensive care in the NICU

Intensive care measures that are initiated in the DR and continued in the NICU are based on the therapeutic goal. The primary aim is to help the infant survive, to promote normal development and minimise permanent impairments. If a decision is made to provide provisional intensive care to an ELGAN, the treatment should be optimised to avoid secondary injuries at all costs. Refraining from applying certain interventions that are routinely used in more mature preterm infants is not justified.

The infant's condition should be re-evaluated frequently under the supervision of experienced neonatologists to determine if the risk assessment made prior to delivery, which led to the decision to provide survival-focused care, still appears justified. Parents should be informed regularly about the infant's clinical course. As long as there is reasonable hope that the primary goal can be reached and the burden of the interventions used appears justified, all necessary therapies are continued.

Redirection of care

If both the neonatal HCPs and the parents recognize that the primary goal can no longer be reached and life-sustaining therapies are no longer justified, other aspects of care should be prioritised (redirection of survival-focused care to comfort-focused palliative care). Whenever life-sustaining therapies are withdrawn, everything must be done to allow the infant to die peacefully and with dignity. If necessary for adequate control of any distress (e.g., pain, dyspnoea), appropriately dosed opiates should be used.

Following redirection of care, parents should be supported by experienced HCPs. They should be given the opportunity to be with their child in an environment that provides adequate privacy. They must be given as much time as they need(59). They should have the opportunity to hold their child during the dying process and/or after death. Most parents feel a deep urge to give their dying child some warmth and support(60). However, most parents will need guidance, as they are confronted with an unfamiliar and extremely stressful situation(59). Spiritual support should be offered, and cultural differences must be considered. Photos, foot- and handprints of their child, as well as symbolic objects are precious memories for parents (59,61). Visits of close ones (e.g., siblings, godparents) should be considered. After the infant's death, ongoing comprehensive support of parents, siblings, and others (e.g., grandparents) must be ensured.

8. *A priori* comfort-focused palliative care

Given an extremely high risk of adverse outcomes (*see Appendix I*), these guidelines do not recommend initiating life-sustaining therapies at less than 23 0/7 weeks. At higher gestational ages, individualised risk assessment and SDM may also lead to the conclusion that the burden likely exceeds the potential benefits. In such situations, survival-focused care is not indicated, and preference should be given to *a priori* comfort-focused palliative care.

8.1. Obstetrical aspects

When a decision has been made prenatally to abstain from survival-focused care and to provide comfort-focused palliative care, foetal surveillance, and other obstetric interventions such as Caesarean section for foetal indications are not indicated.

8.2. Neonatal aspects

The parents should be informed that the infant might show signs of life, such as some movements and/or some respiratory effort, including gasping respiration. The infant should not be separated from the parents.

The fact that the dying process may last several hours should be explained. They should be assured that every effort will be made to minimise any potential suffering (provision of warmth, ideally through skin-to-skin contact, swaddling, and opiates, if needed).

9. Appendix I: Recent outcome data from Switzerland and comparison with outcome data from other high-income countries

Current mortality and morbidity rates in Switzerland

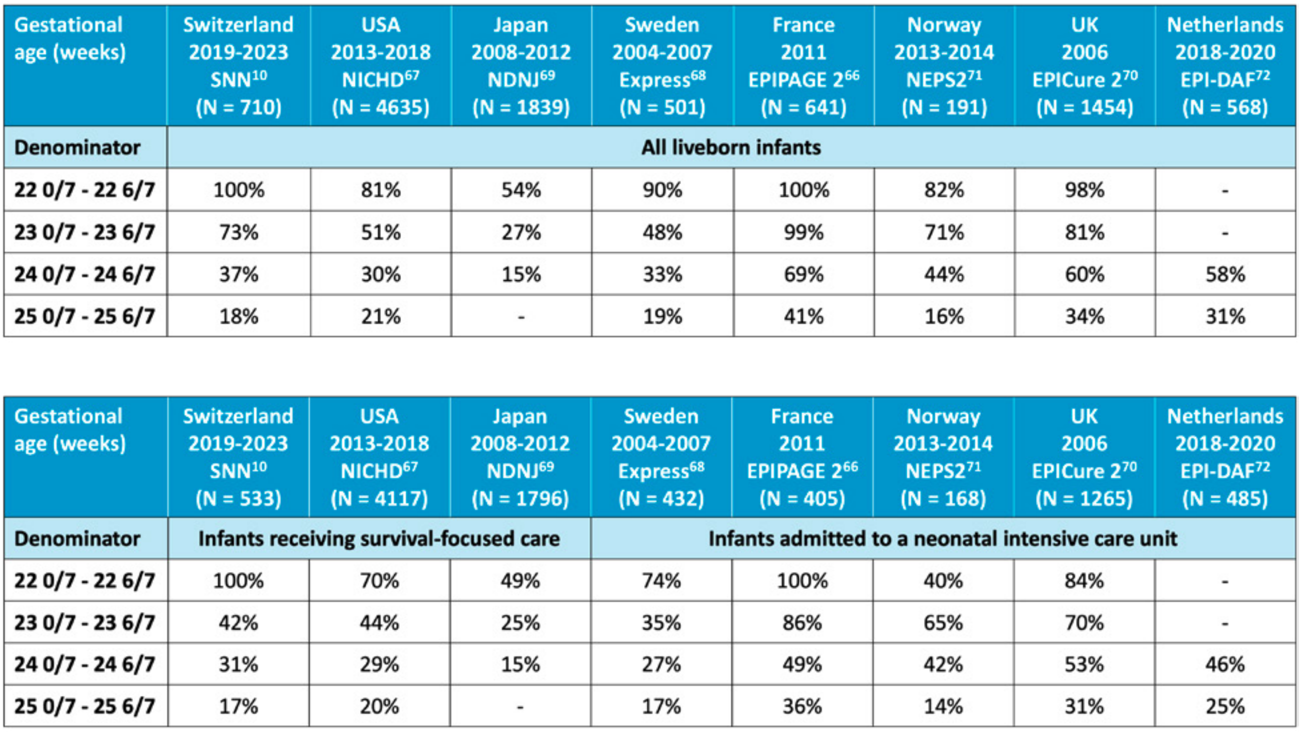
Although gestational age is a major predictor of both short- and long-term outcomes, other factors have a significant impact on the mortality and morbidity risks of infants born at an extremely low gestational age (male gender, low estimated foetal weight, a multiple pregnancy, and the lack of antenatal corticosteroids (*see chapters 4 and 5*).

To make informed decisions regarding perinatal care, it is imperative to have expert knowledge of current national and local outcome data of ELGANs and the impact of additional risk factors as outlined above. The Swiss Society of Neonatology provides an Outcome Calculator to facilitate individualised risk assessment.

Mortality

Developments in perinatal care in recent decades have dramatically increased survival of ELGANs(62-65). Comparisons of various national recommendations from high-income countries and current national(10) and international(66-72) outcome data reveal considerable differences.

It is important to note that calculation of mortality risk among ELGANs will differ depending on the denominator used(73,74). This is particularly evident for infants born at 23 weeks of gestation, where the calculated mortality risk decreases from 73 % (denominator: all liveborn infants) to 42 % (denominator: infants receiving survival-focused care) in Switzerland *(see Table 1)*.



Gestational age (weeks)	Switzerland 2019-2023 SNN[10] (N = 710)	USA 2013-2018 NICHD[67] (N = 4635)	Japan 2008-2012 NDNJ[69] (N = 1839)	Sweden 2004-2007 Express[68] (N = 501)	France 2011 EPIPAGE 2[66] (N = 641)	Norway 2013-2014 NEPS2[71] (N = 191)	UK 2006 EPICure 2[70] (N = 1454)	Netherlands 2018-2020 EPI-DAF[72] (N = 568)
Denominator	**All liveborn infants**							
22 0/7 - 22 6/7	100%	81%	54%	90%	100%	82%	98%	-
23 0/7 - 23 6/7	73%	51%	27%	48%	99%	71%	81%	-
24 0/7 - 24 6/7	37%	30%	15%	33%	69%	44%	60%	58%
25 0/7 - 25 6/7	18%	21%	-	19%	41%	16%	34%	31%

Gestational age (weeks)	Switzerland 2019-2023 SNN[10] (N = 533)	USA 2013-2018 NICHD[67] (N = 4117)	Japan 2008-2012 NDNJ[69] (N = 1796)	Sweden 2004-2007 Express[68] (N = 432)	France 2011 EPIPAGE 2[66] (N = 405)	Norway 2013-2014 NEPS2[71] (N = 168)	UK 2006 EPICure 2[70] (N = 1265)	Netherlands 2018-2020 EPI-DAF[72] (N = 485)
Denominator	**Infants receiving survival-focused care**			**Infants admitted to a neonatal intensive care unit**				
22 0/7 - 22 6/7	100%	70%	49%	74%	100%	40%	84%	-
23 0/7 - 23 6/7	42%	44%	25%	35%	86%	65%	70%	-
24 0/7 - 24 6/7	31%	29%	15%	27%	49%	42%	53%	46%
25 0/7 - 25 6/7	17%	20%	-	17%	36%	14%	31%	25%

Table 1. *Gestational age-specific mortality rates among ELGANs in Switzerland, the USA, Japan, Sweden, France, Norway, the UK, and the Netherlands. Impact of different denominators: «all liveborn infants» (top), «infants receiving survival-focused care» or «infants admitted to a neonatal intensive care unit» (bottom).*

Long-term outcomes following survival to discharge

As the chances of survival for ELGANs increased, the focus of research has shifted to both physical and psychological health as well as the quality of life of these patients well beyond their stay in the NICU. To measure these outcome parameters, standardized assessments of this population are coordinated and systematically performed by the Swiss Neonatal Network and Follow-up Group(75).

Although neurodevelopment remains highly relevant for the assessment and classification of newborn outcomes, other physical and psychological outcomes are also important. Preterm birth survivors are at risk for developmental impairments. In recent years, research has also shown associations between prematurity and long-term respiratory(76-78), cardiovascular(79,80), and renal morbidity(81,82). In addition, a typical behavioural phenotype has been described in children born very preterm, including internalizing symptoms (such as anxiety), attention deficits, and problems with peer relationships(83). Moreover, prematurity is associated with an increased risk of autism spectrum disorder(84,85).

Despite some inconsistencies in earlier studies(86-88), a recent meta-analysis reported lower health-related quality of life in children and adolescents born preterm, particularly among survivors with concurrent neonatal or long-term morbidities(89).

Neurodevelopmental outcome

Swiss and international population-based data on mid- to long-term outcomes of infants born at 22 to 25 weeks' gestation are presented here. The heterogeneity of research designs, age variability at follow-up and outcome definition makes it difficult to select appropriate follow-up studies to identify and compare the prevalence of neurodevelopmental disorders in surviving ELGANs. For this recommendation, only population-based reports with similarities in the above characteristics were selected. While this representative data allows for descriptive comparison between Switzerland and other high-income countries, some have been published more than ten years ago, describing outcomes of babies born more than 15 years ago (*see Table 2*)(10,67,69,70,72,90,91).

Relying solely on outcomes at 2 to 3 years runs the risk of misclassifying long-term cognitive or neuromotor findings. From early school age, more accurate assessment of cognitive functioning and motor and sensory outcomes is possible, and developmental trends of individuals are becoming more discernible(92). For this reason, data on outcomes evaluated at ages 5 to 6.5 years are provided separately (*see Table 3*)(10,93,94). Limiting factors include the small sample size at 22 to 23 weeks' gestation and loss to follow-up of 20 to 40 %(10,67,69,70,72,90,91,93,94).

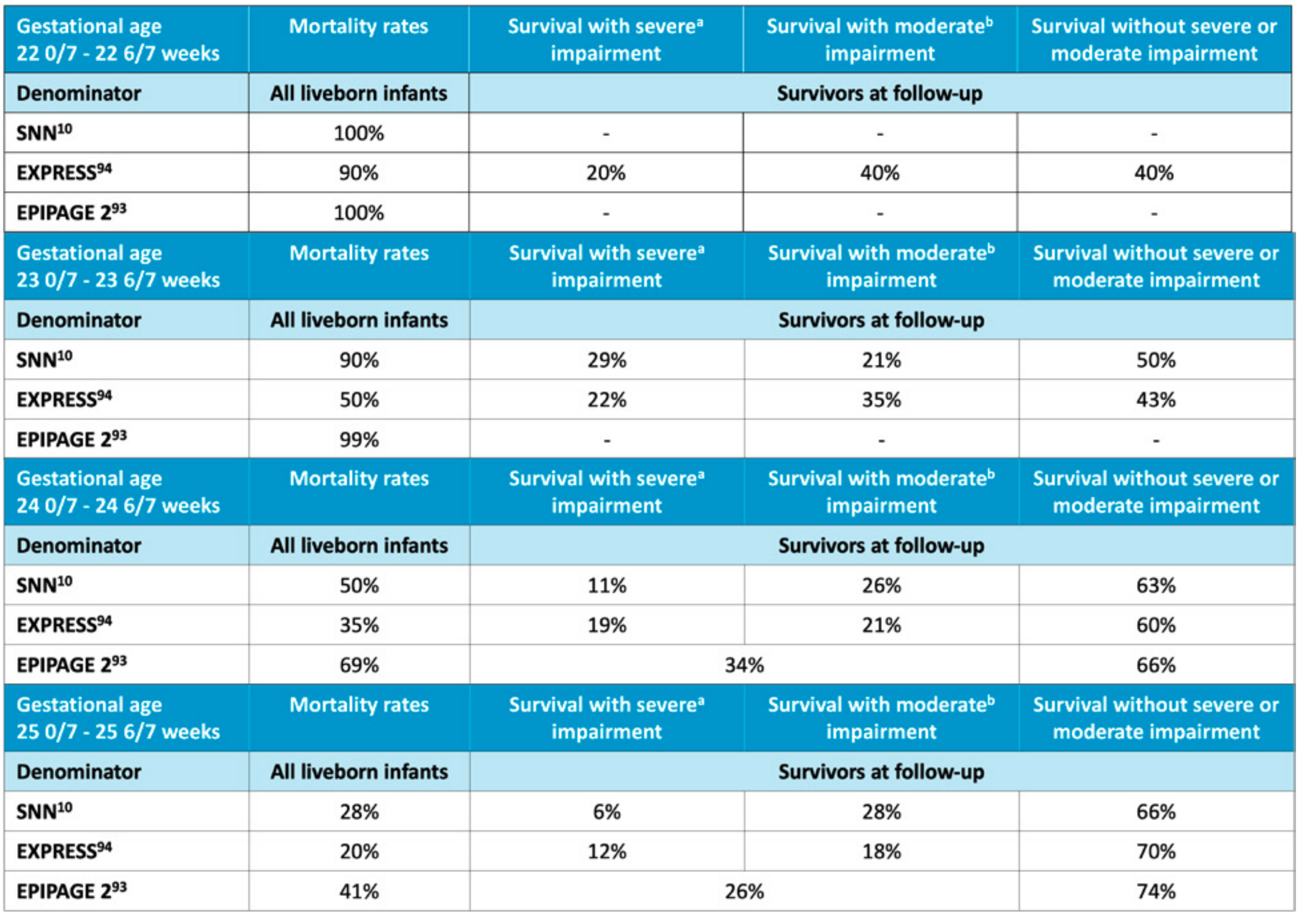
At the corrected age of two to three years (*see Table 2*), about 40 to 50 % of survivors after preterm

Gestational age 22 0/7 - 22 6/7 weeks	Mortality rates	Survival with severe[a] impairment	Survival with moderate[b] impairment	Survival without severe[a] or moderate[b] impairment
Denominator	**All liveborn infants**	**Survivors at follow-up**		
SNN[10]	100%	-	-	-
EXPRESS[91]	90%	40%	20%	40%
EPIPAGE 2[90]	100%	-	-	-
Netherlands[72]	-	-	-	-
NICHD[67]	81%	31%	24%	45%
EPICure[70]	98%	10%	42%	48%
Japan[69]	54%	54%		46%
Gestational age 23 0/7 - 23 6/7 weeks	**Mortality rates**	**Survival with severe[a] impairment**	**Survival with moderate[b] impairment**	**Survival without severe[a] or moderate[b] impairment**
Denominator	**All liveborn infants**	**Survivors at follow-up**		
SNN[10]	79%	19%	23%	58%
EXPRESS[91]	49%	21%	30%	49%
EPIPAGE 2[90]	100%	-	-	-
Netherlands[72]	-	-	-	-
NICHD[67]	51%	34%	35%	31%
EPICure[70]	81%	29%	18%	53%
Japan[69]	27%	42%		58%
Gestational age 24 0/7 - 24 6/7 weeks	**Mortality rates**	**Survival with severe[a] impairment**	**Survival with moderate[b] impairment**	**Survival without severe[a] or moderate[b] impairment**
Denominator	**All liveborn infants**	**Survivors at follow-up**		
SNN[10]	38%	4%	25%	71%
EXPRESS[91]	34%	13%	21%	66%
EPIPAGE 2[90]	69%	74%		26%
Netherlands[72]	58%	13%		87%
NICHD[67]	30%	29%	30%	41%
EPICure[70]	60%	19%	16%	65%
Japan[69]	15%	35%		65%
Gestational age 25 0/7 - 25 6/7 weeks	**Mortality rates**	**Survival with severe[a] impairment**	**Survival with moderate[b] impairment**	**Survival without severe[a] or moderate[b] impairment**
Denominator	**All liveborn infants**	**Survivors at follow-up**		
SNN[10]	17%	9%	14%	77%
EXPRESS[91]	19%	10%	17%	73%
EPIPAGE 2[90]	41%	45%		55%
Netherlands[72]	31%	13%		87%
NICHD[67]	21%	18%	30%	52%
EPICure[70]	35%	16%	12%	72%
Japan[69]	-	-		-

Table 2. *Gestational age-specific mortality rates and rates of permanent neurosensory impairment of liveborn infants at a corrected age of 2-to-3 years among ELGANs in Switzerland (2017-2021, N=742), Sweden, France, Netherlands, USA, the UK, and Japan.*

a) Severe impairment: developmental score < -3SD and/or cerebral palsy level 3 to 5 GMFCS (Gross Motor Function Classification System) (95) and/or bilateral deafness and/or bilateral blindness.

b) Moderate impairment: developmental score < -2SD and/or cerebral palsy level 2 GMFCS (Gross Motor Function Classification System) (95) and or bilateral vision and/or hearing disability.



Gestational age 22 0/7 - 22 6/7 weeks	Mortality rates	Survival with severe[a] impairment	Survival with moderate[b] impairment	Survival without severe or moderate impairment
Denominator	**All liveborn infants**	**Survivors at follow-up**		
SNN[10]	100%	-	-	-
EXPRESS[94]	90%	20%	40%	40%
EPIPAGE 2[93]	100%	-	-	-
Gestational age 23 0/7 - 23 6/7 weeks	**Mortality rates**	**Survival with severe[a] impairment**	**Survival with moderate[b] impairment**	**Survival without severe or moderate impairment**
Denominator	**All liveborn infants**	**Survivors at follow-up**		
SNN[10]	90%	29%	21%	50%
EXPRESS[94]	50%	22%	35%	43%
EPIPAGE 2[93]	99%	-	-	-
Gestational age 24 0/7 - 24 6/7 weeks	**Mortality rates**	**Survival with severe[a] impairment**	**Survival with moderate[b] impairment**	**Survival without severe or moderate impairment**
Denominator	**All liveborn infants**	**Survivors at follow-up**		
SNN[10]	50%	11%	26%	63%
EXPRESS[94]	35%	19%	21%	60%
EPIPAGE 2[93]	69%	34%		66%
Gestational age 25 0/7 - 25 6/7 weeks	**Mortality rates**	**Survival with severe[a] impairment**	**Survival with moderate[b] impairment**	**Survival without severe or moderate impairment**
Denominator	**All liveborn infants**	**Survivors at follow-up**		
SNN[10]	28%	6%	28%	66%
EXPRESS[94]	20%	12%	18%	70%
EPIPAGE 2[93]	41%	26%		74%

Table 3. *Gestational-age-specific mortality rates and rates of permanent neurosensory impairment of liveborn infants at age 5-to-11 years among ELGANs in Switzerland (2013-2017, N=746), Sweden, and France.*

a) Severe impairment: developmental score < -3SD and/or cerebral palsy level 3 to 5 GMFCS (Gross Motor Function Classification System)(95) and/or bilateral deafness and/or bilateral blindness.

b) Moderate impairment: developmental score < -2SD and/or cerebral palsy level 2 GMFCS (Gross Motor Function Classification System)(95) and or bilateral vision and/or hearing disability.

birth at 22 weeks of gestation have a favorable neurodevelopmental outcome (i.e., without moderate-to-severe impairment); this rate increases by approximately 10 % points for each additional gestational week. The rate of severe neurodevelopmental impairment decreases with increasing gestational age. Reported outcome figures vary largely between countries.

At the corrected age of five to 11 years (*see Table 3*), population-based, gestational age-specific data about neurodevelopmental outcomes is scarce, especially for children born most prematurely. One study reported a favourable outcome in 40 % of survivors who had been born at 22 weeks' gestation. This rate increases by about 10 % points for each additional week of gestation. The rate of severe neurodevelopmental impairment, which is 20 to 30 % in surviving children who had been born at 22 to 23 weeks' gestation, decreases to six to 12 % in children who had been born at 25 weeks of gestation. The high outcome variability between various countries may be partly explained by different study methodologies (differences in the age of assessment and the assessment tools used, e.g., classic developmental diagnosis versus parent questionnaires).

10. Appendix II: Visual Aids

Visual aids may help parents to better understand statistical data on various outcomes. Moreover, the use of visual decision aids has been associated with improvements in the quality of decisions due to a closer alignment of values and choices(96-98). To avoid any bias, both chances of survival and survival without severe impairment and risks of mortality and survival with severe morbidity should be displayed. Ideally, most recent local (rather than national) outcome data should be used (provided the number of births in a particular week of gestation is sufficient for statistical conclusions).

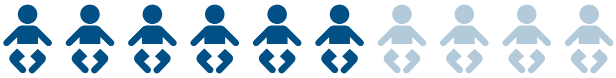
Outcome of babies born alive who receive survival-focused care

23 weeks of gestation

Survival and mortality rates to discharge from hospital

Cohort 2019 – 2023

Live-births (N=142)
Infants with survival-focused care (N=65)



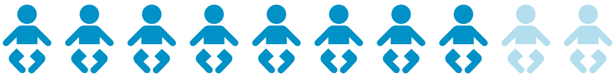
6 in 10 babies **survive**
(59%)

4 in 10 babies **die**
(41%)

Severe disability among survivors who presented to follow-up (2 years)

Cohort 2017 – 2021

N at birth 160
N at follow-up 27



8 in 10 survivors
do not have severe disability
(81%)

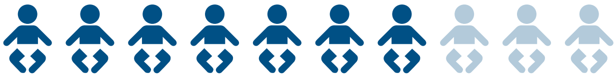
2 in 10 survivors
have severe disability
(19%)

24 weeks of gestation

Survival and mortality rates to discharge from hospital

Cohort 2019 – 2023

Live-births (N=241)
Infants with survival-focused care (N=217)



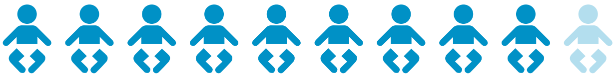
7 in 10 babies **survive**
(69%)

3 in 10 babies **die**
(31%)

Severe disability among survivors who presented to follow-up (2 years)

Cohort 2017 – 2021

N at birth 236
N at follow-up 113



9 in 10 survivors
do not have severe disability
(96%)

1 in 10 survivors
have severe disability
(4%)

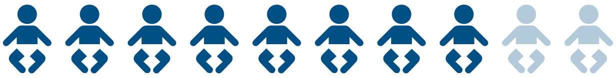
Outcome of babies born alive who receive survival-focused care

25 weeks of gestation

Survival and mortality rates to discharge from hospital

Cohort 2019 – 2023

Live-births (N=248)
Infants with survival-focused care (N=244)



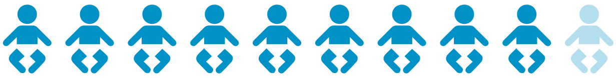
8 in 10 babies **survive**
(83%)

2 in 10 babies **die**
(17%)

Severe disability among survivors who presented to follow-up (2 years)

Cohort 2017 – 2021

N at birth 257
N at follow-up 175



9 in 10 survivors
do not have severe disability
(91%)

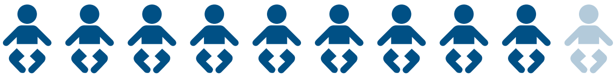
1 in 10 survivors
have severe disability
(9%)

26 weeks of gestation

Survival and mortality rates to discharge from hospital

Cohort 2019 – 2023

Live-births (N=298)
Infants with survival-focused care (N=294)



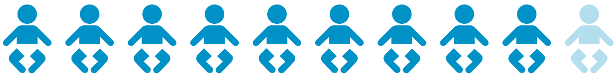
9 in 10 babies **survive**
(88%)

1 in 10 babies **die**
(12%)

Severe disability among survivors who presented to follow-up (2 years)

Cohort 2017 – 2021

N at birth 326
N at follow-up 222



9 in 10 survivors
do not have severe disability
(91%)

1 in 10 survivors
have severe disability
(9%)

Fig. 4. *Visual aids to illustrate both chances for survival and risk of mortality (data shown reflects national outcome data from ELGANs born in Switzerland between 2019 and 2023 who received survival-focused care), as well as chances for survival without severe disability and risks of survival with severe disability (data shown reflects national outcome data from ELGANs born in Switzerland between 2017 and 2021 who were admitted to a NICU; overall follow-up rate 79 %).*

Of note: data shown does not consider the impact of additional risk factors; therefore, prognosis from individualised risk assessment may deviate considerably from data show above (see Figures 1, 2).

Mortality: expressed as mortality at hospital discharge

Severe impairment: expressed as impairment (developmental score < -3SD and/or cerebral palsy level 3 to 5 GMFCS [Gross Motor Function Classification System](95) *and/or bilateral deafness and/or bilateral blindness).*

11. Appendix III: Principles of ethical decision-making

Guiding principles for decision-making

Decisions about life-sustaining treatment for premature infants at the margin of viability should be based on the deliberation of the following principles: preserving life, avoiding harm, furthering quality of life, and providing equal chances. It can be difficult to adequately balance these principles. A first conflict can arise between the duty to preserve life and the unavoidable burden inflicted by neonatal intensive care. It is widely accepted that the burden of treatment can be too heavy to justify its initiation or continuation. A second conflict lies in the tension between concerns for the future quality of life and the duty to provide equal chances to all patients, and to avoid discrimination against ELGANs as a group, especially against those with an increased risk of future disabilities(99). The estimation of the future quality of life must not be limited to the probable functional status but based mainly on the possibility of achieving satisfaction with life(100). The decision to withhold or withdraw life-sustaining treatment should be motivated by the desire to protect the extremely preterm infant from undue suffering.

Careful deliberation of these aspects in the individual patient should lead to answering the question: «Can suffering imposed on the infant by various interventions be ethically justified when confronted with a particular prognosis for survival and future quality of life?». The answer to this question defines the infant's best interest and depends heavily on the personal values of the decision-makers(11-13, 19-28). It is therefore indispensable that HCPs reflect on their own values and help parents to do the same.

Parental authority and the infant's best interest

Over the last decades, the relationship between neonatal HCPs and parents has changed in Switzerland(101). The Swiss population increasingly values patient autonomy and parental authority and supports active parental participation in the decision-making process. They explicitly prefer to reach a decision through a shared dialogue between neonatal caregivers and parents(13). The principle of respecting the patient's autonomy, which in context of neonates is replaced by parental authority as the legal proxy of the child, is clearly promoted and re-emphasised in the Swiss Civil Code (Art. 304) for the protection of adults and children(102). This law, enacted in 2013, strengthens without any ambiguity the role of parents in the decision-making process. Because of their close and unique relationship to their infant, parents are crucial in this process as they have the possibility to introduce a valuable perspective into the decision-making such as their values, opinions and desires for their child and their family(11, 19, 103, 104). The formulation of the infant's best interest is closely linked to the family's best interest. The guidelines of the Swiss Academy of Medical Sciences define decision-making in accordance with the patient's best interest as follows: «In cases where a patient has never had decisional capacity or no evidence of presumed wishes can be obtained, decisions – in the absence of a subjective judgement – can only be based on the patient's (objective) best interests. The treatment promoting these interests is that which is the preferred, medically indicated option for the patient's specific clinical situation (i.e., treatment of choice) and appears appropriate for the individual situation. Here, the authorized representative must decide whether the patient can reasonably be expected to undergo this treatment, or which option is to be chosen if various treatments are equally indicated»(105). On the other hand, parents cannot decide against the best interest of their child, i.e., they cannot decline life-sustaining treatment if it is clearly indicated, nor can they demand it, if the probability of success is extremely low.

Shared decision-making

An important gap still prevails between a declared general support of SDM by neonatal HCPs, their attitudes and the implementation of SDM into daily practice(11, 12, 19). To support and accelerate the actual transition from an informed consent to a shared decision approach(106), neonatal HCPs first and foremost need to accept parental authority regarding medical decisions for their infant, and to actively involve parents as competent surrogate decision makers. SDM goes beyond the ethical-legal minimal standard of informed consent by integrating and balancing both perspectives, namely the best interest standard for the infant and parental values, goals, perspectives, and decision-making preferences.

On these grounds and with the aim of promoting a uniform practice across Switzerland, these recommendations explicitly call for mandatory implementation of an SDM model in neonatal units(38). This change shifts the main focus away from the result of the decision-making towards the process which led to the final decision(107). Parents and neonatal caregivers mutually and continuously share information, and thus reach a decision together that can be supported by all. The role of neonatal HCPs is to provide information on the current medical situation and probable outcome, and to empower parents to participate in the decision-making process. Ideally, the neonatal team should refrain from presenting a single treatment plan to the parents. Instead, they should formulate medically and ethically reasonable and justifiable options for a given infant and discuss these with the parents(108). Parental involvement spans all phases of the decision-making process: from mutual exchange of information to assessment of burden and benefit of various treatment options until reaching and ultimately implementing a collaborative decision. Importantly, the nature, extent and form of participation of parents, neonatal physicians and nurses may change over time and between different decisional phases. Therefore, the degree of their involvement and their roles should be continuously assessed and adapted to best suit their actual needs and abilities(101). SDM puts emphasis on facilitating a partnership between parents and perinatal professionals. Most parents expect to be actively involved in SDM; at the same time, they appreciate not to be left alone with decision-making[109]. It is important to realize that, depending on their cultural and biographical background, parental wishes and abilities to participate in the decision-making process can differ considerably. Parents who are willing to exercise their right to decide to its full extent should be supported in doing so. Those hesitating to express their preferences should be encouraged to participate in the decision-making process, but a clear wish to delegate decision-making to HCPs should be respected. The overall goal of SDM is to reach optimal medical decisions that align with the infant's best interest and parental preferences[38].

Visual aids may help parents to understand the medical situation and to relate the expected prognosis to their values (*see Appendix II: Visual Aids*). This can empower them to participate in SDM, help align between values, goals, and preferences, thereby improving the decision quality, and ultimately reduce the potential for conflicts[37, 98, 110]. Most parents see it as their responsibility to actively participate in decision-making[13, 111-113]. Contrary to a still prevailing worry among neonatal HCPs[114], involving parents in the decision-making process does not present an undue long-term burden on them. To the contrary, when parents experience the decision-making as shared, it is associated with decreased feelings of powerlessness, anger, and grief, all of which impact on parental long-term quality of life[23, 115-117]. This process of SDM requires considerable effort and time from the HCPs[107], but is likely to provide sounder decisions and greater satisfaction for parents[117].

Decision-making in the face of prognostic uncertainty

Mortality and morbidity rates of preterm infants show a strong correlation with gestational age leading to wide agreement that there is a degree of immaturity, which will prevent any success of life-sustaining treatment and, therefore, renders its use unjustifiable. Similarly, it is also generally accepted that there is a level of maturity at and above which withholding of life-sustaining intensive care in the absence of other serious conditions would definitely be against the best interest of the child. When faced with an equivocal risk assessment, parental authority must be respected. On the other hand, professional ethical views of HCPs must not be ignored, and individual HCPs cannot be forced to implement treatment options that would be morally inacceptable to them[118]. In addition, parents have no right to demand a medical treatment considered to offer little or no likelihood of benefit [119].

The motivation for good health care is the conviction that a particular treatment is beneficial. If this is not the case, severe moral distress may arise for professionals obliged to participate in such a treatment[25,120,121]. For all situations where individual risk assessment is equivocal, or whenever the need for an ethical discussion arises, either from the neonatal HCPs and/or from the parents, an SDM process must be initiated with the participation of all the decision-makers. In several conversations, careful attention should be paid to the fears and hopes of parents to help them understand their values. To be able to listen to the parents with empathy, it is important for HCPs to reflect on their own values and avoid undue influence on the dialogue.

Since there is no possibility to prove the moral correctness of decisions taken when faced with an ethical dilemma, the focus has moved away from the sole result of decision-making towards the process of decision-making itself[107] and towards its long-term consequences. Successful decision-making will be defined by how the parties involved (parents, HCPs) judge the process and how they cope with the consequences of the decision in the long run. Obviously, the impact of these consequences is much more important for the parents. The decision should be determined by parental values, either explicitly, or, if not possible, through empathic mediation by HCPs. Experience has shown that the following aspects characterise decision-making that will least likely result in persistent accusations and feelings of guilt: open and careful information, sound and credible justification of the decision, as well as honest and empathic communication and support[122].

Disagreement between parents and health care professionals

The Swiss Civil Code for the protection of adults and children does not empower a particular party (e.g., physicians, nurses, or parents) to make a final decision. It does, however, concede to parents to prevail in cases of disagreement, particularly in equivocal best interest situations. This is in line with societal expectations in Switzerland[13]. Most situations of dissent between parents and neonatal caregivers, however, can be solved through continuing mindful dialogue, by granting parents time and opportunities to discuss their views with other key persons, and if needed, by thoughtfully meeting their actual needs within the decisional process. It can be helpful to obtain additional input from a clinical ethics consultation.

Health care resources

Health-care resources are finite. The question could be raised whether a considerable proportion of available health care resources should be allocated to the treatment of barely viable preterm infants with a very unfavourable prognosis, if at the same time resources are lacking in other areas of the health care system.

If rationing of potentially helpful therapies is unavoidable, it should be done by rejecting therapies with marginal effectiveness, limited usefulness, or a very poor cost-benefit ratio for all patients rather than by excluding certain categories of patients (e.g., preterm infants at the limit of viability) from a particular therapy[123]. Such decisions must always be made on a societal level; economic considerations should not interfere with ethical decision-making in an individual case[124].

SDM - Training and Quality Assessment

Neonatal caregivers must be offered training in SDM. If feasible, inclusion of parent representatives (usually with personal experience regarding extreme prematurity and additional educational training) should be considered(125). Continuing multi-professional education of physicians, midwives, and neonatal nurses by formal teaching and participation in ethical case discussions is recommended. Finally, the quality of SDM should be reviewed regularly (e.g., yearly).

12. References

1) Berger T, Büttiker V, Fauchère JC, Holzgreve W, Kind C, Largo R, et al. Empfehlungen zur Betreuung von Frühgeborenen an der Grenze der Lebensfähigkeit (Gestationsalter 22-26 SSW) (in German). Schweiz Aerztezeitung. 2002;83(29/30):1589-95.
2) Berger TM, Bernet V, El Alama S, Fauchère JC, Hosli I, Irion O, et al. 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. 2011;141:1-13.
3) Obstetric Care consensus No. 6: Periviable Birth. Obstet Gynecol. 2017;130(4):e187-e99.
4) Obstetric Care Consensus No. 6 Summary: Periviable Birth. Obstet Gynecol. 2017;130(4):926-8.
5) ACOG Practice Bulletin: Clinical Management Guidelines for Obstetrcian-Gynecologists: Number 38, September 2002. Perinatal care at the threshold of viability. Obstet Gynecol. 2002;100(3):617-24.
6) Ancel PY, Breart G, Bruel H, Debillon T, D'Ercole C, Deruelle P, et al. [Propositions for perinatal care at extremely low gestational ages – Working group on "Extremely low gestational ages" for SFMP, CNGOF, and SFN]. Gynecol Obstet Fertil Senol. 2020;48(12):850-7.
7) Bührer C, Felderhoff_Mueser U, Gembruch U, et al. Frühgeborene an der Grenze der Lebensfähigkeit (Entwicklungsstufe S2k, AWMF-Leitlinien-Register Nr. 024/019, Juni 2020). Z Geburtshilfe Neonatol. 2020;224:244-55.
8) Mactier H, Bates SE, Johnston T, Lee-Davey C, Marlow N, Mulley K, et al. Perinatal management of extreme preterm birth before 27 weeks of gestation: a framework for practice. Arch Dis Child Fetal Neonatal Ed. 2020;105(3):F232-9.
9) Royal College of Obstetricians & Gynaecologists. Perinatal Management of Pregnant Women at the Threshold of Infant Viability (The Obstetric Perspective). RCOG Scientific Impact Paper No 41. 2014:1-15.
10) Swiss Neonatal Network, on behalf of the Swiss Society of Neonatology. Data extracted from Swiss Neonatal Network (22.04.2024).
11) Fauchère JC, Klein SD, Hendriks MJ, Baumann-Hölzle R, Berger TMB, Bucher HU. Swiss neonatal caregivers express diverging views on parental involvement in shared decision-making for extremely premature infants. Acta Paediatr. 2021;110(7):2074-81.
12) Hendriks MJ, Bucher HU, Klein SD, Streuli JC, Baumann-Hölzle R, Fauchère JC. Exploring societal solidarity in the context of extreme prematurity. Swiss Medical Weekly. 2017;147:w14418.
13) Hendriks MJ, Klein SD, Bucher HU, Baumann-Hölzle R, Streuli JC, Fauchère JC. Attitudes towards decisions about extremely premature infants differed between Swiss linguistic regions in population-based study. Acta Paediatr. 2017;106(3):423-9.
14) Bajwa NM, Berner M, Worley S, Pfister RE. Population based age stratified morbidities of premature infants in Switzerland. Swiss Medical Weekly. 2011;141:w13212.
15) Doyle LW, Roberts G, Anderson PJ. Outcomes at age 2 years of infants < 28 weeks' gestational age born in Victoria in 2005. J Pediatr. 2010;156(1):49-53.e1.
16) Harrison JE, Weber S, Jakob R, Chute CG. ICD-11: an international classification of diseases for the twenty-first century. BMC Med Inform Decis Mak. 2021;21(Suppl 6):206.
17) Richmond S, Wyllie J. European Resuscitation Council Guidelines for Resuscitation 2010 Section 7. Resuscitation of babies at birth. Resuscitation. 2010;81(10):1389-99.
18) Wilkinson AR, Ahluwalia J, Cole A, Crawford D, Fyle J, Gordon A, et al. Management of babies born extremely preterm at less than 26 weeks of gestation: a framework for clinical practice at the time of birth. Arch Dis Child Fetal Neonatal Ed. 2009;94(1):F2-5.
19) Bucher HU, Klein SD, Hendriks MJ, Baumann-Hölzle R, Berger TM, Streuli JC, Fauchère JC. Decision-making at the limit of viability: differing perceptions and opinions between neonatal physicians and nurses. BMC Pediatrics. 2018;18(1):81.
20) Cavolo A, Dierckx de Casterle B, Naulaers G, Gastmans C. Physicians' Attitudes on Resuscitation of Extremely Premature Infants: A Systematic Review. Pediatrics. 2019;143(6).
21) Cuttini M, Kaminski M, Saracci R, de Vonderweid U. The EURONIC Project: a European concerted action on information to parents and ethical decision-making in neonatal intensive care. Paediatr Perinat Epidemiol. 1997;11(4):461-74.
22) Cuttini M, Nadai M, Kaminski M, Hansen G, de Leeuw R, Lenoir S, et al. End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries. EURONIC Study Group. Lancet. 2000;355(9221):2112-8.
23) Cuttini M, Rebagliato M, Bortoli P, Hansen G, de Leeuw R, Lenoir S, et al. Parental visiting, communication, and participation in ethical decisions: a comparison of neonatal unit policies in Europe. Arch Dis Child Fetal Neonatal Ed. 1999;81(2):F84-91.
24) de Leeuw R, Cuttini M, Nadai M, Berbik I, Hansen G, Kucinskas A, et al. Treatment choices for extremely preterm infants: an international perspective. J Pediatr. 2000;137(5):608-16.
25) Klein SD, Bucher HU, Hendriks MJ, Baumann-Hölzle R, Streuli JC, Berger TM, et al. Sources of distress for physicians and nurses working in Swiss neonatal intensive care units. Swiss Medical Weekly. 2017;147:w14477.
26) Miljeteig I, Sayeed SA, Jesani A, Johansson KA, Norheim OF. Impact of ethics and economics on end-of-life decisions in an Indian neonatal unit. Pediatrics. 2009;124(2):e322-8.
27) Partridge JC, Martinez AM, Nishida H, Boo NY, Tan KW, Yeung CY, et al. International comparison of care for very low birth weight infants: parents' perceptions of counseling and decision-making. Pediatrics. 2005;116(2):e263-71.
28) Simeoni U, Vendemmia M, Rizzotti A, Gamerre M. Ethical dilemmas in extreme prematurity: recent answers; more questions. Eur J Obstet Gynecol Reprod Biol. 2004;117 Suppl 1:S33-6.
29) Beauchamp T, Childress J. Principles of biomedical ethics. Oxford, New York, Toronto: Oxford University Press; 2001.
30) Kind C. Ethische Überlegungen als besondere Herausforderung für den Geburtshelfer und den Neonatologen. Der Gynäkologe. 2001;34:744-50.
31) Duff RS, Campbell AG. Moral and ethical dilemmas in the special-care nursery. N Engl J Med. 1973;289(17):890-4.
32) Mercurio MR. The role of a pediatric ethics committee in the newborn intensive care unit. J Perinatol. 2011;31(1):1-9.
33) Cummings J. Antenatal Counseling Regarding Resuscitation and Intensive Care Before 25 Weeks of Gestation. Pediatrics. 2015;136(3):588-95.
34) Katz AL, Webb SA. Informed Consent in Decision-Making in Pediatric Practice. Pediatrics. 2016;138(2).
35) Lemyre B, Moore G. Counselling and management for anticipated extremely preterm birth. Paediatr Child Health. 2017;22(6):334-41.
36) Weise KL, Okun AL, Carter BS, Christian CW. Guidance on Forgoing Life-Sustaining Medical Treatment. Pediatrics. 2017;140(3).
37) Winyard A. The Nuffield Council on Bioethics Report: Critical care decisions in fetal and neonatal medicine – ethical issues. J Patient Saf Clin Risk. 2007;13(2).
38) Sullivan A, Cummings C. Historical Perspectives: Shared Decision Making in the NICU. NeoReviews. 2020;21(4):e217-e25.
39) Allen G, Laventhal N. Should Long-Term Consequences of NICU Care Be Discussed in Terms of Prognostic Uncertainty or Possible Harm? AMA J Ethics. 2017;19(8):743-52.
40) Haward MF, Murphy RO, Lorenz JM. Message framing and perinatal decisions. Pediatrics. 2008;122(1):109-18.
41) Janvier A, Barrington K, Farlow B. Communication with parents concerning withholding or withdrawing of life-sustaining interventions in neonatology. Semin Perinatol. 2014;38(1):38-46.
42) Janvier A, Farlow B, Baardsnes J, Pearce R, Barrington KJ. Measuring and communicating meaningful outcomes in neonatology: A family perspective. Semin Perinatol. 2016;40(8):571-7.
43) Kett JC. Prenatal Consultation for Extremely Preterm Neonates: Ethical Pitfalls and Proposed Solutions. J Clin Ethics. 2015;26(3):241-9.
44) Sullivan A, Arzuaga B, Luff D, Young V, Schnur M, Williams D, Cummings C. A Qualitative Study of Parental Perspectives on Prenatal Counseling at Extreme Prematurity. J Pediatr. 2022;251:17-23.e2.
45) Papadimitriou V, Tosello B, Pfister R. Effect of written outcome information on attitude of perinatal healthcare professionals at the limit of viability: a randomized study. BMC Med Ethics. 2019;20(1):74.
46) Surbek D, Roos T, Hodel M, Pfister RE, I. H, Akademie Feto-maternale Medizin A, Schweizerische Gesellschaft für Neonatologie S. Glucocorticoidtherapie zur antenatalen Lungenreifung bei drohender Frühgeburt: Indikationen und Dosierung (Expertenbrief No. 56) 2019. Available from: https://

www.sggg.ch/fileadmin/user_upload/PDF/56_Lungenreifungsinduktion_bei_drohender_Fruehgeburt.pdf.

47) Deutsche Gesellschaft für Gynäkologie und Geburtshilfe D, Österreichische Gesellschaft für Gynäkologie und Geburtshilfe O, Schweizerische Gesellschaft für Gynäkologie und Geburtshilfe S. Prävention und Therapie der Frühgeburt (142-143). AWMF online – Leitlinienprogramm der DGGG, OEGGG und SGGG. 2022:142-3.

48) Hösli I, Sperschneider C, Drack G, Zimmermann R, Surbek D, Irion O, Akademie Feto-maternale Medizin A. Tokolyse bei vorzeitiger Wehentätigkeit (Expertenbrief No. 41) 2013. Available from: https://www.sggg.ch/fileadmin/user_upload/PDF/41_Tokolyse_2013.pdf.

49) Deutsche Gesellschaft für Gynäkologie und Geburtshilfe D, Österreichische Gesellschaft für Gynäkologie und Geburtshilfe O, Schweizerische Gesellschaft für Gynäkologie und Geburtshilfe S. Prävention und Therapie der Frühgeburt (191-197). AWMF online – Leitlinienprogramm der DGGG, OEGGG und SGGG. 2022:191-7.

50) Kenyon SL, Taylor DJ, Tarnow-Mordi W. Broad-spectrum antibiotics for preterm, prelabour rupture of fetal membranes: the ORACLE I randomised trial. ORACLE Collaborative Group. Lancet. 2001;357(9261):979-88.

51) Deutsche Gesellschaft für Gynäkologie und Geburtshilfe D, Österreichische Gesellschaft für Gynäkologie und Geburtshilfe O, Schweizerische Gesellschaft für Gynäkologie und Geburtshilfe S. Prävention und Therapie der Frühgeburt (124-126, 160). AWMF online – Leitlinienprogramm der DGGG, OEGGG und SGGG. 2022:124-6, 60.

52) Deutsche Gesellschaft für Gynäkologie und Geburtshilfe D, Österreichische Gesellschaft für Gynäkologie und Geburtshilfe O, Schweizerische Gesellschaft für Gynäkologie und Geburtshilfe S. Prävention und Therapie der Frühgeburt (161-163). AWMF online – Leitlinienprogramm der DGGG, OEGGG und SGGG. 2022:161-3.

53) Roos T, Hösli I, Bassler D, Hodel M, Surbek D, Akademie Feto-maternale Medizin A, Schweizerishe Gesellschaft für Neonatologie S. Magnesiumsulfat zur fetalen Neuroprotektion bei drohender Frühgeburt (Expertenbrief No 66) 2019 Available from: https://www.sggg.ch/fileadmin/user_upload/PDF/66_Magnesiumsulfat_zur_fetalen_Neuroprotektion.pdf.

54) Deutsche Gesellschaft für Gynäkologie und Geburtshilfe D, Österreichische Gesellschaft für Gynäkologie und Geburtshilfe O, Schweizerische Gesellschaft für Gynäkologie und Geburtshilfe S. Prävention und Therapie der Frühgeburt (166-167). AWMF online – Leitlinienprogramm der DGGG, OEGGG und SGGG. 2022:166-7.

55) Deutsche Gesellschaft für Gynäkologie und Geburtshilfe D, Österreichische Gesellschaft für Gynäkologie und Geburtshilfe O, Schweizerische Gesellschaft für Gynäkologie und Geburtshilfe S. Prävention und Therapie der Frühgeburt (165-166). AWMF online – Leitlinienprogramm der DGGG, OEGGG und SGGG. 2022:165-6.

56) Seidler AL, Aberoumand M, Hunter KE, Barba A, Libesman S, Williams JG, et al. Deferred cord clamping, cord milking, and immediate cord clamping at preterm birth: a systematic review and individual participant data meta-analysis. Lancet. 2023;402(10418):2209-22.

57) Seidler AL, Libesman S, Hunter KE, Barba A, Aberoumand M, Williams JG, et al. Short, medium, and long deferral of umbilical cord clamping compared with umbilical cord milking and immediate clamping at preterm birth: a systematic review and network meta-analysis with individual participant data. Lancet. 2023;402(10418):2223-34.

58) Manley BJ, Dawson JA, Kamlin CO, Donath SM, Morley CJ, Davis PG. Clinical assessment of extremely premature infants in the delivery room is a poor predictor of survival. Pediatrics. 2010;125(3):e559-64.

59) Shelkowitz E, Vessella SL, O'Reilly P, Tucker R, Lechner BE. Counseling for personal care options at neonatal end of life: a quantitative and qualitative parent survey. BMC Palliat Care. 2015;14:70.

60) 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 Res. 2017;27(14):2100-15.

61) Koopmans L, Wilson T, Cacciatore J, Flenady V. Support for mothers, fathers and families after perinatal death. Cochrane Database Syst Rev. 2013;2013(6):Cd000452.

62) Helenius K, Sjörs G, Shah PS, Modi N, Reichman B, Morisaki N, et al. Survival in Very Preterm Infants: An International Comparison of 10 National Neonatal Networks. Pediatrics. 2017;140(6).

63) Patel RM. Short- and Long-Term Outcomes for Extremely Preterm Infants. Am J Perinatol. 2016;33(3):318-28.

64) Stoll BJ, Hansen NI, Bell EF, Walsh MC, Carlo WA, Shankaran S, et al. Trends in Care Practices, Morbidity, and Mortality of Extremely Preterm Neonates, 1993-2012. JAMA. 2015;314(10):1039-51.

65) Younge N, Goldstein RF, Bann CM, Hintz SR, Patel RM, Smith PB, et al. Survival and Neurodevelopmental Outcomes among Periviable Infants. N Engl J Med. 2017;376(7):617-28.

66) Ancel PY, Goffinet F, Kuhn P, Langer B, Matis J, Hernandorena X, et al. Survival and morbidity of preterm children born at 22 through 34 weeks' gestation in France in 2011: results of the EPIPAGE-2 cohort study. JAMA Pediatrics. 2015;169(3):230-8.

67) Bell EF, Hintz SR, Hansen NI, Bann CM, Wyckoff MH, DeMauro SB, et al. Mortality, In-Hospital Morbidity, Care Practices, and 2-Year Outcomes for Extremely Preterm Infants in the US, 2013-2018. JAMA. 2022;327(3):248-63.

68) Fellman V, Hellström-Westas L, Norman M, Westgren M, Källén K, Lagercrantz H, et al. One-year survival of extremely preterm infants after active perinatal care in Sweden. JAMA. 2009;301(21):2225-33.

69) Kono Y, Yonemoto N, Nakanishi H, Kusuda S, Fujimura M. Changes in survival and neurodevelopmental outcomes of infants born at < 25 weeks' gestation: a retrospective observational study in tertiary centres in Japan. BMJ Paediatr Open. 2018;2(1):e000211.

70) Moore T, Hennessy EM, Myles J, Johnson SJ, Draper ES, Costeloe KL, Marlow N. Neurological and developmental outcome in extremely preterm children born in England in 1995 and 2006: the EPICure studies. BMJ. 2012;345:e7961.

71) Stensvold HJ, Klingenberg C, Stoen R, Moster D, Braekke K, Guthe HJ, et al. Neonatal Morbidity and 1-Year Survival of Extremely Preterm Infants. Pediatrics. 2017;139(3).

72) van Beek PE, Rijken M, Broeders L, Ter Horst HJ, Koopman-Esseboom C, de Kort E, et al. Two-year neurodevelopmental outcome in children born extremely preterm: the EPI-DAF study. Arch Dis Child Fetal Neonatal Ed. 2022;107(5):F467-F474.

73) Adams M, Berger TM, Borradori-Tolsa C, Bickle-Graz M, Grunt S, Gerull R, et al. Association between perinatal interventional activity and 2-year outcome of Swiss extremely preterm born infants: a population-based cohort study. BMJ Open. 2019;9(3):e024560.

74) Serenius F, Blennow M, Maršál K, Sjörs G, Källén K. Intensity of perinatal care for extremely preterm infants: outcomes at 2.5 years. Pediatrics. 2015;135(5):e1163-72.

75) Adams A, Natalucci G, Bassler D, Group oBOTSNNF-u. An overview of the Swiss Neonatal Network & Follow-up Group (SwissNeoNet). Pediatr Med. 2023;6(7):1-12.

76) Islam JY, Keller RL, Aschner JL, Hartert TV, Moore PE. Understanding the Short- and Long-Term Respiratory Outcomes of Prematurity and Bronchopulmonary Dysplasia. Am J Respir Crit Care Med. 2015;192(2):134-56.

77) Peralta GP, Piatti R, Haile SR, Adams M, Bassler D, Moeller A, et al. Respiratory morbidity in preschool and school-age children born very preterm and its association with parents' health-related quality of life and family functioning. Eur J Pediatr. 2023;182(3):1201-10.

78) Peralta GP, Piatti R, Haile SR, Adams M, Bassler D, Moeller A, et al. Correction to: Respiratory morbidity in preschool and school-age children born very preterm and its association with parents' health-related quality of life and family functioning. Eur J Pediatr. 2023;182(3):1211-2.

79) Luu TM, Rehman Mian MO, Nuyt AM. Long-Term Impact of Preterm Birth: Neurodevelopmental and Physical Health Outcomes. Clin Perinatol. 2017;44(2):305-14.

80) McEniery CM, Bolton CE, Fawke J, Hennessy E, Stocks J, Wilkinson IB, et al. Cardiovascular consequences of extreme prematurity: the EPICure study. J Hypertens. 2011;29(7):1367-73.

81) Akalay S, Rayyan M, Fidlers T, van den Heuvel L, Levtchenko E, Arcolino FO. Impact of preterm birth on kidney health and development. Front Med (Lausanne). 2024;11:1363097.

82) Crump C, Sundquist J, Winkleby MA, Sundquist K. Preterm birth and risk of chronic kidney disease from childhood into mid-adulthood: national cohort study. BMJ. 2019;365:l1346.

83) Johnson S, Marlow N. Early and long-term outcome of infants born extremely preterm. Arch Dis Child. 2017;102(1):97-102.

84) Crump C, Sundquist J, Sundquist K. Preterm or Early Term Birth and Risk of Autism. Pediatrics. 2021;148(3):e2020032300.

85) O'Reilly H, Ni Y, Johnson S, Wolke D, Marlow N. Extremely preterm birth and autistic traits in young adulthood: the EPICure study. Mol Autism. 2021;12(1):30.

86) Bolbocean C, van der Pal S, van Buuren S, Anderson PJ, Bartmann P, Baumann N, et al. Health-Related Quality-of-Life Outcomes of Very Preterm or Very Low Birth Weight Adults: Evidence From an Individual Participant Data Meta-Analysis. Pharmacoeconomics. 2023;41(1):93-105.

87) Cheong JLY, Haikerwal A, Anderson PJ, Doyle LW. Outcomes into adulthood of infants born extremely preterm. Semin Perinatol. 2021;45(8):151483.

88) Zwicker JG, Harris SR. Quality of life of formerly preterm and very low birth weight infants from preschool age to adulthood: a systematic review. Pediatrics. 2008;121(2):e366-76.

89) Kim SW, Andronis L, Seppänen AV, Aubert AM, Barros H, Draper ES, et al. Health-related quality of life of children born very preterm: a multinational European cohort study. Qual Life Res. 2023;32(1):47-58.

90) Pierrat V, Marchand-Martin L, Arnaud C, Kaminski M, Resche-Rigon M, Lebeaux C, et al. Neurodevelopmental outcome at 2 years for preterm children born at 22 to 34 weeks' gestation in France in 2011: EPIPAGE-2 cohort study. BMJ. 2017;358:3448.

91) Serenius F, Källén K, Blennow M, Ewald U, Fellman V, Holmstrom G, et al. Neurodevelopmental outcome in extremely preterm infants at 2.5 years after active perinatal care in Sweden. JAMA. 2013;309(17):1810-20.

92) Marlow N, Doyle LW, Anderson P, Johnson S, Bhatt-Mehta V, Natalucci G, et al. Assessment of long-term neurodevelopmental outcome following trials of medicinal products in newborn infants. Pediatr Res. 2019;86(5):567-72.

93) Pierrat V, Marchand-Martin L, Marret S, Arnaud C, Benhammou V, Cambonie G, et al. Neurodevelopmental outcomes at age 5 among children born preterm: EPIPAGE-2 cohort study. BMJ. 2021;373:741.

94) Serenius F, Ewald U, Farooqi A, Fellman V, Hafstrom M, Hellgren K, et al. Neurodevelopmental Outcomes Among Extremely Preterm Infants 6.5 Years After Active Perinatal Care in Sweden. JAMA pediatrics. 2016;170(10):954-63.

95) Palisano RJ, Hanna SE, Rosenbaum PL, Russell DJ, Walter SD, Wood EP, et al. Validation of a model of gross motor function for children with cerebral palsy. Phys Ther. 2000;80(10):974-85.

96) Guillén Ú, Mackley A, Laventhal N, Kukora S, Christ L, Derrick M, et al. Evaluating the Use of a Decision Aid for Parents Facing Extremely Premature Delivery: A Randomized Trial. J Pediatr. 2019;209:52-60.

97) Haward MF, Gaucher N, Payot A, Robson K, Janvier A. Personalized Decision Making: Practical Recommendations for Antenatal Counseling for Fragile Neonates. Clin Perinatol. 2017;44(2):429-45.

98) Stacey D, Lewis KB, Smith M, Carley M, Volk R, Douglas EE, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev. 2024;1(1):Cd001431.

99) Janvier A, Barrington KJ, Payot A. A time for hope: guidelines for the perinatal management of extremely preterm birth. Arch Dis Child Fetal Neonatal Ed. 2020;105(3):F230-1.

100) Swiss Academy of Medical Sciences. Intensive care interventions (p. 14). Medical-ethical guidelines of the Swiss Academy of Medical Sciences 2013 Available from: https://www.samw.ch/en/Publications/Medical-ethical-Guidelines.html.

101) Streuli JC, Bergsträsser E. 'Shared decision-making' in der Kinder- und Jugendmedizin. Paediatrica. 2015;26:12-5

102) Schweizerisches Zivilgesetzbuch ZGB, Die Bundesversammlung der Schweizerischen Eidgenossenschaft. Erwachsenenschutz, Personenrecht und Kindesrecht. Zivilgesetzbuch ZGB (Swiss Civil Code). 2013;Bundesblatt 2008/2013.

103) Dinten-Schmid B. Die Verantwortung der Eltern im ethischen Entscheidungsprozess in der Neonatologie: die beziehungs-ethischen Perspektiven. [Master Thesis]: Zurich; 2015.

104) de Boer A, De Proost L, de Vries M, Hogeveen M, de Vries MC, Verweij E, Geurtzen R. Voices of experience: what Dutch parents teach us about values and intuition in periviable decisions. Arch Dis Child Fetal Neonatal Ed. 2024:doi: 10.1136/archdischild-2024-327400. Online ahead of print.

105) Swiss Academy of Medical Sciences. Management of dying and death (p. 27). {Swiss Academy of Medical Sciences, 2013 #363} 2018. Available from: https://www.samw.ch/en/Publications/Medical-ethical-Guidelines.html.

106) Kon AA. The shared decision-making continuum. Jama. 2010;304(8):903-4.

107) Lantos JD. Ethical Problems in Decision Making in the Neonatal ICU. N Engl J Med. 2018;379(19):1851-60.

108) Rosenbaum L. The Paternalism Preference--Choosing Unshared Decision Making. N Engl J Med. 2015;373(7):589-92.

109) Zimmermann K, Bergsträsser E, Engberg S, Ramelet AS, 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 Palliat Care. 2016;15:30.

110) Moore GP, Lemyre B, Daboval T, Ding S, Dunn S, Akiki S, et al. Field testing of decision coaching with a decision aid for parents facing extreme prematurity. J Perinatol. 2017;37(6):728-34.

111) Boss RD, Hutton N, Sulpar LJ, West AM, Donohue PK. Values parents apply to decision-making regarding delivery room resuscitation for high-risk newborns. Pediatrics. 2008;122(3):583-9.

112) McHaffie HE, Laing IA, Parker M, McMillan J. Deciding for imperilled newborns: medical authority or parental autonomy? J Med Ethics. 2001;27(2):104-9.

113) McHaffie HE, Lyon AJ, Hume R. Deciding on treatment limitation for neonates: the parents' perspective. Eur J Pediatr. 2001;160(6):339-44.

114) Paris JJ, Graham N, Schreiber MD, Goodwin M. Has the emphasis on autonomy gone too far? Insights from Dostoevsky on parental decisionmaking in the NICU. Camb Q Healthc Ethics. 2006;15(2):147-51.

115) Caeymaex L, Jousselme C, Vasilescu C, Danan C, Falissard B, Bourrat MM, et al. Perceived role in end-of-life decision making in the NICU affects long-term parental grief response. Arch Dis Child Fetal Neonatal Ed. 2013;98(1):F26-31.

116) Caeymaex L, Speranza M, Vasilescu C, Danan C, Bourrat MM, Garel M, Jousselme C. Living with a crucial decision: a qualitative study of parental narratives three years after the loss of their newborn in the NICU. PLoS One. 2011;6(12):e28633.

117) Hendriks MJ, Abraham A. End-of-Life Decision Making for Parents of Extremely Preterm Infants. Journal of obstetric, gynecologic, and neonatal nursing: JOGNN. 2017;46(5):727-36.

118) Kind C. Why medical professionals need their own ethics. Bioethica Forum. 2017;10:89-90.

119) Swiss Academy of Medical Sciences. Intensive care interventions (p. 15). Medical-ethical guidelines of the Swiss Academy of Medical Sciences 2013. Available from: https://www.samw.ch/en/Publications/Medical-ethical-Guidelines.html.

120) McCarthy J, Gastmans C. Moral distress: a review of the argument-based nursing ethics literature. Nurs Ethics. 2015;22(1):131-52.

121) Prentice T, Janvier A, Gillam L, Davis PG. Moral distress within neonatal and paediatric intensive care units: a systematic review. Arch Dis Child. 2016;101(8):701-8.

122) Batton DG. Clinical report-Antenatal counseling regarding resuscitation at an extremely low gestational age. Pediatrics. 2009;124(1):422-7.

123) Zimmermann M. Wie können faire Allokationsentscheidungen auf der Makroebene getroffen werden? Bioethica Forum. 2011;4:81-7.

124) Hendriks MJ, Lantos JD. Fragile lives with fragile rights: Justice for babies born at the limit of viability. Bioethics. 2018;32(3):205-14.

125) Pomey MP, Flora L, Karazivan P, Dumez V, Lebel P, Vanier MC, et al. The Montreal model: the challenges of a partnership relationship between patients and healthcare professionals. Sante Publique. 2015;27(No 1 Supplement):S41-S50.