

Perinatal Care at the threshold of viability

Part II: Decision-making at the threshold of viability and ethical challenges at Neonatal Intensive Care Units (NICUs)

Final Report



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Versorgung Frühgeborener an der Grenze der Lebensfähigkeit

Teil II: Entscheidungsfindung
an der Grenze
der Lebensfähigkeit
und Berufsethik bei
neonatologische
Intensivstationen

Endbericht



Ludwig Boltzmann Institut
Health Technology Assessment

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Abbreviations

AAP	American Academy of Pediatrics
AC	active care
ACOG	American College of Obstetricians and Gynecologists
AHA	American Heart Association
BAPM	British Association of Perinatal Medicine
BE	birth weight
CBA	cost-benefit analysis
CC	comfort care
EC	ethics committee
ELBW	extremely low birth weight
EP	extremely preterm
FIGO	International Federation of Gynecology and Obstetrics
GA	gestational age
ILCOR	International Liaison Committee on Resuscitation
IND	individualized care
IVF	in vitro fertilization
NDI	neuro-developmental impairment
NICU	neonatal intensive care unit
NICHD	Eunice Kennedy Shriver National Institute for Child Health and Human Development
NR	no recommendation
ÖGKJ	Austrian Society for paediatric and adolescent medicine
PAGE	Prognosis for Average Gestation Equivalent Infant
PW	parental wishes
QoL	quality of life
VLBW	very low birth weight
SR	systematic review
WAPM	World Association of Perinatal Medicine

Zusammenfassung

Einleitung

Die Grenze der Lebensfähigkeit ist in der fötalen Entwicklung als der Zeitpunkt definiert, an dem ein Säugling eine begründete Chance auf extrauterines Überleben hat. Die Bestimmung dieses Zeitpunktes mit der größtmöglichen Genauigkeit ist bedeutsam, um möglicher Fehlversorgung durch Überwie Unterversorgung entgegenzuwirken. Die unmittelbare Herausforderung dabei ist, auf der einen Seite die Belastung, der Kind und Familie ausgesetzt sind, zu minimieren, auf der anderen Seite dem Kind die Chancen auf ein Überleben zu ermöglichen. An der Grenze der Lebensfähigkeit geborene Kinder haben sowohl während, als auch im Anschluss an die Entbindung ein höheres Sterberisiko. Zudem ist die Wahrscheinlichkeit, mit ernsthaften medizinischen Einschränkungen geboren zu werden, oder eine oder mehrere neurologische Beeinträchtigungen zu entwickeln, die allesamt eine erhöhte Morbidität zur Folge haben, groß. Extreme Frühgeburten (22.+0 bis 27.+6 Gestationswoche) sind selten (< 1 %): im Jahr 2016 kamen in Österreich insgesamt 350 extreme Frühgeburten zur Welt, was einem Anteil von 0,4 % aller Geburten und 5 % aller Frühgeburten entspricht.

Methoden

Dieser Bericht umreißt die aktuellen Erkenntnisse über Entscheidungspraktiken (Leitlinien, Entscheidungsmodelle und Kommunikationsstrategien) und ethische Herausforderungen in der Versorgung von Säuglingen an der Grenze der Lebensfähigkeit. Ziel ist es, einen umfassenden Überblick über die Komplexität der Entscheidungsfindung zu geben. Ein „mixed methods“ Ansatz wurde gewählt, um die Forschungsfragen zu Modellen guter Praxis, sozialen Faktoren und ethischen Herausforderungen bei der Entscheidungsfindung auf neonatologischen Intensivstationen (NICU) zu beantworten.

Die systematische Literaturrecherche zur MIP-Frage (Methodik, Problem, TeilnehmerInnen) wurde in der Zeit zwischen dem 21.06.2017 und dem 23.06.2017 in sechs Datenbanken (Medline über Ovid, Embase, The Cochrane Library, CRD (DARE, NHS) EED, HTA), PsychInfo, CINAHL) durchgeführt. Die systematische Suche beschränkte sich nicht auf ein spezifisches Studiendesign, schloss aber nur deutsch-sprachige und englische Publikationen im Publikationszeitraum 1990-2017 ein. Nach der Deduplizierung wurden insgesamt 385 Zitate gefunden. Zusätzlich ergab eine Handsuche 43 Quellen, was insgesamt 428 Treffer ergab. 80 Publikationen wurden schließlich ausgewählt.

Zusätzlich wurden Interviews mit den Klinikvorständen der Neonatologie von fünf Perinatalstationen und einem klinischen Ethiker durchgeführt, um die für den österreichischen Kontext spezifischen Informationen zu sammeln. Daten aus der systematischen Literaturrecherche sowie die Interviews wurden getrennt analysiert und anschließend in die Literatúrauswertung integriert. Für die Analyse ethischer Herausforderungen diente die Checkliste potenzieller ethischer Fragen aus dem „EUnetHTA Core Model[®] Application for Rapid REA“ als Rahmen, neben einem Tugendethik-Ansatz.

Definition Grenze der Lebensfähigkeit bedeutsam für Entscheidung der Versorgung

höhere Gesundheitsrisiken für zu früh geborene Kinder

extreme Frühgeburten 2016 in Österreich: 0,4 % (350) aller Geburten und 5 % aller Frühgeburten

Ziel des Berichts: Überblick über Erkenntnisse über Entscheidungspraktiken (Leitlinien, Entscheidungsmodelle und Kommunikationsstrategien)

Mixed Methods: Systematische Literatursuche in 6 Datenbanken 428 Publikationen identifiziert, 80 ausgewählt

Interviews mit den Klinikvorständen der Neonatologie

EUnetHTA Core Model[®] zur Identifikation ethischer Fragestellungen

Ergebnisse

Prozesse der Entscheidungsbildung

<p>Leitlinien länder- und kontextspezifisch</p> <p>Konsensus: palliative Versorgung unter 22 Wochen GA und aktiver Versorgung ab 25 Wochen GA,</p> <p>große Unterschiede zwischen Ländern: von 22. bis 24. Woche GA Grauzone,</p> <p>partizipative Entscheidungsfindung</p> <p>Unterstützung durch Ethik Komitees</p> <p>Institutioneller Bias: institutionelle Entscheidungen führen zu Ergebnissen, die die Statistiken beeinflussen, die wiederum die Vorgaben legitimieren</p> <p>Framing Bias: Art der Präsentation von Risiken und Chancen beeinflusst Entscheidungen</p>	<p>Zur Beurteilung der Kriterien und Prozesse in der Entscheidungsfindung an der Grenze der Lebensfähigkeit wurde eine Analyse von Leitlinien, von Entscheidungsmodellen relevant für den österreichischen Kontext und zur Kommunikation mit den Eltern durchgeführt. Eine Reihe von Leitlinien-Empfehlungen medizinischer Fachgesellschaften, bis zu welchem Zeitpunkt palliative Behandlung durchgeführt und ab wann Interventionen mit kurativer Absicht vorgesehen sind, liegen vor. Die Grenze der Lebensfähigkeit rangiert dabei zwischen einem Gestationsalter (GA) von 22 bis 25 Wochen. Bei einem GA von 23 und 24 Wochen wird von der <i>Grauzone</i> der Lebensfähigkeit gesprochen, die mit einer beträchtlichen Bandbreite an Versorgungsansätzen einhergeht: In 23 % der Leitlinien gab es keine Empfehlung (n = 7), in 30 % wird palliative Versorgung empfohlen (n = 10), in weiteren 30 % individuelle Entscheidungen (n = 10) und in 18 % die Berücksichtigung des Elternwunsches (n = 6).</p> <p>Besonders innerhalb der <i>Grauzone</i> hängt der Entscheidungsbildungs-Prozess von den Eltern in ihrer Rolle als Ersatz-Entscheider ab. Diese sogenannte partizipative Entscheidungsfindung ist in österreichischen NICUs bei einem GA von 23 Wochen etabliert. Ethikkomitees und psychologische Unterstützung spielten zwar laut der Interviewten in allen 5 betrachteten NICUs eine gewisse Rolle, Ausmaß und Charakter dieser Unterstützung sind aber sehr unterschiedlich. Während manche Krankenhäuser klinische Ethiker strukturell verankert haben, nehmen andere ethische Unterstützung auf nicht-institutionalisierte Weise in Anspruch.</p> <p>Gespräche mit Eltern spielen im Entscheidungsfindungs-Prozess eine wichtige Rolle. Das Spektrum der kognitiven Verzerrungen (Biases), die bei beiden Seiten – bei den NICU-ExpertInnen sowie bei den Eltern – vorliegen können, scheinen teilweise die Unterschiede in den klinischen Ergebnissen zwischen den einzelnen Krankenhäusern zu erklären. Auf der einen Seite liegt ein „institutioneller Bias“ vor, wenn es etwa bei der routinemäßigen Durchführung von palliativer Versorgung in der 23. Gestationswoche zu niedrigen Überlebensraten für diese Kinder kommt. Die niedrigen Überlebensraten bestätigen wiederum die Politik der „nur“ palliativen Versorgung. Auf der anderen Seite gibt es bei der Kommunikation mit den Eltern einen „Framing Bias“, etwa durch die Art der Darstellung von klinischen Ergebnissen (z. B. Verwendung proportionaler Ergebnisdaten). Eltern neigen dazu, irrational ein Verfahren zu wählen, bei dem das Risiko des Todes als 24 von 100 beschrieben wird, aber sie neigen dazu, es nicht zu wählen, wenn das Risiko als 120 von 1.000 beschrieben wird. Daher ist es notwendig, die Auswirkungen dieser möglichen Verzerrungen bei der Entscheidungsfindung in neonatologischen Intensivstationen zu erkennen, da sie ein unvermeidbarer Teil des kommunikativen Prozesses sind, der bei der Entwicklung von Leitlinien für gemeinsame Entscheidungsfindungsverfahren und Kommunikationstrainings für NICU-Fachkräfte berücksichtigt werden muss.</p>
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Ethische Herausforderungen

Weitere soziale, kulturelle, religiöse und rechtliche Aspekte bilden den Kontext, in dem die ethischen Herausforderungen zu bewältigen sind. Die Herausforderungen sind aber Kontext-abhängig und können sehr unterschiedlich sein. In Österreich stehen die ethischen Herausforderungen vor dem Hintergrund der Kant-Philosophie der Deontologie (Pflichtethik), der christlichen Kultur, der gesetzlichen Forderung nach Lebensverlängerung ohne Rücksicht auf Qualität des Lebens sowie gewisser sozioökonomischer Ungleichheit und der aktuellen Migrationsproblematik. Die wichtigsten Herausforderungen, die sowohl in den Interviews als auch in der Literatur hervorgehoben wurden, sind die Frage, was das „beste Interesse“ (für das Kind, für die Eltern) ist und was eine gerechte Entscheidung ausmacht. Die Handhabung einer ethisch schwierigen Situation ist zwischen NICUs, Krankenhäusern und Ländern unterschiedlich: Die Bedeutung von Ethikkomitees als institutionalisierte Unterstützung in schwierigen Entscheidungssituationen wird aber mehrfach betont.

Die Anerkennung der Notwendigkeit von ethischer Auseinandersetzung setzt die Erkenntnis voraus, dass die „offensichtliche“ Frage „was zu tun ist“ nicht immer ausreicht, sondern auch die „tragische“ Frage und das moralische Dilemma existiert, „wo die Grenzen zwischen richtig und falsch“ verschwimmt. Die Etablierung ethischer Rahmenbedingungen kann eine Entscheidungsfindung auch in Fällen, wo es keine ethisch richtige Antwort gibt, unterstützen. In NICUs kann eine solche strukturelle Unterstützung dazu beitragen, den Teamzusammenhalt und die Qualität der Entscheidungsfindung wie der Versorgung zu verbessern. Nur wenn die Organisationsstruktur die Anerkennung moralischer Dilemmata zulässt, können situations-adäquate Entscheidungen gefällt werden.

Fazit

Entscheidungsbildung an der Grenze der Lebensfähigkeit ist zu einem Großteil Kontext-abhängig: verschiedene Länder erlassen unterschiedliche Leitlinien, die vor dem Hintergrund vielfältiger Zusammenhänge operieren. Kognitive Wahrnehmungen beeinflussen jedoch den Entscheidungsfindungs-Prozess besonders dann, wenn partizipative Entscheidungsfindung mit Eltern stattfindet und sollten in den Leitlinien Beachtung finden. Die Bedeutung der Unterstützung durch Ethikkomitees ist unterschiedlich, wird allerdings als Hilfe für die Entscheidungsbildung, ebenso wie für Lösung von Konflikten in Situationen ethischer Dilemmata, als hilfreich angesehen.

ethische Herausforderungen kontextabhängig

Hintergrund in Österreich Rolle von Ethikkomitees und ethischer Unterstützung

Anerkennung moralischer Dilemmas essentiell zur Entwicklung einer Organisationskultur

zahlreiche Faktoren beeinflussen Entscheidungsbildung und sollte bei Leitlinien beachtet werden

Summary

Introduction

definition of the limit of viability

higher health risks for premature infants

2016 in Austria: 0.4% (350) of all premature births and 5% of all births were extremely premature

The limit of viability is defined as the point in foetal development at which the infant has a reasonable chance of extra-uterine survival. Determining this point with as much precision as possible is important for the sake of limiting the possible overuse as well as underuse of care. To prevent inflicting unnecessary burden on the infant and the family on the one hand, yet to give sufficient chances for survival to the infant on the other is the imminent challenge. Children born around the limit of viability are at increased risk of death both during and after delivery. They are also at risk of being born with severe medical conditions or of developing a spectrum of neurodevelopment impairments both leading to high morbidity. This is the case in less than 1% of all pregnant women that give birth extremely preterm, between weeks 22+0 days to 27+6 days of gestation. In Austria, 350 infants were born extremely preterm in 2016, which accounts for 0.4% of all births, and 5% of all preterm births.

Methods

objective of the report, overview of guidelines, good practice models, communication strategies, ethical challenges

systematic literature search in 6 databases, 428 publications identified, 80 citations selected

interviews with heads of departments of neonatology

EUnetHTA Core Model® used for identification of relevant ethical issues

This report outlines the current evidence on decision-making practices (guidelines, decision models, and communication strategies) and ethical challenges at the limit of viability. The aim is to provide a comprehensive overview of the complexity of decision-making encountered by NICU professionals. A mixed method approach is applied to answer the research questions on *good practice* models, social factors, and ethical challenges in NICU decision-making.

The systematic literature search followed the MIP (Methodology, Issue, Participants) question and was conducted in the period between 21.06.2017 and 23.06.2017 in six following databases (Medline via Ovid, Embase, The Cochrane Library, CRD (DARE, NHS-EED, HTA), PsychInfo, CINAHL).

The systematic search was not limited to a specific study design, but it was limited to specific languages (German and English) and the publication period 1990-2017. After deduplication, overall 385 citations were included. In addition, a hand search yielded 43 sources, resulting in overall 428 hits. 80 publications were finally selected.

Interviews with the heads of departments of neonatology of five perinatal care centres and a clinical ethicist were conducted to gather the data specific to the Austrian neonatal context. Data from the systematic literature search as well as the interviews were analysed separately and subsequently integrated into literature review. For the analysis of ethical challenges, the checklist of potential ethical issues from the EUnetHTA Core Model® Application for rapid REA served as an ethics framework alongside a virtue ethics approach.

Results

Decision-making procedures

The assessment of decision-making at the limit of viability included an analysis of guidelines, decision models specific to the Austrian context, and communication with parents. There was a range of guideline recommendations on when to initiate active and when comfort (palliative) care. The limit of viability oscillated between 22 and 25 weeks of gestational age (GA). Weeks 23 and 24 of GA remain to be the *grey zone* of viability that is followed by a considerable variation in practices. There was no recommendation in 23% of cases (n = 7), comfort care in 30% of cases (n = 10), individual decision in 30% of cases (n = 10), and parental wishes in 18% of cases (n = 6).

Especially in the *grey zone*, the decision-making processes at the limit of viability depend upon the role of parents, surrogate decision-makers. The role of such shared decision-making is established in the Austrian NICU context in week 23 of GA. Based upon data from the interviews, the role of both ethics committees as well as psychological support was present in all five NICUs. There remained a variation in the use of support from ethics committees. While some hospitals included clinical ethics as such in their structures, others made use of ethics support in non-institutionalized ways.

Communication with parents was shown to play an important role in the decision-making processes. The spectrum of cognitive biases at play at both sides, among NICU professionals as well as among parents, seem to be partly responsible for the between hospital variations in outcomes. On the one hand, there are institutional biases that a policy of routinely providing comfort care at 23 weeks of GA will lead to low survival rates for those infants. The low survival rates will, in turn, validate the policy even though the causal relationship runs the other direction. While on the other hand, there are framing biases at play when communicating with parents, for instance, through the use of proportional outcome data. Patients tend to irrationally choose a procedure where the risk of death is described as 24 out of 100, but they tend not to choose the one where the risk is described as 120 out of 1,000. Hence, it is necessary to recognize the impact of these biases on the decision-making in NICUs as they are an inevitable part of the process that needs to be taken into account when developing guidelines for shared decision-making procedures and communication trainings for NICU professionals.

Ethical challenges

All the context above together with social, cultural, religious, and legal aspects make up the setting against which the ethical challenges take their shape and form. The challenges thus vary with context and so in Austria, the ethical challenges operate at the backdrop of Kantian philosophy of deontology, Christian culture, legal requirement of prolonging life without caring about its quality, socio-economic inequalities, and current migration challenges. The main challenges highlighted in the interviews as well as in the literature concerned discerning what the best interest is and what makes up a just decision. The topic of institutionalization of legal support as part of ethics committees was mentioned in the interviews and so it is now put forth for further consideration.

guidelines are country and context specific

consensus: palliative care under 22 weeks of GA and active care from 25 weeks of GA, big differences between countries: weeks 23 and 24 are the "grey zone"

shared decision-making process with parents when in the "grey zone"

numerous biases influence communication and the decision-making

institutional bias

framing bias

awareness of the influence of biases is essential for improving the decision-making processes

ethical challenges are context dependent

background in Austria: socio-economic, cultural, legal aspects

**role of ethics committee
as support in difficult
decisions**

Handling of an ethically challenging situation also differs between hospitals and between countries. Depending on whether clinical ethics is taken to be an integral part of medicine, ethics committees and ethics support play an important role in systems of countries such as the UK. In Austria, there is a variation in the role that ethics play in different NICU centres. Recognition of the role of ethics requires a recognition that answering the obvious question of “what to do” does not always suffice. Acknowledging the tragic question and recognizing the ethical dilemmas, where the lines between right and wrong are blurred, leads to actions taken towards establishing ethics frameworks to support decision-making. In NICUs, such structural support can help in allowing the team members to recognize the ethical dilemmas, improve team cohesion, and quality of care provided. Only when the organizational structure allows ethical dilemmas to be recognized, adequate decisions can be made.

**recognizing ethical
dilemmas is essential for
improving decision
quality**

Conclusion

**many factors influence
decision-making and
should be hence
accounted for in the
guidelines**

Decision-making at the limit of viability is, to a large extent, context dependant. Different countries issue different guidelines that operate at the backdrop of different contexts. Cognitive biases, however, influence the decision-making processes especially in the *grey zone* where shared decision-making with parents is involved. The role of ethics support also varies with context, but its role in supporting NICU professionals in decision-making as well as in the challenges encountered when facing the ethical dilemmas is inevitable.

1 Introduction

Globally, less than 1% of all pregnant women give birth extremely preterm, before the completion of 28 weeks of pregnancy [1]. In Austria, 350 infants were born extremely preterm (EP) in 2016, accounting for 0.4% of all births. [2]. Despite these relatively small numbers of EP births, extreme prematurity is a leading cause of infant death as well as short and long-term morbidity [3]. According to US data, prematurity accounts for almost 45% of children with cerebral palsy, 35% with visual impairment, and 25% of cognitive or hearing impairment [4].

Epidemiology and management

Children born around the limit of viability are at increased risk of death both during and after delivery. They are also at risk of being born with severe medical conditions or of developing a spectrum of neurodevelopment impairments both leading to high morbidity [5]. The success rate have improved over time as the technological advances, pathophysiological understanding and evidence-based management push the limit of viability lower [6]. Yet, different countries, and different hospitals within countries, have different success rates in securing disability free survival.

The causes of EP birth are often unknown, but the risk factors are manifold. According to Eunice Kennedy Shriver National Institute for Child Health and Human Development (NICHD), the risk factors include previous experience of preterm birth, pregnancy with multiple gestations, use of assisted reproductive technology, or certain abnormalities of the woman's reproductive organs [7]. Furthermore, medical conditions during pregnancy such as various infections, high blood pressure, bleeding, and many others as well as mother's ethnicity, age, or lifestyle contribute to the risk of preterm labour [8].

Management options of EP birth include prevention, preparation for the delivery, as well as active and comfort care treatment options post-delivery. For the prevention of EP birth, progesterone hormone treatment and cervical cerclage (that stitches the cervix close) are the treatment options at hand [9]. When preparing for delivery, medications such as tocolytics or magnesium sulphate (that also reduces the risk of cerebral palsy) can stop or delay delivery and thus provide time for administration of corticosteroids to speed up the development of the foetus's lungs and other organs, and to allow the pregnant mother to be transferred to a specialized perinatal centre [10]. At the delivery, active care options include the application of surfactant therapy, intubation, and supportive ventilation (for instance by use of continuous positive airway pressure, CPAP, LISA and INSURE approaches). Comfort care (or palliative care) treatment options aim at improving an infant's quality of life (QoL) to treat symptoms and minimize pain and suffering [11].

Definition of preterm birth

Prematurity is defined as birth before the completion of 37 weeks of gestation (up to 36 weeks +6 days or before 37+0 weeks). The degrees of prematurity are typically defined by gestational age (GA) or birth weight (BW) [12].

**„extreme“ Frühgeburten
2016 in Österreich:
0,4 % (n = 350) aller
Geburten**

**höhere
Gesundheitsrisiken
für zu früh geborene
Kinder neurologische
Beeinträchtigungen**

**Gründe für
Frühgeburten
häufig unbekannt**

viele Risikofaktoren

**Prävention,
vorbereitende prä- und
post-natale Maßnahmen
als Behandlungsoptionen**

**palliative vs. aktive
Behandlung**

**Frühgeburt =
Entbindung vor Ablauf
der 37. Woche**

**Frühgeburten:
Klassifikation nach
Gestationsalter oder
Geburtsgewicht**

The classification based upon GA defines preterm births as:

- ✧ Late preterm birth – GA between 34+0 weeks and 36+6 weeks
- ✧ Moderate preterm birth – GA between 32+0 weeks and 33+6 weeks
- ✧ Very preterm birth – GA between 28+0 weeks and 31+6 weeks
- ✧ Extremely preterm birth – GA less than 28+0 weeks

The classification based upon BW defines degrees of prematurity as:

- ✧ Low birth weight (LBW) – BW less than 2500 g
- ✧ Very low birth weight (VLBW) – BW less than 1500 g
- ✧ Extremely low birth weight (ELBW) – BW less than 1000 g

**Verwendung des
Gestationsalters
eher anerkannt**

For the purposes of this review, we primarily used the classification according to GA, however, some studies were included that categorized preterm birth by BW. The definition based on GA is also the common measure used in guidelines (GLs) to determine the limit of viability and decide if active treatment or comfort care should be pursued [13].

Limit of viability

**Grenze der
Lebensfähigkeit
= Zeitpunkt, ab dem
das Kind eine
Überlebenschance hat**

The limit of viability is defined as the point in foetal development at which the infant has a reasonable chance of extra-uterine survival [5]. This definition of the limit of viability is changing over time due to improvements in treatment and care and resulting improvements in outcomes, and differs in different countries [14]. However, there is a considerable consensus that with an active intervention, most infants born after 25+0 weeks of GA will survive, while there is little chance for survival and survival without severe impairment in infants born below 22+0 weeks of GA [5]. The probability of survival and survival without impairment increases significantly over these few weeks, thus considered the limit of viability. Determining this point with as much precision as possible is important in order to prevent inflicting unnecessary burdens on the infant and the family on the one hand, yet to give sufficient chances for survival to the infant on the other hand. Apart from low chances for survival, chances for survival without the risk of severe and permanent disability need to be considered for decision-making at the limit of viability. Furthermore, these decisions are relevant for the sake of limiting the possible overuse as well as underuse of resources in NICU clinics.

**ab Woche 25 hohe,
bis Woche 22
sehr geringe
Überlebenschance**

**Wahrscheinlichkeit
einer Beeinträchtigung
ebenfalls abhängig von
Zeitpunkt der Geburt**

Current practices in Austria

**Grenze der
Lebensfähigkeit bei
Woche 22-24**

In Austria, the limit of viability is defined as birth at 22+0 to 23+6 weeks of GA. Similarly to some other European countries such as Germany, active treatment for (EP) infants starts at 23+0 weeks of GA (23+0- 23+6), i.e. after the completion of 23 full weeks of pregnancy, as shared decision-making process considering outcome prognosis with the parents. At 24+0 weeks of GA, proactive care is recommended. For infants born at 22+6 weeks of GA and below, comfort care approach is pursued due to the low survival rates (0-10%) and even lower rates of survival without severe neurodevelopmental impairment (0-2%) [13]. This recommendation is based on a recently updated consensus guideline by the working group for neonatology and paediatric intensive care and the working group on ethics in paediatric and adolescent medicine of the Austrian Society for paediatric and adolescent medicine (ÖGKJ) [13].

**ab 24. Wochen:
proaktives Vorgehen
empfohlen**

**bis 22. Woche
Überlebensrate: 0-10 %**

1.1 Aim and research questions

The aim of this project is to provide decision support for resource planning of neonatal intensive care units in Austria. This report on *Perinatal care at the threshold of viability* has two parts. Part I is entitled *Systematic Analysis of Clinical Outcomes of Neonatal Intensive Care Units and Resource Needs* and provides an overview of the current level of evidence on outcomes in terms of survival and survival without impairment, and the related resource needs of NICU clinics to inform health care planning [15].

The present report is Part II that focuses on the questions of *good practice* models of decision-making procedures (choosing between active vs comfort treatments), background social factors that serve as the basis for making the decision whether to prolong life, and the ethical challenges with interventions at the threshold of viability (professional ethics perspective).

The following research questions were set forth in the project protocol:

- ✿ What are the *good practice* models in the decision-making procedures (between active vs comfort treatments) that are currently implemented?
 - ✿ What is the position of international guidelines on the limit of viability (with the focus on German speaking countries)?
 - ✿ What are the communication strategies helping parents decide at the limit of viability?
- ✿ Are there social factors that serve as the basis for the decision to prolong life?
- ✿ How are the ethical challenges at the threshold of viability being handled in Austrian NICUs?

1.2 Structure of the report

The report contains two main sections. The first section is concerned with decision-making at the limit of viability in terms of official guidelines, *good practice* decision models, and communication strategies, and is found in chapter 3.1. The second section is concerned with challenges encountered by professionals working at the limit of viability and is found in chapter 3.2.

Ziele des Projektes:

Teil 1:
**systematische Analyse
 der klinischen
 Ergebnisse und
 Ressourcen-Bedarf**

Teil 2:
**Modelle „gutter Praxis“
 bei Entscheidungsfindung**

Fragestellungen:

**Was sagen inter-
 nationale Guidelines?**

**Welche
 Kommunikations-
 strategien werden
 vorgeschlagen?**

**soziale und ethische
 Faktoren und
 Herausforderungen?**

**Gliederung des Berichts:
 2 Abschnitte**

2 Methods

A mixed methods approach was applied to answer the research questions on *good practice* models, social factors, and ethical challenges in NICU decision-making. In the first step, a comprehensive systematic literature search was conducted to gather the available evidence applying the MIP (Methodology, Issue, Participants) question and inclusion criteria as listed in the Table 2.2-1 below. Secondly, interviews with the heads of the departments for neonatology of five perinatal care centres and a clinical ethicist were conducted to gather data specific to the Austrian neonatal context. Data from the systematic literature search as well as the interviews were analysed separately and subsequently integrated into a literature review.

For the analysis of ethical challenges, the checklist of potential ethical issues from the EUnetHTA Core Model® Application for rapid REA [16] served as an ethics framework alongside a virtue ethics approach.

**systematische
Literatursuche
und -auswertung**

**Interviews mit
Klinikvorständen
der Neonatologie**

**EUnetHTA Core Model®:
Checkliste für Analyse
ethischer
Fragestellungen**

2.1 Systematic literature search

The systematic literature search was conducted in the period between 21.06.2017 and 23.06.2017 in the following databases:

- ✧ Medline via Ovid
- ✧ Embase
- ✧ The Cochrane Library
- ✧ CRD (DARE, NHS-EED, HTA)
- ✧ PsychInfo
- ✧ CINAHL

The systematic search was not limited to a specific study design, but it was limited to specific languages (German and English) and the publication period 1990-2017. After deduplication, overall 385 citations were included. The specific search strategy employed can be found in chapter 6.2 in the Appendix.

In addition, a hand search of literature (web-search) was performed and yielded addition 43 sources, resulting in overall 428 hits.

**systematische
Literatursuche
in 6 Datenbanken**

**insgesamt
428 Publikationen
identifiziert**

2.2 MIP Question

Table 2.2-1: Methodology, Issue, Participants (MIP), and inclusion criteria for systematic review

Methodology	Include empirical studies. Both quantitative and qualitative studies – surveys, in-depth interviews, questionnaires, etc.
Issue	Limit of viability, threshold of viability, border of viability, children born at 22 to 25 week of gestation, extremely preterm birth, gestational age 22+0 to 25+6, end of life treatment, “best practice”/“good practice” models of decision-making, social factors, ethics, ethical/moral challenges/dilemmas
Participants	parents, doctors (physicians), ethical council, ethical committee
Setting	Neo-natal intensive care units (NICU)
Publication period	1990-2017
Languages	German/English

2.3 Literature selection

Literaturauswahl One author (MS), reviewed the abstracts and included/excluded them according to the MIP question. The second author (KH) reviewed the included abstracts. Any disagreements were resolved through discussion.

2.4 Flow chart

80 Zitate ausgewählt In total, we identified 385 hits in the systematic search and 43 hand search. 80 publications were finally selected for the analysis.

The selection process is displayed in Figure 2.4-1.

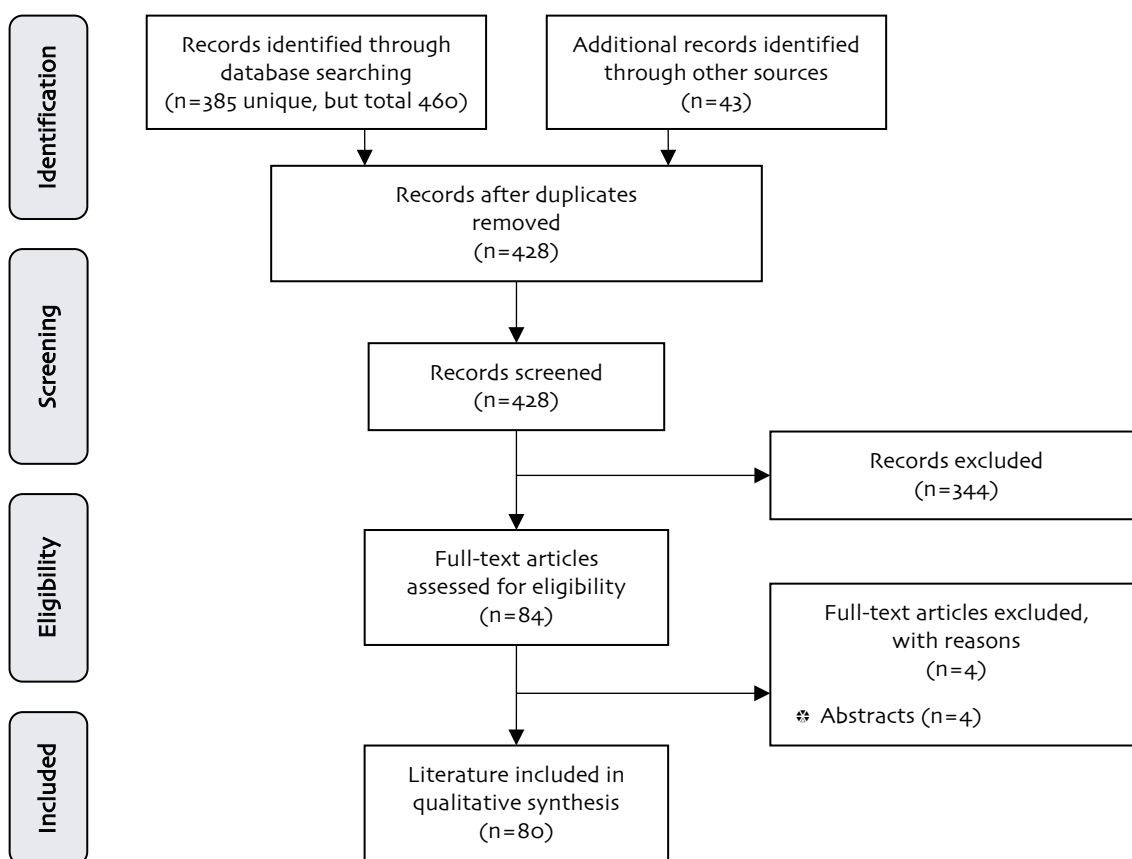


Figure 2.4-1: Flow chart of study selection (PRISMA Flow Diagram)

2.5 Interviews

Six semi-structured interviews were conducted with the aim of identifying *good practice* models, social factors, and ethical challenges specific for the Austrian neonatal context (see Table 2.5-1). Five heads of the departments of neonatology from five out of seven perinatal centres in Austria were interviewed for the purposes of this report. Additionally, one clinical ethics specialist from the University of Vienna was interviewed.

6 Interviews zur Identifizierung von Problemen und Lösungsstrategien

Table 2.5-1: Overview of interview participants

Perinatal center	Interviewee	Function
Medical University Graz	Univ.-Prof. Dr. Urlsberger	Head of department for neonatology
Medical University Innsbruck	Univ.-Prof. Dr. Kiechl-Kohlendorfer, MSc	Head of department for neonatology, deputy director department pediatric care
Kepler University Clinic, Linz	Prim. Dr. Wiesinger-Eidenberger	Head of department for neonatology
University Clinic Salzburg	Priv.-Doz. Dr. Wald	Head of department for neonatology
Medical University Vienna/AKH Wien	Univ.-Prof. Dr. Berger, MBA	Head of the Department of Neonatology, Pediatric Intensive Care and Neuropediatrics, Deputy Director of the Department of Pediatrics and Adolescent Medicine
Institute for Ethics and Law in Medicine, University of Vienna	Dr. Stefan Dinges	Clinical ethics specialist

An email was sent out to the five heads of departments of neonatology in Austria as well as to the Austrian network of bioethicists to identify experts for qualitative interviews. An interview topic list was developed to guide the interview in a semi-structured way. The research questions served as orientation to design the interview guide. The interview topic list, that can be found in the Appendix, was based upon a hand search of relevant initiatives' websites (such as the Scottish Medicine Consortium and its PACE process and relevant literature), and discussed among two researcher.

teil-strukturierter Interviewleitfaden

Interviews were conducted in person or via telephone. All interviews were audio-recorded and afterwards transcribed verbatim. Verbal consent was given by all interview participants prior to recording, audio proof of verbal consent has been collected. An example of the verbatim transcript can be found in the coding examples, Table 6-1 in the Appendix.

transkribiert

The interview duration ranged from 30 minutes to 60 minutes, one single interview lasted one hour and 40 minutes. Two researchers conducted and coded the interviews. Interviews were held in English and in some cases, clarifications were phrased in German.

30-60 Minuten

Prior to the data analysis, written transcripts and summaries were sent to the interview participants to confirm the results. At the time of external review, near to final versions were sent again for final confirmation. If necessary, changes were made in the transcripts and summaries.

Zustimmung zur Veröffentlichung eingeholt

To analyse the transcripts, a combination of open coding and structured thematic analysis was applied. This analysis was performed beginning with fragmentation and open-coding of each transcript. Thereby, every fragment received a code such as a word or short sentence to identify themes.

kodiert

The main codes and themes were organised in a code-tree, which can be found in Table 6-1 (Appendix). In addition, the themes from the interview topic list served as structural guideline to analyse the interviews. Subsequently, the results of all interviews were edited and common themes and codes integrated. Data analysis was performed using the coding software Atlas.ti (Version 8).

2.6 Quality assurance

**Methoden zur
Qualitätssicherung
interner Review
Experten-Review**

This report has been reviewed by an internal as well as an external reviewer. The latter was asked for the assessment of the following quality criteria:

- ✦ Technical correctness: Is the report technically correct (evidence and information used)?
- ✦ Does the report consider the latest findings in the research area?
- ✦ Adequacy and transparency of method: Is the method chosen adequate for addressing the research question and are the methods applied in a transparent manner?
- ✦ Logical structure and consistency of the report: Is the structure of the report consistent and comprehensible?
- ✦ Formal features: Does the report fulfil formal criteria of scientific writing (e.g. correct citations)?

The LBI-HTA considers the external assessment by scientific experts from different disciplines a method of quality assurance of scientific work. The final version and the policy recommendations are under the full responsibility of the LBI-HTA.

3 Results

3.1 Decision-making at the limit of viability

The following section elaborates on the general topic of decision-making at the limit of viability via comparing international guidelines (GLs) on the management of EP infants, analysing the decision-making models in the Austrian context, and outlining the impact of communication with parents on the outcome of decisions.

Entscheidungsfindung an den Grenzen der Überlebensfähigkeit

3.1.1 Guideline comparison

Decision-making at the limit of viability is, to a large extent, context dependant. Different countries issue different GLs to suggest when to go for active and when for comfort (palliative) care. In the following GL comparison, we have compared GLs from high income countries with a particular focus on the GLs of the German speaking countries.

Leitlinien sind länderspezifisch

We could identify three systematic reviews (SRs) of GLs on the management of infants at the limit of viability. A summary of findings of GL recommendations from the most up-to-date SR from high income countries was updated with the most recent GL data from Austria, Germany, and Switzerland by one author (MS) to allow for comparison between the German speaking countries (see Table 3.1-1) [17]. Guillén et al. 2015 identified 30 guidelines that represented 23 high income countries and 4 guidelines from international professional bodies [17].

30 Leitlinien aus 23 Ländern mit hohem Einkommen und 4 Leitlinien aus internationalen Einrichtungen wurden berücksichtigt

Table 3.1-1: Recommendations According to Week of Gestation as of 2015 (German speaking countries update)

Country	Year	Weeks of gestation			
		22	23	24	25
Argentina	2012	CC	NR	NR	NR
Australia	2006	CC	CC	AC	AC
Australia	2013	CC	PW	PW	AC
Austria ¹ [18]	2017	CC	PW	AC	AC
Belgium	2014	CC	CC	PW	PW
Canada	2012	CC	IND	IND	AC
Finland	2014	IND	IND	AC	AC
France	2010	CC	CC	PW	AC
Germany ² [19]	2014	IND	PW	AC	AC
FIGO, international association	2006	NR	NR	NR	NR
ILCOR, international association	2006	CC	NR	NR	NR
WAPM, international association	2010	CC	IND	AC	AC
European Resuscitation Council	2010	CC	PW	PW	AC

¹ Updated according to Austrian GL

² Updated according to German GL

Country	Year	Weeks of gestation			
		22	23	24	25
Ireland	2006	CC	CC	PW	PW
Italy	2008	IND	IND	IND	IND
Japan	2012	NR	NR	NR	NR
Dutch Paediatric Society, the Netherlands	2006	CC	CC	IND	AC
Dutch Ministry of Health, the Netherlands	2010	NR	NR	AC	AC
New Zealand	2011	NR	NR	NR	NR
Poland	2011	CC	CC	IND	AC
Portugal	2012	CC	CC	AC	AC
Singapore	1998	IND	IND	IND	AC
Spain	2004	CC	NR	NR	NR
Sweden	2004	CC	IND	IND	AC
Switzerland [20]	2011	CC	CC	PW ³	AC
Nuffield Council, United Kingdom	2006	CC	PW	AC	AC
BAPM, United Kingdom	2009	CC	CC	AC	AC
Royal College of Obstetricians and Gynaecologists, United Kingdom	2014	CC	IND	IND	AC
AAP, United States	2009	IND	IND	IND	IND
ACOG, United States	2012	IND	IND	IND	IND
AHA, United States	2010	CC	PW	PW	AC
Joint Workshop, United States	2014	CC	IND	AC	AC

AAP = American Academy of Pediatrics; AC = active care; ACOG = American College of Obstetricians and Gynecologists; AHA = American Heart Association; BAPM = British Association of Perinatal Medicine; FIGO = International Federation of Gynecology and Obstetrics; ILCOR = International Liaison Committee on Resuscitation; IND = individualized care; CC = comfort care; NR = no recommendation; PW = parental wishes; WAPM = World Association of Perinatal Medicine.

Resuscitation recommendations and the grey zone

**bis 22. Wochen meist
comfort care (palliativ)**

**ab 25. Woche
aktive Versorgung**

**Grauzone zwischen
23. und 24. Woche:
palliativ, Einzel- und/oder
Elternentscheidungen**

**Ursachen für hohe
Schwankungen in
Grauzone unklar**

There was a range on recommendations on when to initiate active care and when comfort care (see Table 3.1-1). In all the guideline recommendations, the limit of viability oscillated between 22 and 25 weeks of GA. There was an overall agreement that comfort care is to be provided to all EP infants born at 22 weeks of GA and below, as well as that active care is to be provided to all infants born at 25 weeks of GA and above [17]. Hence, there was a clear *grey zone* of 23 and 24 weeks of GA where there was no recommendation in 23% of cases (n=7), comfort care in 30% of cases (n=10), individual decision in 30% of cases (n=10), and parental wishes in 18% of cases (n=6) [17].

It is not clear why there is such a variety between GL recommendations within the grey zone, but some of the explanations highlight context driven factors of particular countries such as societal norms and attitudes towards value of life, level of expertise, case volume, different resource capacities, varying treatment options, or quality of care as discussed in part I or this report [15].

³ Updated according to Swiss GL

There was a variety of recommendations within the *grey zone* also among national bodies within countries (UK, Australia, Netherlands, and US,) which points to further complexity of the topic. In the UK and Australia, all national bodies recommend comfort care at week 22 and active care at week 25, but disagree about week 23 and 24 [17]. Likewise, in the Netherlands, both national bodies (Dutch Paediatric Society and Dutch Ministry of Health) recommend active care at week 25, but disagree about weeks 22 to 24 [17]. In the US, 2 of the 4 guidelines agree on individualized care across 22 to 25 weeks of GA (AAP and ACOG) and the remaining 2 guidelines disagree about the *grey zone* interventions in weeks 23 and 24 (AHA and Joint Workshop).

There are differences among the GLs of the German speaking countries as well. Both Austrian and German GL institutions are in agreement as they both shrink the *grey zone* to one week. They both recommend to start with active care at week 24 and allow parental wishes to decide at week 23 of GA [18, 19]. In the Austrian perinatal care context, there was an agreement among all five interview participants that the latest Austrian guideline published in 2017 is followed in practice [18]. The Swiss GL institution is more restrictive as comfort care is recommended for week 23 and parental wishes are to decide at week 24 of GA [20].

The Austrian GL is thus operating on the lowest limit of viability among high income countries, together with Germany, Australia, and recommendations from independent bodies of the European Resuscitation Council, the Nuffield Council on Bioethics, and the AHA. The specific decision data on the Austrian context follow in the section below.

3.1.2 “Good practice” decision models: The Austrian context

Decision-making process

Decision-making processes at the limit of viability depend upon the role of parents, “surrogate” decision-makers, in the process. The role of such shared decision-making depends on the cultural context, the impact of paternalism from the side of health care professionals, and on expectations of the parents themselves. The Austrian consensual process is presented below. A decision tree of shared decision-making is described (see Figure 3.1-1) and the role of ethics committee, psychological support, and shared decision-making practices are further elaborated on based upon data from the interviews.

The decision tree is derived from an analysis of the decision-making processes in the German speaking countries. Its aim is the visualization of the processes in place in Austria for education of younger NICU team members. Focusing on the German speaking context, Wallner argues that good decision making in neonatology must be context sensitive [21]. The steps of shared decision-making from Figure 3.1-1 are described in the paragraphs below and further complemented by interview data.

1. *Intervention*: The starting point is the question of what intervention to choose. This leads to the central problem of what the medical indication is.
2. *Medical indication*: In the process of evaluating the medical indication, two situations may occur:
 - a. The evaluation is relatively clear and the next step is to find an agreement with parents.

große Unterschiede zwischen Empfehlungen einzelner Länder in Grauzone

österr. Guideline 2017: Grauzone in Österreich nur eine Woche (24.)

Schweiz: restriktiver

viele Faktoren beeinflussen die Entscheidungsfindung:

**kultureller Kontext
medizinischer Paternalismus
Erwartungen der Eltern**

einzelne Schritte der (gemeinsamen) Entscheidungsfindung:

Ermittlung der med. Indikation

uneindeutige Indikation bedingt zusätzliche Expertise

<p>Einverständnis der Eltern nötig</p> <p>rechtlicher Handlungsspielraum von ÄrztInnen bei fehlendem Einverständnis der Eltern</p>	<p>b. The evaluation is highly unclear and it is advisable to seek additional advice (this can mean both medical and technical advice as well as advice from an ethics committee as they both help to improve understating of the factors that contribute to an indication).</p> <p>3. <i>Parental agreement for a given indication:</i> If there is a clear medical indication, an agreement with parents needs to be established (share decision-making model). The action is put in place and its outcomes evaluated (see point 7).</p> <p>4. <i>No parental agreement for a given indication:</i> Despite an honest and intense attempt to find an agreement with parents, it is up to the medical team to decide on the following options:</p> <p>a. In such a situation, there is a possibility (unless it is a situation of imminent danger) to appeal to a court or a child welfare authority to make a decision.</p> <p>b. If the appeal is not possible, the team can choose the course of action without the parental agreement under these two conditions: the intervention is in the best interest of the child and the delay of action would pose a serious threat to the child. This is the case in situations in which parents deliberately refuse an action or in situations where parents are not available.</p> <p>c. Finally, in a situation of a lack of parental agreement, the medical team can stop the intervention on the basis of their duty to act in the child's best interest. This option can be put in place if no serious or lasting damage threatens the health state of the child. This would be the case if there was a very uncertain indication for an intervention, or in cases where a poor outcome of the intervention is likely or expected, or in cases of a prognosis with poor outcomes.</p>
<p>bei unklarer Indikation, keine Durchführung der Intervention</p>	<p>5. <i>Parental agreement if the indication is not given:</i> In case there is no clear medical indication, an agreement with parents needs to be established (share decision-making model). If this is the case, the intervention is not carried out, it is reduced, or canceled. The outcome of this decision should also be evaluated (see below).</p>
<p>bei Meinungsverschiedenheiten mehrere Entscheidungsmöglichkeiten</p>	<p>6. <i>No parental agreement if the indication is not given:</i> If there is no clear indication, if no agreement with parents is achieved, and if parents insist on the implementation of an intervention, it is up to the medical team to decide on the following options:</p> <p>a. In principle, no one has the right to receive an intervention that is not medically indicated (an action with a negative assessment of burden and potential benefits). On the contrary, from a legal and ethical point of view, it could be argued that such an intervention must not be carried out at all because it contradicts the oath of the medical profession. In this case, the medical team has to discontinue the intervention regardless of the parental wishes.</p>
<p>ÄrztInnen können unnötige Eingriffe ablehnen</p>	<p>b. On the other hand, the medical team may be confronted with desperate parents who cling to any hope foreseen, even if the intervention is futile from a medical point of view. In such a situation, it may also be justified to carry through the intervention even though it is no longer medically indicated. However, the ethical limit of such an action is when its burden on the child is too high. Then, the medical team needs to defend the child's best interest and not implement the intervention.</p>
<p>Möglichkeit der Behandlung trotz unzureichender Indikation</p>	

- c. Because this situation is at times psychologically stressful as well as legally delicate, the medical team may need to call the court to make a decision.
- 7. *Evaluation*: Whatever the decision about an intervention, its outcome is to be finally evaluated and the consequences of the decision must be assessed.

ein Gericht kann zur Entscheidung hinzugezogen werden
 Ergebnisse der Entscheidung werden evaluiert

According to the interviews, the steps of shared decision-making outline in Figure 3.1-1 are to a large extent followed in the Austrian decision-making context. The role of ethics committees, psychological support, and shared decision-making processes is further described.

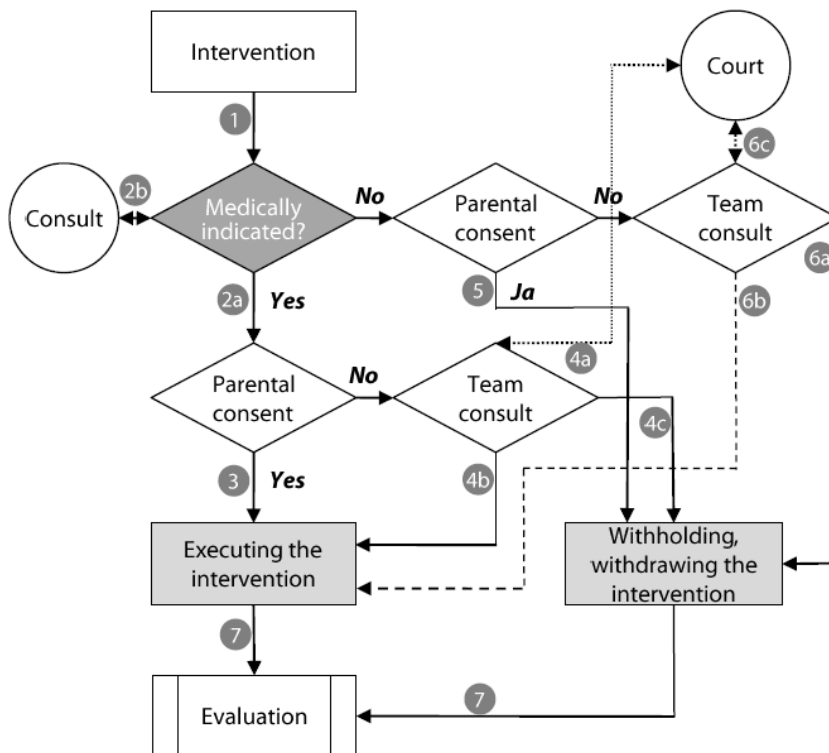


Figure 3.1-1: Decision tree of shared decision-making [21]

Ethics committee

Supporting the decision-making process in Austrian perinatal centres, the question of the involvement of ethics committees (EC), as outlined in step 2b of the decision tree, was discussed in the interviews. The clinical ethicist from University of Vienna clarified that in Austria, there is no clear legal framework that would institute an ethics committee in all hospitals. The five heads of perinatal centres in Austria, however, confirmed that each of their hospitals had an ethics committee in place, but its participation in the NICU decision-making was rare. As the head of NICU AKH Vienna puts it, an unofficial ethics committee is called for support in particularly problematic cases, but for the most part,

österr. Praxis:
 Ethikkomitees
 werden selten in den
 Entscheidungsfindungs-
 prozess mit einbezogen

“I would suggest that the ethical support is from us. This is our work as neonatologists. We are working with that every day. We are making decisions on withdrawal of treatment or (have) end of life discussions with parents really every

other day ... my doctors are really trained in that ... we learn how to insert a central catheter or how we intubate babies and at the same time we learn this, ethical ... decision making.” (Berger, NICU AKH Vienna)

Unterschiede zwischen einzelnen Krankenhäusern in der Zusammenstellung der Ethikkomitees

Furthermore, there appeared to be a distinction between hospital ethics committees and individual committees supporting decision-making in particular NICUs that varied from one hospital to another. While in Salzburg, the hospital ethics committee officially sent one to two members of the ethics committee in case there was an ethically intense case to discuss with the NICU team, in the Viennese AKH, an unofficial committee was called to help with challenging decisions upon the call of the head of NICU AKH Vienna. Also, each NICU committee has a different set up of participants, see Table 3.1-2. The main difference is the extent to which a representative of the nursing staff is on the committee, and in the inclusion of a priest, a clinical ethicist, or as a lawyer.

Table 3.1-2: Decision-making process: ethics committees

Theme: Decision-making process	
Perinatal center	Code: Ethics committee
NICU, AKH	<i>The EC consists of the head of palliative care, head of mobile kinderhospitz, and a lawyer, the head of NICU AKH Vienna, a psychologist taking care of the particular family, one member of the doctors NICU team, and one member of the nurses NICU team</i>
NICU, Graz	<i>The Ethics Committee in Graz consists of: Head of Committee, Pediatrician, Psychologist, Priest. There is no nurse included, but nurses as well as parents are included in the decision process within the NICU.</i>
NICU, Innsbruck	<i>The EC consists of a neonatologist, nurses, also people from different wards (they have ethical experience/education), a psychologist, but there is no lawyer on the committee.</i>
NICU, Linz	<i>There is an EC for the whole hospital that is to support decision-making. It is made up of doctors, social workers, psychologist, priest, medical ethicist and a lawyer (around 8 people). No nurses are part of that committee, but there are nurses involved in the NICU decision-making.</i>
NICU, Salzburg	<i>EC produced an SOP for decision-making two year ago that supplies 1-2 moderators for the NICU team if ethically challenging cases need to be discussed. The committee, however, has no influence on the decision. The decision is made by people in direct contact with the patient who participate in the discussions with moderators: head nurse, 1-2 staff nurses, the psychologist, 2-3 doctors (6-10 people in total).</i>

Psychological support

**psychologische Beratung an allen Zentren
Unterstützung häufig aber auch von Pflegekräften**

The use of psychological support was reported to be homogenous across all five perinatal care centres. All centres reported that there was a psychological support for parents. In some, the Viennese AKH, one psychologist supported the family through the entire hospital stay, whereas in Salzburg, the family was transferred from the obstetrics psychologist to the NICU psychologist. The head of NICU Salzburg named this as a potential point for improvement. Furthermore, the head of NICU Graz suggested that psychological support ideally comes in before birth, when both, a neonatologist as well as a psychologist talk to the parents about the possible courses of action. However, the head of NICU AKH Vienna reminded that counselling also comes from nurses, who spend a lot of time with parents at the bedside.

Shared decision-making

Within the *grey zone*, namely week 23 of GA in the Austrian NICU context, shared decision-making is in place. Before the birth itself, preparations in terms of discussions with parents need to be done (the head of NICU Linz). The possible course of action needs to be agreed with parents so that in case of emergency, the NICU team knows how to proceed. If time permits, talking to the parents, especially in cases of infants at the limit of viability, and discussing the options is the ideal case (the head of NICU Innsbruck). Both the NICU team as well as the parents are, however, in a difficult situation. It is hard for the parents to decide and as the head of NICU Salzburg puts it,

“I think it’s a real big problem because in this week, the parents must say ‘yes’ or ‘no’ and they must live with this decision.” (Wald, NICU Salzburg)

At the same time, the NICU team needs to work in accordance with the parents to the extent possible, as the head of NICU Graz suggests,

“I’m very strongly emphasising this for all our working groups in the NICU that we always have to be in accordance with the parents. If we lose the parents, we lose the infant somehow as well.” (Urlesberger, NICU Graz)

Concerning the decision-making itself, in Austria, there is an established tradition of shared decision-making in the *grey zone*. One emerging problem, however, is the current influx of people from different cultural backgrounds that leads to more paternalistic decisions made. As some of them have no understanding of shared decision-making, for the sake of the best interest of the patient as well as the family,

“We sometimes really have to fall back and make a paternalistic decision.” (Berger, NICU AKH Vienna)

Same is confirmed by the head of NICU Salzburg, who states that for the most part, there is no conflict, but at times, the team must decide that it is time to end treatment. Also for these reasons, the communication with parents is of the utmost importance especially when it comes to decision-making within the *grey zone*.

According to the interviews, the above described decision tree of shared decision-making seems to be followed to a large extent in the Austrian neonatal setting. Especially in the *grey zone*, parental agreement is of the utmost importance and in case of an ethically challenging case, there is ethics committee consultation at hand. The requirement of having an ethics committee that provides ethics support to NICU professionals is put forth for consideration. The point that was not explored in the interviews was the one of the retrospective evaluation of the decisions made and so its fulfilment cannot be assessed.

frühzeitige Einbindung der Eltern innerhalb der Grauzone um schnelle Reaktion zu gewährleisten

entscheidende Rolle des kulturellen Hintergrunds im Verständnis für partizipative Entscheidungsfindung

3.2 Communication with parents: Biases influencing the outcome

**Kommunikations-
strategien mit Eltern
nicht Teil der österr.
Guideline**

**Form und Inhalt der
Kommunikation**

**Potentiale für
verzerrte Information
und Kommunikation**

Finding an agreement with parents of an EP infant before and after the delivery is one of the key tasks of the NICU team. The content that needs to be communicated is highly sensitive, which places even more emphasis on the form of communication. Communication strategies with parents in preparation for the delivery as well as after delivery are not addressed in GLs. The fact that the form of communication has a significant impact on the person's decision-making is well supported by research from behavioural psychology [22]. The same applies to the NICU context of choice as the design in which the options of choices are communicated has an impact on the way parents decide and hence on the outcomes of EP infants. The following section is structured in categories of professional biases, parental understanding, and information-giving and choice.

Professional biases

**NICU ExpertInnen-
Kommunikation
mit Eltern**

3 Bias-Arten

Communication with parents is shaped by the perceptions and biases of health care professionals in NICU teams. This can, for instance, affect the presentation of treatment options and alternatives. Parents will have to decide based on information received from health care professionals and on the form in which NICU professionals communicate to them. These parental decisions then affect institutional statistics, which in return influence the information provided in the future. Providers need to acknowledge their professional biases, in particular: institutional, personal, and informational [23].

Institutional bias

**institutioneller Bias:
basiert auf strukturellen
und kulturellen Normen
und Werten von
Institutionen**

**Outcomes verifizieren
institutionelle
Entscheidungen,
sind allerdings
möglicherweise auch
Folgen der Vorgaben**

Institutional biases can be seen on the example of GLs. As outlined above, each country has its own set of GLs that give recommendations in terms of interventions according to the week of GA [17]. In high income countries, these defaults do not differ when it comes to week 22 and 25 of GA, but they do differ in the treatment options provided in the *grey zone* cases. The differences in approach seem to be connected to expertise, regionalization of care, and resource capacities (see part I or this report [15]) as well as to values and norms of particular societies. GLs thus reflect both facts as well as values [24]. They are based on empirical data as well as on value systems of particular societies in terms of their view of sanctity versus quality of life, or their perception of disability. As suggested by Lantos 2009, "the policy that limits treatment for infants born at 24 weeks of gestation will lead to low survival rates for those infants. The low survival rates will seem to justify and validate the policy, even if the true causal relationship runs in the other direction" [25]. Converging evidence also comes from the US context from Rysavy et al., 2015 [26] elaborated on in part I of this report [15].

**„self-fulfilling
prophecies“ bestätigt
in RCT**

This path creates self-fulfilling prophecies because such defaults both reflect on the social norms as well as create them. This is also supported by an RCT with adult volunteers that studied the impact of defaults in the NICU context. Participants were randomised to receive either resuscitation or comfort care as the delivery room management default option for a hypothetical delivery of an infant at 23 weeks of GA. Those participants that were told that the default option was resuscitation were more likely to opt for resuscitation and the effect persisted on multivariate regression analysis [27]. The default option created a norm that the participant had the tendency to follow.

Personal bias

Not only institutional, but also personal biases have an impact on the assessment of viability by the NICU professionals and subsequently, on the outcome. This can be observed on surveys and assessments of hypothetical scenarios, where different studies come to different conclusions regarding correct estimation of chances for survival, or chances for intact survival. While NICU professionals in one Australian narrative review underestimated survival and positive outcomes of babies between weeks 22 and 26 of GA [28], in another Australian and US survey, they also overestimated major neurosensory disability at both week 24 and 28 of GA [29] and long term disability [30]. To the contrary, however, UK NICU professionals in a questionnaire survey overestimated infant survival and underestimated intact infant survival rate [31]. A Finish survey found that NICU professionals with the longest years' working experience were reluctant to administer steroids to mothers at the lowest weeks of GA [32] and a US study equally revealed the personal biases of the health care professionals by pointing to the correlation between the obstetricians' willingness to intervene and the periviable outcomes [33]. In this way, personal biases influence the chances for survival of extremely premature infants.

Informational bias

NICU professionals make their decisions also based upon their information biases. Firstly, reliance on *how the baby looks* right after the delivery is one of the strategies of neonatologists for predicting survival estimates. Same was suggested in the interviews that,

“if the 23 weeker doesn't have any vital signs (and the parents don't want us to do, really everything), comfort care comes in ... the baby shows what to do.”
(Kiechl-Kohlendorfer, NICU Innsbruck)

However, a possible issue with overreliance on early clinical signs was shown in an Australian study where the neonatologists' ability to predict survival based on appearance and early response was poor. Videos on 10 EP infants were shown to 17 neonatal fellows at 20 seconds, 2 minutes, and 5 minutes after birth. Predictive ability of the neonatal fellows was inaccurate and the level of experience did not affect accuracy of the prediction of survival [34].

Secondly, labelling a periviable infant by the gestational week was shown to skew the estimates for survival and uncover an information bias of the NICU team. In a Canadian survey, relying on GA alone led to incorrect assessment of outcomes compared to when the preterm infant was described by its prognosis [35]. Furthermore, in a US survey among obstetrician-gynaecologists, GA was weighted more heavily than parental resuscitation preferences [33], even though the ultrasound evidence of GA may vary as much as two weeks [36].

To avoid the information bias of decisions based on GA alone or on the infant's appearance, the PAGE (Prognosis for Average Gestation Equivalent Infant) framework was proposed to help decision making in the *grey zone* of viability [37, 38]. This framework was also recently incorporated into the South Australian GL [37]. Alternatively, using the Eunice Kennedy Shriver National Institute for Child Health and Human Development (NICHD) calculator provides the prognosis based estimate of outcomes based on birth weight, sex, singleton birth, and the application of antenatal corticosteroids [39].

Individueller Bias:
beeinträchtigt die
objektive Bewertung
von Ergebnissen

Fehleinschätzungen
zur Überlebensfähigkeit
als Konsequenz

Information als Bias:
ein Indikator zur
Einschätzung der
Überlebensfähigkeit
ist das Aussehen des
Säuglings

die Präzision
dieser Methode ist
allerdings gering

Einschätzung der
Überlebensfähigkeit
anhand des
Gestationsalters ist
häufig ungenau

das PAGE Netzwerk
und das NICHD bieten
Indikatoren zur
Entscheidungs-
unterstützung

gezielte Fortbildungen können das Entscheidungsverhalten von NICU-ExpertInnen verbessern

Educational interventions show that personal and informational biases of NICU professionals can improve. A survey examining the relationship between knowledge of participants and their attitude towards resuscitation showed knowledge gaps. After the educational presentation, NICU professionals changed their attitudes and were more prone to resuscitate at all GAs regardless of parental wishes than before [40]. Another survey with hypothetical case scenarios showed that after the educational intervention, respondent improved significantly in the accuracy of their survival and disability estimates [30]. Professional biases – institutional, personal, or informational – are inevitable and thus need to be acknowledged as they unavoidably influence the outcomes of respective institutions.

Parental understanding

Entscheidungen von Eltern durch ausreichendes Verständnis der klinischen Situation

Because preterm infants cannot communicate their preferences autonomously, decisions must be made by proxy [20]. If needed, this surrogate role can be played also by the NICU team or by a societal body such as an ethics committee, or a court of law – which was outlined in the decision tree above (see Figure 3.1-1) [21]. Especially in the *grey zone*, however, it is the legal guardians that, ideally, give consent with the help of NICU professionals in a shared decision-making procedure. Given the surrogate role of parents, it is more precise to say that they cannot give informed consent as such, but an informed permission [36]. The element of informed permission include the competence of the decision-maker, adequate understanding of the clinical situation, and a commitment to act in the best interest of the patient, the EP infant [36].

Anpassung der Kommunikationsstrategie an Einzelsituation

To improve the competence of parental decision-making and to ensure an adequate understanding of the clinical situation of their newborn, it is important to realize that communication with parents cannot follow a one size fits all approach. Parents enter the NICUs with their own individual stories, concerns, needs, and capacity to understand.

Bedürfnisse von Eltern sind von NICU Team zu berücksichtigen

Different parents have different information needs. A recurring theme in the literature calls for parents to be provided with the most accurate prognosis and care options possible in order to make a competent decision [23, 41]. Parents, however, seem to have needs that are so heterogeneous that acting by the principle is not sufficient. As stated by the head of NICU AKH Vienna in the interviews, some parents require all the detail possible [23], while others would not be influenced at all by the information provided because of their own value frameworks in place [42]. As the clinical ethicist from University of Vienna puts it,

“some of the parents are really not conscious about the consequences of the situation of the newborn child ... the decision-making process really depends on this ... the level of education and economic possibilities.”

(Dinges, clinical ethics, University of Vienna)

Wissensbedarf der Eltern ist sehr unterschiedlich

When making a decision, parents are put under extreme stress [43] and some prefer that the competent NICU professional decides on their behalf [22, 28]. Because parents differ in their capacity and need to understand, it is important that the NICU professionals try to capture the level of understanding of parents and identify their main concerns. As put by the head of NICU AKH Vienna, the NICU team needs to develop a sense of who these parents are in order to ensure effective communication for both sides. The head of NICU Innsbruck further states that if the communication from the side of NICU professional is personal and empathetic, it is nearly always possible to work with the parents.

Zeit und Verständnis für Eltern sind essentiell für gemeinsame Entscheidungsfindung

“If you talk to them, if you have enough time for them, if you try to understand them, I think you won’t have a problem. (...) We answer their questions, we talk about outcome, about survival, about major handicaps, we also talk about what will happen if the baby will come during the next days. If possible, we show them the neonatal intensive care unit ... we describe what will happen, that the baby will need respiratory support, tube feeding, central venous line, and so on, and so on” (Kiechl-Kohlendorfer, NICU Innsbruck)

Furthermore, both the head of NICU AKH Vienna and the clinical ethicist from University of Vienna (who also works as a clinical ethicist at the St. Joseph Hospital Vienna) state that in their hospital, a Videodolmetsch system is used to facilitate the discussions with parents that do not speak German or English. The head of NICU Linz states that in their NICU in Linz, the NICHD calculator is used to explain the variables influencing the outcome data to parents. As supported by both the literature and the interviews, the data communicated to the parents need to be personalized as parents have different informational needs to be begin with.

Real life data

There is, however, also a discrepancy between the information that parents can be provided with in the NICU and information that parents would actually need to make a better informed decision. Parents typically receive information about outcomes, prognosis, and care options, however, to make an informed decision, parents would need to know the translation of the numbers they are given into their real life. They would like to find out how the prognosis would influence their family situation, what quality of life (QoL) their child would have, or whether their child would be happy [23].

Janvier, Barrington, and Farlow 2014 suggest that parents should be given reassurance about coping strategies, for instance that after experiencing a severe complication, patients tend to return to their baseline QoL after 24 months [23]. Furthermore, they should receive information on the risk of developing psychological problems because there is a substantial increase in depression, anxiety, and financial stress after the birth of a preterm infant, which, however, generally decreases over time [23]. They should also be given information that there is an increase in family cohesion, less conflict than in typical families, and no increase in divorce in families with preterm infants [23].

Because parents come from different backgrounds and have different informational needs, the communication from the side of NICU professionals needs to adjust. Moreover, apart from medical data about outcomes, real life psychological data about the impact of having an EP infant need to be communicated to the parents [23].

Information-giving and choice biases

When communicating with parents, no neutral or uniformed tools can solve the problem of the biases of NICU professionals and the individuality of parents. For that reason, doctors, counsellors, as well as nurses need to be aware of their own biases and they need to use their best judgment to provide balanced information to parents that is also personalized. On the one hand, parents seem to want to participate in decisions regarding delivery room resuscitation [42], yet on the other hand, they want the competent professionals to help in the process [22]. As the head of NICU AKH Vienna puts it that in her NICU, during communication with parents, they get an idea of the medical

Unterstützungssysteme können das Verständnis rund um die Entscheidung vereinfachen

Diskrepanz zwischen eigentlich notwendiger und tatsächlich bereitgestellter Information

wahrscheinliche Outcomes müssen an Eltern kommuniziert werden

Aus- und Folgewirkungen auf das Leben der Eltern sollten kommuniziert werden

Bewusstsein um vorhandene Bias (vgl. Oben) Grundlage für differenzierte Entscheidungsbildung

data as well as an idea of what the NICU team thinks is worth-while doing (not with regards to resources and money, but in the interest of the EP infant and the family). In this way, she continues, parents realize very early that it is a very individualistic patient-centred approach. In the process of information giving, however, different cognitive biases are at play (see Table 3.2-1), in particular, a framing bias.

Table 3.2-1: Cognitive biases and their influence on decision-making [23]

Cognitive biases	The possible influence of the bias on the communication between NICU professionals and parents
<i>Anchoring effect:</i> tendency to rely on the first piece of information received (the anchor). This piece of information is used to make subsequent judgments.	Speaking about risks before benefits may create a negative anchor on parents' perception.
<i>Focusing effect:</i> placing too much importance on one aspect of the situation that falsifies the prediction of a future outcome.	Speaking about all possible disabilities an EP infant may have for a lengthy period and not speaking about the likely abilities.
<i>Availability effect:</i> estimation of a probability of an event is associated with vivid memories of similar events happening before.	If doctors tell the parents that their child is going to die three times, but it survives nonetheless, parents overestimate the chances for survival in case of another event.
<i>Effective forecasting:</i> connected to the framing bias, individuals often predict the future health states inaccurately. Individuals tend to be more resilient than they predict.	Parents may find it difficult to imagine living with a disabled child, but manage it better than they anticipated nonetheless.
<i>Loss aversion:</i> is a tendency to strongly prefer avoiding losses to acquiring gains (the loss of 100 EURO causes more loss of satisfaction than the satisfaction gained from winning 100 EURO).	Framing the information via losses and gains may have an impact on parents, i.e., losing a child vs getting a child.

Framing bias

Framing-Bias:
Diskrepanz zwischen
Gesagtem und
Gehörtem wird
durch Formulierung
beeinflusst

Prozentangaben werden
häufig fehlinterpretiert

Framing-Effekt tritt
auch bei Entscheidung
zwischen palliativer und
aktiver Versorgung auf

Framing bias is one of many cognitive biases that reveals that people react to a particular choice in different ways depending on the way it is presented. Sometimes, there seems to be a discrepancy between what NICU professionals think that they communicate to parents, and what parents actually perceive. Structured interviews with mothers and counsellors reveal that mothers perceived the counselling about resuscitation of extremely premature infants directive, even though the majority of counsellors believed that mothers were given a choice of treatment options [44]. When communicating with parents, framing bias of how the data is presented is inevitable. Communicating proportional outcomes constitutes the majority of information that is being communicated to parents, however, many individuals do not understand percentages [23]. Patients tend to choose a procedure where the risk of death is described as 24 out of 100, but they tend to not choose the one where the risk is described as 120 out of 1,000. Even though the risk is smaller in the latter, patients tend not to choose that procedure because 120 is a larger number than 24 [23].

Also, the way in which the selection between active and comfort care is framed for the parents, has an impact on the choice parents make. A randomized survey found a trend toward a framing effect on the treatment preference. Participants for whom the prognosis was framed as survival and non-disability rates were more likely to choose resuscitation than participants for whom prognosis was framed as mortality and disability rates [45, 46]. Framing bias can also be seen when presenting a list of complications of an intervention, although there is also evidence against it [47]. When the list starts with the rarest and ends with them most common complication, patients tend to choose

against the intervention. When presented in the opposite order, patients tend to choose for it [23]. Other cognitive biases that have an impact on the decision-making at the limit of viability are described in Table 3.2-1.

Furthermore, it is often the case that what makes the crucial difference in accepting a difficult message for a patient is not *what* doctors say, but *how* they say it [23, 36]. Parents are understandably sensitive when discussing the health state of their vulnerable newborn and hence, NICU professionals ought to be particularly aware of using the right language. Parents said that the following terms should be avoided: *doing everything, nothing we can do, no hope, lethal, incompatible with life, futile, vegetable, this child will cause harm to (you, your kids, your job, your finances, and your couple), you can have another one, and we do not take these kids in our NICU*. Parents also disliked their child not to be called by name, but be called a *24 weeker* or *Short gut* [48]. Boss et al. found out that bereaved families at NICUs felt abandoned by doctors who seems untouched by the grief of the experience or who appeared to be *following the protocol* or *acting by the book* [36, 42]. The transfer of information alone thus seems not to guarantee human interaction. To build the environment of trust, NICU professionals need to approach the situation personally, individually, and be sensitive to the language they use [20].

Parents do not decide based on rational choice theory. Firstly, the complexity and stressful setting in which decisions about peri-viability are made makes it impossible for parents to step back from their emotions. And secondly, modern behavioural psychology tells us that rational decision theory does not describe well the way people decide in general. When faced with the task of assessing probabilities and making decisions, people use non-rational, yet predictable, strategies such as educated guess, common sense, or rule of thumb. Hence, emotions and mental shortcuts are not to be seen as undesirable interferences with the rational processes, but as inevitable parts of the process that need to be taken into account when developing GLs for shared decision-making procedures [23]. Communication with parents is inevitably influenced by the biases of both the NICU professionals as well as the parents themselves. There is no neutral form of communication with the parents, but personalized information attempting to provide balanced data for the particular parent based upon the best judgment of the NICU professional is the way forward. Communication trainings that help doctors to reflect on what the other one understands can also help recognize communication biases and thus improve the process of shared decision-making, as suggested in the interview with the head of NICU AKH Vienna where such trainings were, to some extent, already available for doctors.

**Wortwahl und
Betonung wichtig
Kommunikation
sensibler Informationen**

**Eltern brauchen
Empathie durch
NICU-Team**

**Extremsituationen
führen zu irrationalen/
emotionalen
Entscheidungen**

**Kommunikations-
training minimiert
persönliche und
professionelle Biases**

3.3 Ethical challenges at NICUs: The case of professional ethics

Umgang mit ethischen Herausforderungen in österreichischen NICUs

To answer the research questions of social factors that influence decision-making and the handling of ethical challenges in the Austrian context, data from both the literature as well as interviews were used. The following section firstly sets the socio-cultural, religious, and legal context at the backdrop of which the ethical challenges are actually present. Secondly, the challenges are divided into those that concern the obvious and the tragic questions [49]. It is suggested that issues concerning uncertainty, best interest, and justice are the main sources of tragic ethical dilemmas. It is further argued that there is a need for ethics support that allows NICU professionals to recognize the tragic ethical dilemma, improve the team cohesion, and develop in professional life.

3.3.1 Context

Socioeconomic, cultural, and religious context

Socioeconomic context

**Einfluss
sozioökonomischer
Faktoren auf
Frühgeburtenrate:
höher in benachteiligten
sozialen Gruppen**

Socioeconomic background of parents seems to be connected to their chances of giving birth in a NICU due to two main reasons. Firstly, socioeconomic inequalities play a large role in the incidence of very preterm birth. A UK study found that mothers from the most deprived areas were nearly twice as likely to have a preterm infant as those from the least deprived areas [50]. Survival to discharge did not seem to vary with deprivation, but the overall burden of mortality was greater in the more deprived areas [50]. For the Austrian context, same was confirmed in interviews, indicating that socioeconomic background plays a major role in the epidemiology of pre-term births, as most pre-term births occur in the lowest social classes (as stated by the head of NICU Graz). Secondly, the use of assisted reproductive technology, which is correlated with the increased incidence of preterm birth [51], is more prevalent in higher socioeconomic classes [50]. As highlighted in the interviews, there is an increase in twin deliveries that require intensive care. There are two reasons for the increase: one, women get pregnant later, post 35, when the chances of twins are higher and two, in vitro fertilization (IVF) increases the risk of multiple deliveries (as stated by the head of NICU Graz). IVF pregnancies are furthermore a challenge as multiple pregnancies can occupy much of the NICU unit, creating a prioritization challenge for the NICU professionals (as stated by the clinical ethicist from University of Vienna).

**künstliche
Befruchtung führt zu
mehr Frühgeburten
eher in „höheren“
Klassen relevant
Zwillingsgeburtsraten
steigen mit Alter der
Mutter und Anteil
an IVF
Erwartungen der Eltern
an NICU vom
sozioökonomischen
Hintergrund abhängig**

While most parents want everything to be done for their baby (as stated by the head of NICU AKH Vienna) parental expectations may vary with their socioeconomic background. As stated in the interviews, parents that have been waiting for the first pregnancy for years tend to fight for the survival of the baby regardless of possible disabilities compared to parents who already have children (as stated by the head of NICU Innsbruck). The head of NICU Salzburg further suggests that parents from higher social classes who strive for their first child tend to want everything to be done, while parents from lower social classes with more children tend to ask for a chance for the baby, yet if it does not work, they tend to let the baby go (as stated by the head of NICU Salzburg).

Cultural and religious context

The historical and cultural context creates norms over against which ethical dilemmas are played out. In Austria, the context is mainly dominated by the Kantian moral philosophy and the catholic religion. As stated in the interviews, the post-World War II context in Austria and that history of blame tends to lean more towards solidarity and Kantian ethics, than, for example, British utilitarianism (as stated by the head of NICU AKH Vienna). As the clinical ethicist from University of Vienna puts it,

“you have in Austria, even if not in practise, a catholic culture and that means to support life. In Germany you have a catholic-protestant mixture and they will deal with economics.” (Dinges, clinical ethics, University of Vienna)

Depending on the cultural and religious demographics of the NICU patients, health care professionals ought to be aware of the various religious approaches to extreme prematurity. In the Austrian context, the population is for the most part made up of Christian denominations (81.7%), Muslims (4.2%), no religion (12%), and other (2%) [52]. Yet, important to note is the increased prevalence of Muslim patients due to the current influx of migrants (reported by interviewees), which poses new cultural challenges including language and value issues particularly so in the multicultural Viennese context.

Within each of the prevalent religions in Austria, there is a diversity of approaches to morality of the limit of viability. Whereas there are varying beliefs regarding sanctity of life in the Christian Protestant religious groups, the Christian Catholic belief holds the moral value of the foetus from the moment of conception, which suggests active treatment as the default option [53]. The Muslim approach to extreme prematurity depends upon the particular school of thought (as also stated by the clinical ethicist from University of Vienna). In some, the limit is 25 weeks and 2 days of GA, however, there is a strong belief that NICU professionals should not hasten death. In the Muslim culture, NICU professionals have a major role in the decision-making on the family's behalf [53]. This is confirmed also by the interviewees, where the head of NICU AKH Vienna states that there is an increased number of patients with Muslim background and it is very hard to have shared decision-making discussions with them about end of life.

According to the head of NICU Innsbruck, culture, religion, and language of the parents tend to influence the decision-making more than their socioeconomic situation. A challenge is the lack of intercultural understanding as it requires more people to be involved such as translators or priests. As she puts it, it is a necessary complication. Furthermore, as the head of NICU Graz states, one of the challenges is counselling parents that do not speak German, especially if they come from totally different cultural backgrounds.

“It's very difficult to counsel someone in an ethical situation with a translator.” (Urlesberger, NICU Graz)

Awareness of the cultural and socio-religious context may help the NICU professionals to better understand their patients as well as the expectations on their role in the decision-making process.

kulturelle und religiöse Einstellung beeinflusst Entscheidungsverhalten gegenüber Frühgeburten

steigende Anzahl muslimischer Eltern stellt NICU vor neue Herausforderungen

Einstellung zu Frühgeburten variiert zwischen verschiedenen christlichen Glaubensgruppen

Tendenz zur Erhaltung des Lebens von Säuglingen bei muslimischen Eltern

Einfluss von Kultur, Religion und Sprache größer als sozio-ökonomische Situation

sprachliche Unterschiede als zusätzliche Herausforderung für NICU Team

Bewusstsein für sozio-religiösen Kontext kann Verständnis verbessern

Legislative challenges

medizinische Interventionen nur mit Einverständnis rechtlich abgesichert

Angst vor Rechtsstreit vermindert ärztlichen Entscheidungswillen

NICU ÄrztInnen können auch bei medizinisch sinnvoller Entscheidung zur Nicht-Behandlung rechtlich belangt werden

rechtliche Beratung in Ethikkomitees reduziert Angst vor Rechtsstreitigkeiten

In the Austrian legal context, a medical procedure is legal only when the patient's consent is given. Because periviable infants cannot give consent themselves, parents represent their children as surrogate decision-makers. Parents, however, must regard their child's best interest in the first place in their decision-making [18]. If this is not the case, NICU professionals can override the parental decision. If, for instance, the chances of success of an intervention are too low, the NICU professionals can discontinue the treatment upon their discretion [18]. This situation, however, is open to make NICU professionals fear litigation. A US survey among neonatologists points to their fear of litigation that makes the number of resuscitated infants higher [54]. When the doctors see parents as litigious, they have the tendency to defer to parental wishes rather than to adhere to their best judgment [55].

Even though the US common law context differs from the civil law context of Austria, the theme *fear of litigation* was also mentioned in the qualitative interviews. According to the head of NICU Salzburg, the current Austrian legal setting is challenging for NICU doctors as it states that one should prolong life without looking for the QoL – that is a problem at heart of the ethical challenges encountered at NICUs [20]. Once NICU doctors decide not to treat a patient, they are easily prosecutable. The fear may increase the possibility of keeping infants alive and prolong suffering for an unnecessary long period of time. Due to the current technological advances, it is possible to sustain vital signs of almost all preterm patients, according to the head of NICU Salzburg, even though these patients would not be able to breath on their own. According to the head of NICU Linz, there were legal challenges before their ethics committee was established. The committee includes a lawyer whose legal support diminished the concern of litigation even in challenging cases. Having legal support as part of ECs is thus put forth as a point for consideration.

The particular legal context and the potential threat thus seem to have an impact on the behaviour of NICU professionals in Austria, but legal advice was reported to reduce the possible fear of litigation.

3.3.2 Ethical challenges

ethische Herausforderungen: „offensichtliche“ und „tragische“ Fragestellung

The above outlined context determines the type of ethical challenges that NICU professionals encounter in their professional life. The following ethical challenges reflect on the Austrian setting as well as on general challenges found in the literature. They are split in two categories, the obvious and the tragic question explained below.

The obvious and the tragic questions

offensichtliche Frage:
Was ist zu tun?

tragische Frage:
Gibt es eine moralisch tragbarere Alternative?

In all situations of choice, we face what M. Nussbaum calls the *obvious question* that is, what shall we do? Sometimes, however, we also face, or should face, what she calls the *tragic question* that is, is any of the alternatives open to us free from serious moral wrongdoing [49]? At times, in the ethically intense situations of NICU decision-making at the limit of viability, the tragic question concerning transgression of the moral and often the civil law is at stake. That is the true tragic ethical dilemma to which there is no clear solution.

The mere consideration of costs and benefits – as in a cost-benefit analysis (CBA) that is, however, not explicitly used in the Austrian context – helps answer the obvious question, but it often obscures the presence of the tragic question by suggesting that the obvious question is the only pertinent one. CBA indeed helps us figure out, among the options open to us, which one contains the largest net measure of good. However, CBA does not encourage us to divide the alternatives into two distinct classes, those that involve serious moral wrongdoing and those that do not [49]. This distinction, however, is an important one as it makes us engage in a form of ethical reasoning that, in itself valuable, is distinct from the mere CBA. In the situations of NICU decision-making, it does not always suffice to find an answer to the obvious question only. Recognizing the tragic question allows for the role of ethics in the decision-making process. It can further help the NICU team in its cohesion, in improving the quality of care delivered, as well as in allowing the members of the NICU team to acknowledge and work with the ethical dilemmas individually.

cost-benefit analysis als Entscheidungsunterstützung, berücksichtigt keine moralischen Aspekte

Extremsituationen erfordern zusätzlich ethische Argumentation

Obvious question

Answering the obvious question in the solidarity-based context of Austrian NICUs is primarily concerned with the harm-benefit ratio. Because cost-effectiveness analyses as well as benefit-harm ratios have no explicit pre-assigned threshold, what decides then is the weighing of the principles of *beneficence* and *non-maleficence* as the two main tension points. The principle of *beneficence* (doing good) is the major force behind the efforts to resuscitate an EP baby, while the principle of *non-maleficence* (doing no harm) calls for inflicting no unnecessary harm to the EP baby and its family [56]. Hence, the goal of neonatal medicine is to minimize undertreatment as well as overtreatment by attempting to save each baby that has reasonable chances for meaningful survival and let go the one that does not in order to prevent unnecessary harm [38]. Stratification of decision-making is outlined in Table 3.3-1. Zones B and C, the *grey zone*, represent the category of decisions in which balancing the principles of *beneficence* and *non-maleficence* is particularly challenging.

Hauptfaktoren bei der Beantwortung der „offensichtlichen“ Frage

Vermeidung von Fehlversorgung (Unter- wie Überversorgung) als oberstes Ziel der Neonatologie

Table 3.3-1: Stratification of decision-making at the limit of viability [20]

Zone	Intensive care	Burden of intensive care	Comment
A	not indicated	not acceptable	parents cannot insist on an unreasonable intervention
B	not recommended, but acceptable in individual cases	likely not to be acceptable	parental authority should be respected – <i>zone of parental discretion</i>
C	conditionally recommended, but non-initiation acceptable in individual cases	likely to be acceptable	parental authority should be respected – <i>zone of parental discretion</i>
D	recommended	acceptable	parent cannot reject interventions that are in the infant's <i>best interest</i>

In the group of EP babies within the *grey zone*, there are four possible outcomes:

1. comfort care leading to death,
2. active care leading to death,
3. active care leading to serious neuro-developmental impairments (NDIs), and
4. active care leading to discharge with no significant NDIs [38].

4 mögliche Outcomes bei Säuglingen innerhalb der Grauzone

**korrekte Beurteilung
aller Informationen und
zusätzliche Zeit
ermöglicht bessere
Entscheidungen in der
Grauzone**

In situations where there exists an alternative open to us that is free from serious moral wrongdoing, which is the clearly the case in zones A and D, the obvious question suffices. What helps in better answering the obvious question in the *grey zone* is the correct assessment of baseline and outcome data, and more time for making a decision. These help to pinpoint as best as possible which of the four outcomes listed is most probable.

Uncertainty in the assessment of baseline and outcome data

**Interpretation-
unsicherheiten durch
starke Schwankungen
der Baselinedaten:**

It is the knowledge of baseline and outcome data that provides the frame for discussions about active care versus comfort care. The assessment of baseline data, however, is marked with serious uncertainty. Foetal weight can vary as much as 15% and GA estimate as much as two weeks [36]. GA estimates vary depending on the assessment tools used. Maternal dating based upon last menstrual period rarely underestimates the GA, whereas crown to rump measurements have an accuracy of +/- 3days, and the New Ballard Exam was shown to overestimate GA by 2 weeks, with range of +/- 4 weeks [38]. Also, as discussed in chapter 3.3, the neonatologist's ability to predict survival based on baseline appearance data and early response was poor as well [34].

**GA kann je nach
Methode um +/- 3 Tage
bis +/- 4 Wochen
variieren**

Moreover, the assessment of outcome data is subject to biases (institutional, personal, and informational bias) and gaps in knowledge (after an educational intervention, NICU professional were more prone to resuscitate regardless of GA) [57] as outlined in chapter 3.3. For that reason, further care needs to be taken when analysing outcome data due to the common denominator problem of whether the data reported include all babies (including stillbirths), all born alive babies, or all successfully resuscitated babies [36] (see part I of this report [15]).

**verschiedene Biases,
Wissenslücken sowie die
„Nenner-Problematik“
verzerren Analysen**

Empirical and ethical uncertainty

**Unsicherheiten bei
Baseline-, Outcome- und
empirische Daten laden
zu Werturteilen durch
NICU ÄrztInnen ein**

Uncertainties about baseline and outcome data couple with the empirical uncertainty of what it is like to live through the experience of comfort care, active treatment that leads to death, or active treatment that leads to NDI [38], which thus lead to further ethical uncertainty. The lack of clarity in these three categories of data (baseline, outcome, and empirical) invite value judgments to be made by NICU professionals.

**in Aussagen zur
Aussichtslosigkeit von
Interventionen werden
quantitative und
qualitative
Informationen
häufig vermischt**

For instance, discerning whether an intervention is futile, beneficial, or in the *grey zone* requires a judgment to be made. Whereas quantitative futility implies that an intervention *does not work*, qualitative futility generally means that an intervention is *not worth it* [58]. NICU professionals seem to conflate these two meanings into one and communicate to the parents their opinion on qualitative instead of quantitative futility. They make a judgment about what the experience of living with a major NDI must be like without having had the experience of it. Furthermore, they make a judgment on what the threshold QoL worth striving for is, assuming that survival with intolerable deficits may be worse than death. This decision, however, should be taken together with the parents, for it is the parents who primarily give meaning to the prognosis. It seems to be clear that below 22 weeks of GA, an intervention can be considered qualitatively futile [58], but, depending on the GA estimate, the *grey zone* examples of weeks 23 and 24 of GA remain to be hard to discern. The baseline, outcome, and empirical uncertainties complicate the decisions made and thus invite ethical uncertainty and respective value judgments to decide what is worth and what is not.

**Entscheidungen sollten
vorhandene Werturteile
berücksichtigen**

Buying time

If it was clear that intensive care would always lead to survival with acceptable QoL and so no unnecessary pain and thus also no moral wrongdoing would be inflicted, deciding around the limit of viability would not pose any tragic ethical dilemmas [59]. Because this is not always the case, providing active care at the beginning and only later deciding on whether to withdraw care is one of the strategies that *buys time* for decision-makers. Also, as stated by the head of NICU Innsbruck, in case there was no time for discussions with the parents before the delivery or the GA is uncertain, active care is the default option. That is to say that by default, care is not withheld (not started), but that care may be eventually withdrawn (stopped), if deemed appropriate.

The strategy of buying time, however, is not free from facing the tragic. Firstly, it is unclear if buying time improves the positive predictive value of death as one study suggests that it does not because NICU professionals were inaccurate in predicting which baby would die even with the prolonged passage of time [59]. Secondly, even though there is a consensus in the literature that withholding (not starting) active care and withdrawing (stopping) it is morally equivalent, it remains to be noted that withdrawal carries with it a psychological and emotional weight on parents (coupled with loss aversion, see Table 3.2-1) and, depending on the context, a higher risk of legal liability for NICU professionals [60].

According to the interviews, there is a reasonable accuracy on the baseline data of the foetus. The institutional statistics provide the institution specific outcome data that are at times coupled with the US NICHD calculator mentioned above. Hence, the more accuracy on the data of the foetus there is, the less of tragic ethical dilemmas are faced by the NICU professionals. The extent to which uncertainty remains, it remains unclear if there exists an alternative free from serious moral wrongdoing. The non-objectivity of outcome data combined with the empirical and ethical uncertainty thus make what otherwise could be an obvious question become a tragic question. There is a risk that infringement on the moral law will occur when active treatment makes the EP baby and her family suffer unnecessarily (overtreatment) as well as when EP baby has chances for survival that are not realized (undertreatment). Hence, it does not suffice to approach the NICU decision-making at the limit of viability merely as an obvious question that needs to be answered, but it is important to recognize the tragic aspect of it particularly in the *grey zone* of decision-making.

Tragic question

Further to the challenges caused by various uncertainties, ambiguity about what baby's best interest is and ambiguity about what makes up a just decision make the decision-making in the NICU fall under the category of the tragic. As stressed out during interviews, these uncertainties and ambiguities in the *grey zone* that make up a true ethical dilemma happen very rarely, but nonetheless pose challenges to professional ethics of NICU teams.

Behandlungsmaßnahmen können auch dem Zeitgewinn für Entscheidungen dienen

ein Abbruch ist immer noch möglich

moralische Gleichwertigkeit von Unterlassen und Zurücknehmen von Interventionen:

unterschiedliche Auswirkungen auf Eltern

genauere Daten über den Fötus reduzieren ethischer Dilemmas

Fehl- (Über-/Unter-)behandlungen führen zur Verletzung moralischer Grundsätze

Ambivalenz zwischen Kindeswohlergehen und angemessener Entscheidungsfindung = ethisches Dilemma, „tragische“ Frage

<p>wenn keine Entscheidung frei von ernsthaftem Fehlverhalten ist ethisches Dilemma</p>	<p>Best interest</p>	<p>Ambiguity about best interest of the baby is one of the key aspects of ethical dilemmas encountered at NICU. It is not clear what exactly that best interest is as well as it is not clear whose best interest is to be decisive. This ambiguity makes the alternatives of the decision such that none of them is clearly free from serious moral wrongdoing. It may create a tension between members of the NICU team as well as between the NICU teams and parents.</p>
<p>Feststellung des Patientenwohls/-interesses nahezu unmöglich:</p>	<p><i>What is best interest?</i></p>	<p>The best interest principle is grounded in the idea of <i>beneficence</i>. The aim is to find out, lacking the opinion of the one concerned, what would the given individual choose itself. Yet, due to the empirical uncertainty of what it is like to be a patient at NICU, it is not fully knowable what is beneficial to a vulnerable baby. For instance, a Canadian study points to the lack of understanding of pain that EP babies go through while at NICU. Among other themes, the qualitative study states that NICU professionals recurrently mentioned the subtlety and unpredictability of pain indicators, the complex nature of pain assessment, as well as the uncertainty in the management of pain [61]. Hence, the lack of clear clinical facts on the experience in NICUs make the best interest principle ambiguous.</p>
<p>Schmerzindikatoren sind häufig ungenau und unvorhersehbar</p>	<p><i>Whose best interest?</i></p>	<p>Not only are the clinical facts about what exactly is beneficial in part unknowable, but the meaning of the word <i>best</i> is also inevitably connected to the subject who evaluates the case. Different subjects, different stakeholders, may interpret the best interest of the EP baby differently. Same was the case in the cochlear implants example. At the beginning, when the implants were introduced to the clinical practice, the clinical staff valued the intervention differently from the way parents did. While the clinicians praised the fact that the use of cochlear implants brings about partial hearing, the parents objected that the technology represented a negative value judgment on deaf culture and upon its most important feature, sign language [62]. In case of NICUs, the evaluation of both best interest as well as QoL of the baby and the family is subject to individual judgment [63]. Opinions on the threshold of QoL may differ and just as the parents valued the cochlear implant intervention differently to the way clinicians did, it may also be the case when passing judgments on the best interest of a babies at NICUs.</p>
<p>die Definition des „Besten“ für den Patienten ist subjektiv</p>	<p>jede Entscheidung ist Folge individueller Einschätzung, variiert von MedizinerInnen zu Elternteil</p>	
<p>rechtliche Herausforderung bei Unterscheidung zwischen Interesse des Neugeborenen und dem der Eltern</p>	<p><i>Whose best interest?</i></p>	<p>As required by Austrian legislation, when deciding within the <i>grey zone</i>, parents must regard the best interest of their newborn child in the first place. But, the distinction between best interest of the newborn and best interest of the family is overly individualistic and hence questionable [38]. The best interest principle calls for negating all other interests except for the baby's self-regarding interest. However, when focusing on the baby's best interest individually, one tends to put it into contrast with the parents' and family interests [38]. Those, however, are interrelated and so what is best for the family has the tendency to be also best for the baby. Also for this reason, decisions within the <i>grey zone</i> tend to be left to be within the <i>zone of parental discretion</i> as the non-individualistic nature of the best interest principle puts the objective appeal to it into question [37]. As the head of NICU Graz put it above, losing the parents somehow also means losing the baby as well.</p>
<p>durch enge Verknüpfung beider Interessen wird Differenzierung abstrakt</p>		

Professional challenges with best interest

When to step in to decide? NICU team versus parents

Ambiguity about what the best interest is, combined with the unavoidability of surrogate decision-making bring about challenges to the professional ethics of NICU teams. Sometimes, the parents want the team to *do everything for the baby* (regardless of the suffering inflicted), while other times, parents want to quit active treatment (regardless of the baby's chances for meaningful survival).

“If it were easy to always know what the best interest of the child is, we would not need to discuss it”. (Berger, NICU AKH Vienna)

The head of NICU AKH Vienna continues saying that complications arise when there is a conflict between what the NICU team thinks is the best interest for the patient and what parents think. Rarely do parents want to stop the treatment and the team thinks the baby has good chances for meaningful survival – allegedly, that exclusively happens with very educated parents. Parents tend to want to prolong life, but as the head of NICU Salzburg adds, the professional conflict also arises when it comes to prolonging life that has little chances for meaningful survival. The aim of the NICU team is the best interest of the child, which may get in conflict with parental wishes. Because the concept of best interest is by no means always clear and objective, the NICU team may get into such conflicting situations, which, however, according to the interview data, happen very rarely.

When such situations do occur, it seems that there is no alternative that is free from serious moral wrongdoing. On the one hand, the NICU professionals interfere with the *zone of parental discretion* that lays the entire weight of the decision on the parents [37], while on the other hand, the NICU professional are in conflict with their own *act of profession* that commits them to serve the best interest of the patient [64]. As babies at NICUs cannot make autonomous decisions for themselves [56], the legal guardians are expected to be the surrogate decision-makers and decide on their behalf [24]. However, because parents are not always in the right to decide [65], as they face a decision they presumably never anticipated and so they may be ill prepared to make such a decision about their baby [66], the clinicians may be more competent to make the decision amidst the tragic ethical dilemma. Knowing when to step in and when to override parental discretion, however, presents a professional conflict where no single principle is clearly the right one.

NICU team cohesion challenge

NICU professionals at large seem to be more prone than the obstetric personnel to be more interventional at weeks 21-23 [31]. As suggested in interviews as well as in the literature, neonatologists are different from obstetricians in their approach. The basic difference is that neonatologists seem more pro-life, pro-caring for babies with complications, and are more hopeful that intensive care will not lead to further complications. Obstetricians are said to be more focused on the best interest of the parents, in particular the mothers, and on avoiding impairment (as stated by the head of NICU AKH Vienna).

**Herausforderung:
Widerspruch elterlicher
Interessen zu
eindeutigen
medizinischen
Diagnosen**

**Eltern wollen selten
Behandlung beenden**

**moralisches
Fehlverhalten bei
Konflikten
unausweichlich**

**eigenmächtiges Handeln
der NICU ExpertInnen
im Zweifelsfall
notwendig**

**NeonatologInnen
häufiger für
Interventionen als
GeburtshelferInnen
und Pflegepersonal**

<p>Meinungsunterschiede innerhalb des NICU-Teams häufig Konsequenz des direkten Erlebens des Leidens der Eltern</p>	<p>However, a reoccurring theme in the interviews as well as in the literature was the one of team cohesion that is underlined by the experience of futility and the following divide between the nursing staff and the medical doctors. Because the families of extremely preterm babies may spend months by their baby's hospital bed, neonatal nurses, who are the constant caregivers, spend more time with the families than doctors do. Nurses attempt to meet the baby's needs, but at the same time may then get in the role of being the family advocates [67]. This puts them into a difficult position for two reasons.</p>
<p>moralischer Zwiespalt verursacht Stress und Spannungen insb. bei Pflegekräften</p>	<p>Firstly, nurses are close to the suffering of vulnerable babies and hence tend to experience futility of medical treatment more than doctors do. Being so close to suffering and thus going through the normative tension inherent to the situation makes the nurses experience moral distress [68]. One of the most common causes of distress is supporting patients at the end of their lives when comfort care would be more humane. Nurses report that they struggle with causing suffering through carrying out active treatment when they could comfort instead [68]. The experience of moral distress, however, differs from the experience of a moral dilemma in that the nurses know what the right course of action is, but the institution and other co-workers (doctors in the case of NICUs) create obstacles for them to act according to their conscience [69].</p>
<p>das „kostbare Baby Syndrom“ ist besonders stark bei IVF-Kindern: diese Eltern sind besonders verzweifelt</p>	<p>Secondly, being so close to parents makes the nurses experience the parental anguish of wanting to bring their baby home that the nurses at times see will presumably not be fulfilled [70]. Encountering parental anguish and extreme sadness is a particular issues in case of IVF babies born extremely prematurely. Seeking parenthood, longing for a baby, or the desperation to become parents are themes supporting the existence of the <i>precious baby syndrome</i> that neonatal nursing staff named in an Australian qualitative study [70]. Even though the nurses refused the idea of one baby being more precious than the other, the term precious was frequently used when referring to babies conceived particularly through IVF. Furthermore, another Australian study found that nurses often find themselves in challenging situations where they have to <i>keep secrets</i> from the parents about the health state of the baby where they experience fear of inadvertent disclosure, fear of parents being unable to cope with potentially catastrophic news, or fear of knowing of a burden that could damage trust between them and the parents [67].</p>
<p>ungleiche Bewertung einer Situation kann in Geheimhaltung von Komplikationen gegenüber Eltern gipfeln</p>	<p>There is, hence, a divide between nurses and doctors, where nurses are clearly more prone to withhold resuscitation [71]. In a Swiss survey among NICUs, 35% of doctors and 64% of nurses stated that some babies were treated too intensively [72], which points to a divide that seems to be present also within the Austrian NICU teams. As suggested by the head of NICU Graz, there are differences between doctors and nurses when it comes to near death situations. The nurses tend to be more restrictive when it comes to medical help that seems to be correlated with their imminent experience of futility. As the head of NICU Salzburg states, the biggest ethical challenge is the divide between nurses and the medical doctors when it comes to active and comfort care. This Austrian experience goes in hand with the vast moral distress literature.</p>
<p>Pflegekräfte neigen im Vergleich zu ÄrztInnen viel häufiger dazu, Wiederbelebnungsmaßnahmen zurückzuhalten</p> <p>größte ethische Herausforderung ist Zwiespalt zwischen ÄrztInnen und Pflegekräften bei der Entscheidung zwischen palliativer und aktiver Versorgung</p>	<p>Regardless of this disagreement, it is stressed in the interviews that when facing the parents, the teams have only one opinion (as stated by the head of NICU Salzburg and the head of NICU Linz). This is needed for the sake of professional care delivery as the role of the NICU team is not only to safeguard the best interest of the EP baby, but also to support the parents in their situation of distress.</p>

Just decision

Ambiguity about what makes a just decision is another key aspect of ethical dilemmas encountered at NICUs. NICU professionals may experience this struggle with distributive justice issues as well as with justice as fairness issues. Limited resources, influx of new technologies, and issues with fairness make the alternatives of decisions such that, at times, none of them is clearly free from serious moral wrongdoing.

Distributive justice

The experience of limited capacity of the neonatal unit and the increase in resource needs for EP babies (see part I of this report [15]) put the question of distributive justice to the forefront. Just distribution of resources is therefore another ethical challenge faced by NICU professionals. As the clinical ethicist from University of Vienna puts it, it is a challenge for the NICU professionals to remain focused on the particular patient with its particular needs and at the same time experience the tension created by the macro question of limited resources. This micro-macro tension may increase also alongside the constant influx of new technologies. As reported in a UK qualitative study among nurses, the use of advanced technology brought with it increased ethical dilemmas [73]. While fifty years ago, the majority of neonatal deaths occurred regardless of the best efforts of NICU teams, today, the majority of neonates die after the life-sustaining interventions are withdrawn [74]. As the head of NICU Salzburg puts it, it is possible to keep the baby alive for a markedly longer period of time with the current technologies, which poses new challenges with QoL and end of life treatments. Moreover, the context of scarce resources by definition makes the decision-making at NICU a tragic one, as putting resources into the NICU patients indirectly takes these resources away from other groups in need, thus causing them a serious moral wrongdoing.

Justice as fairness

The principle of justice also calls for fairness in treatment, impartial behaviour that does not support favouritism or discrimination. In this respect, two issues in particular are relevant for the NICU professionals: age discrimination and disability as a changing category that may be responsible for causing serious moral wrongdoing to the EP babies.

Age discrimination

While an older individual may get the treatment required, the same does not apply to an EP baby with similar outcomes [75]. This case of gestational ageism is a recurrent theme in the literature [38]. Doctors seem to have the tendency to accept family's refusal of resuscitation of an extremely preterm baby even if they think that resuscitation is in the patient's best interest [76]. In an Australian survey, 96% of doctors were willing to comply with families' wishes to withhold intensive care, despite 77% of them believing that resuscitation would be in the baby's best interest [74]. This is much less common for older patients suggesting that doctors feel less obliged to treat EP babies [77]. It remains a question to what extent can prematurity justify making exceptions to common principles in medical practice [78].

Unklarheit, was eine „gerechte“ Entscheidung ausmacht

ethische Fragestellung der gerechten Verteilung limitierter Ressourcen

neue Technologien führen zu Verbesserungen der Maßnahmen zur Lebenserhaltung von Säuglingen, bergen aber auch neues Konfliktpotential

Fragen der Fairness bei der Behandlungsentscheidungen

Tendenzen zur Altersdiskriminierung gegenüber Säuglingen

96 % der ÄrztInnen folgen Willen der Eltern, 77 % davon wider besserem Wissen

Disability a changing category

wandelndes Verständnis
von Behinderung und
Beeinträchtigung

derzeit ethisch
unbedenkliches
Verhalten in Zukunft
womöglich verwerflich

Vermeidung von
unnötigem Leid als
einziges Argument
gegen lebenserhaltende
Maßnahmen

The above outlined case of gestational ageism is particularly problematic because disability is a changing category. Almost three decades ago, Down syndrome children were left to die because of their “unacceptable” outcomes, yet today, life-sustaining interventions are no longer considered optional in this segment of the population. The category of disability has changed with respect to Down syndrome even though it remains to be the case that if children with Down syndrome were categorized according to current NICU categorization tools for long-term outcomes, they would be classified as having profound impairments. Their IQ averages below 50, many cannot live independently, and they often die in early adulthood [58]. Moreover, doctors tend to conflate survival and disability. They judge disability more harshly than parents and are more likely to think that being severely disabled is worse than being dead [58]. Thus putting the NICU challenges into perspective, the future understanding of disability may change and hence influence the perceptions of NICU professionals concerning active treatment and concerning the notion of moral wrongdoing. Therefore, in order to prevent moral wrongdoing, as Berger 2011 suggests, the decision to withhold or withdraw life-sustaining therapies needs to be motivated by the desire not to inflict unnecessary suffering on the EP baby and not by the wish to prevent survival with disabilities [20].

Professional challenges with justice

Abwägen zwischen
gerechter Verteilung
der Ressourcen und
Anteilnahme
Entscheidungen als
Herausforderung

Zufriedenheit abhängig
von Ablauf und
Qualität der
Entscheidungsbildung

Ambiguities about distributive justice as well as about justice as fairness present professional ethics challenges to the NICU professionals. The NICU team has to balance the compassionate approach that shows authentic emotions towards each particular baby with the just distribution of resources approach [36]. As put by the US President’s Council on Bioethics: “There are no simple formulae to guide us, no algorithms for calculating the relative weights of benefits and harms. Seeking the best care possible will always require wise and prudent judgment of the people on the spot.” [79]. Because proving moral correctness in the light of a tragic ethical dilemma is not possible, the success of *grey zone* decisions will ultimately depend on how the parties involved judge the process of decision-making and how they cope with the consequences of the decisions. Berger 2011 suggests that careful communication adapted to parental needs, credible justification of the professional decision, and honest empathetic communication are least likely to result in persistent accusation and feelings of guilt on both sides of the shared decision-making process [20].

Why to recognize the tragic question?

Bedeutsamkeit der
tragischen Frage:

zur Klärung der
ethischen Alternativen

zur Anerkennung
des Dilemmas

zur Suche nach
Lösungen

If there is a tragic question at stake, answering merely the obvious question of what shall we do may take our attention away from the ethical dilemma in the background. If none of the alternatives open is free from serious moral wrongdoing, tragedy is imminent [49]. It is hence important to pose the tragic question because of the following reasons:

1. it clarifies the nature of ethical alternatives and informs the decision-maker about differences between self-interest and commitment, prudential and moral values,
2. it recognizes the existence of a tragic ethical dilemma to which there is no right and wrong answer, thus
3. motivating one to make appropriate reparations, if possible, and lastly
4. the recognition of tragedy leads one to look for solutions that can avoid tragedy in the future [49].

Recognizing the presence of the tragic question can have impact on both the NICU team as well as the individual. In case of NICUs, recognizing the fact that there is a separate tragic question that is different from the obvious question leads to the recognition of the role of ethics support in the NICU decision-making environment that may lead to increased quality of care delivered. In terms of the individual NICU professional, recognizing the tragic question may help with the experience of moral distress and thus allow the members of the NICU team to acknowledge and work with the ethical dilemmas individually.

Organizational ethics

Currently, in the Austrian NICU context, there is a limited role for clinic ethics support as well as a limited role for ethics committees. Recognizing the role of ethics in decision-making influences the structural set up of organizations.

Team discussions, in house supervision, and ethics moderation are mechanisms that the interview participants mentioned are already partly in place to support the NICU teams. As the head of NICU Graz puts it, there is always disagreement within the team, but communication and discussion are necessary so that the group decides together. He further continues that possibly, ethics moderation is a tool that will be used in the future (even though it is not needed very often). The head of NICU Innsbruck stresses the same point that within the team, conflicts about whether to go for active or comfort care can be for the most part resolved by discussion. She says that it is necessary to take time and discuss the challenging issues especially with the younger nurses. If overwhelmed with the number of ethically challenging cases in the ward in the Viennese AKH, supervision is also done, but in an individualized way. The head of NICU Salzburg states that there is a new model of supervision that happens every month in Salzburg that was started recently and that when needing to solve an ethical conflict within the team, the ethics committee sends one to two moderators for help.

The clinical ethicist from University of Vienna reinforces the point that ethics moderation is important for the NICU teams. A moderation process is particularly necessary in order to minimize the variety of opinions in the team and then after to go with one opinion to support parents in the ethics consultation. Bringing the issue from the personal conflict to a conflict at the value level helps in improving the decision. He further states that this is often the experience from ethics moderation:

“thank you so much you are here, that we can talk together. It helps us to make our own decisions clearer. And to improve our decision making competences.”
(Dinges, clinical ethics, University of Vienna)

Especially when facing complex situations, the role of ethics moderation is inevitable. There are few hospital like Barmherzige Brüder that deal with explicit structures of clinical ethics (as well as the members of Vinzenz-Holding) (as stated by the clinical ethicist from University of Vienna). For the most part, if hospital departments face an ethically challenging case, it is solved informally by calling the relevant people.

**Schaffung von
Bewusstsein für
ethischen Konflikt
führt zu höheren
Qualitätsstandards**

Organisations-Ethik

**Diskussionen im Team,
Supervision als
essentielle Teile der
Entscheidungsfindung**

**ethische Moderation
potenziell förderlich bei
Überforderung oder
mangelndem Konsens**

**teaminterne
Beschränkung auf
eine Option zur
Konfrontation der
Eltern**

**in komplexen
Situationen ist
ethische Moderation
unvermeidbar**

**klinische Ethikkomitees
und Teambuilding-
Maßnahmen können die
Entscheidungsqualität
deutlich steigern**

Spannungen reduzieren

In both Italy and the UK, the argument carries further, suggesting that clinical ethics committees have a role to play in quality of the service delivered [54, 80]. It is also supported by a Canadian survey that suggests that organizational culture has an impact on the improvement of quality at a NICU [81]. Since ethics support may improve the organizational culture through making the ethical tension points become transparent and to some extent solved within the teams, it may indirectly improve the service delivered. In general, group oriented culture leads to better outcomes, however in Canadian NICUs, hierarchical culture is associated with even better patient outcomes [81]. For that reason, the clinical ethicist from University of Vienna further argues not only for ethics consultations from the outside, but also for the need of team buildings for NICU professionals in order to support the teams' cohesion also on ethical issues from the inside. He states that doctors often

“don't know from each other because there is no time to talk about that. There is no team building and I think, my personal belief is ... nurses are in teams, and that helps them to survive everyday hospital work. But doctors, the physicians, are not in real teams.” (Dinges, clinical ethics, University of Vienna)

**50 % der ÄrztInnen und
78 % der PflegerInnen
wünschen sich häufigere
Gruppendiskussionen
über ethische Aspekte**

**offene
Diskussionskultur
als Voraussetzung
für Qualitätsgewinn**

Recognizing the tragic question has an impact on the individual as well. A Swiss survey among NICU professionals states that 50% of doctors and 78% of nurses wished for more group discussions about ethical issues [72]. It suggests that the topic of ethics receives less attention than it is supposed to. In the interviews, it was suggested, however, that to speak openly about ethics in the NICU teams, the organizational set up must be such that it is allowed. The clinical ethicist from University of Vienna states that undoubtedly, all medical doctors have a strong moral orientation to do good medicine, but that does not mean that they can reflect on their value stance and so if the framework is lacking, the doctor that recognizes the uncertainty inherent to ethical dilemmas encountered at NICUs ends up without support.

“That's all part of, we call it organisational ethics, in the way the organisation is reflecting good structures and hence offers good medicine. (...) Before you address the co-workers about the virtues, what is the framework within the organisation? Because in my opinion, you have to first set up your framework that it's allowed, that it's a question of quality to ask ethical questions. And then you can address the co-workers and say 'what is your position in that ethical issue?' But first you have to make clear that it's allowed. (...) A lot of physicians are doing a good work, even dealing with the ethical decision-making, but they have less support, they cannot be sure if another physician in the next batch or if the leader of the hospital are supporting them in their decision making ... or if they risk something, if they use more or less resources, and so on ...”

(Dinges, clinical ethics, University of Vienna)

**Management muss
einbezogen, ethische
Dilemmata als Faktor
für Behandlungsqualität
anerkannt werden**

If the NICU management openly recognizes the tragic ethical dilemmas that are at times experienced by NICU professionals, it makes it easier for the individual to progress not only as professionals, but also as moral agents. It may have impact on the team cohesion and hence also on the quality of care delivered. Allowing clinical ethics to play a role especially in normatively challenging situations such as those encountered within the *grey zone* at NICUs may lead to improved quality of the team as well as quality of growth of the NICU professional within it.

4 Discussion and Conclusion

This report outlined the current evidence on decision-making practices (guidelines, good practice models, and communication strategies) and ethical challenges at the limit of viability. We aimed to provide a comprehensive overview on the complexity of decision-making encountered by NICU professionals. The relationship between the findings and corresponding considerations for the purposes of health care planning are discussed here.

Guidelines and practices

There is a number of GLs in the academic literature that provide country specific data on the management of decision-making at the limit of viability. They reflect both on the scientific data as well as on practices of particular social contexts driven by factors such as level of expertise, case volume, different resource capacities, varying treatment options, or quality of care (as discussed in part I or this report [15]). Especially within the *grey zone*, GLs further reflect on the societal perspectives on the value of life and on where the balance between overuse and underuse of treatment lays [24]. Different countries issue different GLs that need to be updated periodically due to advances in technology. Given the vast number of GLs, it was not anticipated that only a small number of SRs would be found in the literature. The SR used in this report was most up-to-date and fitted the context of high income countries.

According to the SR that was updated for the German speaking countries, currently, high income countries have an overall consensus that comfort care is in place below 22 and active care above 25 weeks of GA. Weeks 23 and 24 of GA remain to be the *grey zone* of viability that is followed by a considerable variation of recommendations [17]. This variety leads directly to a variety of practices. While an EP baby at 24 weeks of GA would not routinely receive active treatment in Switzerland [20], the same baby would receive active treatment in Austria or Germany [18]. Apart from active and comfort care, the GLs further influence the shared decision-making practices. By delineating where the grey zone of decision-making stands, the setup of GLs influences at what point the shared decision-making processes come in place. While in the Austrian and German GLs, parental wishes decide at 23 weeks of GA, the Swiss GL suggests comfort care at the same point and parental wishes come in place later at 24 weeks of GA (see Table 3.1-1).

Outcomes and biases

Especially within the *grey zone*, the difference in practices leads to a difference in outcomes. The Swiss policy of routinely providing comfort care at 23 weeks of GA leads to low survival rates for those babies [20]. The low survival rates, in turn, validate the policy even though the causal relationship runs the other direction [25]. These outcomes then become part of institutional statistics that further influence counselling and so the outcomes based on historical data influence the decision-making of parents and thus the future outcomes. Institutional biases such as this and other biases that are at play during shared decision-making processes (see Table 3.2-1) are in part responsible for the variation in outcomes between hospitals.

Ziele des Berichts:

Guidelines/Leitlinien, Modelle guter Praxis Kommunikationsstrategien

teilweise Einbeziehung ethischer Fragestellungen in Leitlinien

nur wenig Übersichtsarbeiten verfügbar

Konsensus: palliative Versorgung unter 22 Wochen GA und aktiver Versorgung ab 25 Wochen GA,

große Unterschiede zwischen Ländern: von 22. bis 24. Woche GA Grauzone,

partizipative Entscheidungsfindung

institutioneller Bias: institutionelle Entscheidungen führen zu Ergebnissen, die die Statistiken beeinflussen, die wiederum die Vorgaben legitimieren

**weitere Biases
beeinflussen
Entscheidungen und
sollten berücksichtigt
werden**

As behavioural psychology argues, the real decision-making involves the use of mental shortcuts (biases) and one ought not to perceive them as undesirable interferences with the rational decision-making process. It is necessary to recognize the impact of these biases on the decision-making in NICUs as they are an inevitable part of the process that needs to be taken into account when developing GLs for shared decision-making procedures [23]. Good practice decision models need to include not only psychological support for the parents and ethics support for the NICU professionals that are already to some extent acknowledged, but also support in terms of communication strategies with parents as those influence outcomes as well [24]. Furthermore, there is a need for training of NICU professionals aiming first, at recognition of the biases and second, at the reduction of influence of their personal and informational biases on the parents.

Ethical challenges

**soziale, kulturelle,
religiöse und rechtliche
Aspekte bilden den
Kontext für die
ethischen
Fragestellungen und
Herausforderungen**

All the context above together with social, cultural, religious, and legal aspects make up the setting in which ethical challenges take their shape and form. The challenges can thus vary with context and hence a member of the Austrian NICU nursing staff would presumably find it morally distressful to administer comfort care to a Swiss EP baby at 24 weeks of GA (because those babies are routinely treated in Austria) (see Table 3.1-1). In Austria, the ethical challenges operate at the backdrop of Kantian philosophy of deontology, Christian culture, legal requirement of prolonging life without caring about its quality, socio-economic inequalities, and current migration challenges [18]. Ethical challenges in terms of discerning what best interest is and what makes up a just decision were highlighted as some of the main concerns both in the interviews as well as in the literature. The topic of institutionalization of legal support as part of ethics committees was mentioned in the interviews and so it is now put forth for further consideration.

**einzelne Länder und
Krankenhäuser mit
unterschiedlichen
Herangehensweisen**

Handling of an ethically challenging situation also differs between hospitals and between countries. Depending on whether clinical ethics is taken to be an integral part of medicine, ethics committees and ethics support play an important role in systems of countries such as the UK [82]. As stated in the interviews, in Austria, there is a variation between hospitals and their use of ethics committees and ethics support. While some include clinical ethics in their structures, other make use of ethics support in non-institutionalized ways. Also, it remains a question to what extent is the retrospective evaluation of decisions practiced, formally or informally. Recognition of the role of ethics requires a recognition that answering the obvious question does not always suffice. Acknowledging the tragic question, where the lines between right and wrong are blurred, leads to actions being taken towards establishing ethics frameworks to support decision-making at NICUs. In NICUs, such structural support can help in improving team cohesion (as stated in the interviews) and quality of care provided [82]. Only when the organizational structure allows for ethical dilemmas to be recognized, the NICU professionals can acknowledge and work with them individually

**Beachtung ethischer
Gesichtspunkte kann zu
erhöhter Entscheidungs-
und Versorgungsqualität
führen**

Limitations

There are several limitations to this report. Firstly, we limited the search language to German and English, which, according to the high volume of articles published especially on the topic of ethics in NICU, presumably led to leaving out of some literature. Nonetheless, we consider the literature used robust enough to provide a good overview of the decision-making models and ethical challenges at NICUs.

Secondly, even though this literature review was based on a systematic literature search complemented by a thorough hand search, the way of reporting remained non-systematic because no common denominator was found that would allow for comparison between the variety of studies. Hence, also no quality assessment or risk of bias tools were used. And thirdly, the SR on GLs was not updated in full as only German speaking GLs were updated to the publication date of this report.

**Einschränkungen
dieses Berichts:**

**nur deutschsprachige
und englische Literatur**

**systematische Suche
nach Publikationen,**

**aber nicht systematische
Aufbereitung**

5 Literature

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6 Appendix

Table 6-1: Code tree

Overall theme	Code	Sub code	Coding example
Decision-making	Decision models	Guidelines	"we follow the guidelines ... of the ÖGKI, uh and uh ... we treat routine- really routinely at 24+0, so there's no question about that if we treat it or not"(Wald, NICU Salzburg)
		Grey zone	"we really try to implement this, this uh new guideline from ... in Austria, yeah. We recognise that in in comparison to the the ... so the guideline in Switzerland and in Germany uh it's so ... there is a wider uhm ... space ... for for decision making. And and therefore w-we we think we have to offer really a process of uh uh, consultation, counselling in that process. If the mother wants, yeah."(Dinges, clinical ethics, University of Vienna)
		Psychological support	"the SOP would be that ideally the mother and the father have ... a counselling talk before birth, with the pediatrician and a psychologist. Or let's say neonatologist and plus psychologist ... it's not necessarily that both together talk to them, because this is, a resource problem, but both groups have to talk to them, yes. This is the ideal situation."(Urlesberger, NICU Graz)
		Ethics committee	"yeah, we do have, they come together immediately if you need this committee and if. ... the nurses are in this committee, there are people from people different wards who don't have to do anything with, with the patients, we are in psychologist and so they can meet immediately and you have a a written m paper afterwards m regarding the discussion and also the decision ..."(Kiechl-Kohlendorfer, NICU Innsbruck)
	Communication with parents	Individualized	"regarding treatment, it's mostly it's possible, or always, nearly always to ... work... together with the parents. If you talk to them, if you have enough time for them, if you try to understand them, I think you won't have a problem, regarding this question."(Kiechl-Kohlendorfer, NICU Innsbruck)
		Paternalism	"we sometimes really have to fall back and make a paternalistic decision."(Berger, NICU AKH Vienna)
Ethical challenges	Context	Cultural-religious context	"nowadays I think or for me is a-, it's a challenge that we have so many different cultures. ... and ... or we ... maybe ... don't understand every religious aspect that's going on in the parents."(Kiechl-Kohlendorfer, NICU Innsbruck)
		Social context (typology of parents and guidelines)	"So it's a language problem, and if you look at the immigrants of the last years, it's not only language, but it's a s-social situation, they they don't, they are not really able to imagine the situation (at NICU) ..."(Urlesberger, NICU Graz)
		Legal context	"yes it was a challenge before the ethic commission was established. Now we have uh uh a judge in the commission and uh also uh with Medizinrecht, also, uh medical ..."(Wiesinger-Eidenberger, NICU Linz)
	Obvious question	Uncertainty (vigorousness assessment)	"sometimes you are not even sure, i-if is it ih, a 23 weeker, or is it a 24 weeker for instance"(Kiechl-Kohlendorfer, NICU Innsbruck)
	Tragic question	Best interest	"if it were easy to know what the best interest of the child is, we would not need to discuss it". (Berger, NICU AKH Vienna)
		Moral distress	"nurses sometimes want to stop therapy. because of futility and futility is a very difficult thing."(Urlesberger, NICU Graz)
		Professional virtues	"They must have the feeling for the very small and we ... the very ... tiny and and ... also ill babies. So, it's a, it's a kind of ... of 'I like this'. So, at my ... my, my I - I ha- started my trai- aso my training o-on the NICU. First day on the NICU and I went into the NICU and i said 'Okay, that's it'."(Wiesinger-Eidenberger, NICU Linz)

6.1 Interview material

INTERVIEW GUIDE

Objective of the study

Against the backdrop of medical advances in neonatal intensive care and the increased survival rate of infants at the limit of viability, the aim of this project is to assess resource planning, outcomes, and ethics of children born extremely prematurely in neonatal intensive care units (NICUs) in Austria.

In the first part, we aim to provide evidence on the clinical outcomes of extremely preterm infants as well as data into the resources needed at NICUs to care for these infants. In the second part, we aim to provide information on “good practice” models of decision-making procedures (choosing between active vs palliative treatments), the social factors that serve as the basis for making the decision whether to prolong life (parents’ age, educational background, or socio-economic status), and the ethical challenges with interventions at the threshold of viability.

Information on the interview:

The interview will take approximately 30 minutes. The interview will be recorded, transcribed and a copy of it will be sent back to you to confirm the content. Personal information provided during the interview will be kept confidential. The following questions will be the main topics that will guide the interview:

Guiding Questions for semi-structured interviews:

Part I: Resource Needs NICU for preterm infants:

5. Where are current short comings and resource needs in NICUs?

- ❖ Does your clinic have staffing requirements? Are staffing requirements feasible?
- ❖ What is the doctor per patient and nurse per patient ratio on average?
- ❖ Do you need more health personnel (doctors/nurses) depending on the gestation week of your patients?
- ❖ Institutional guidelines, differences in management guidelines

6. workload and resource needs by gestation week:

- ❖ Average lengths of stay/differences of LOS in relation to in gestation weeks
- ❖ differences in resource needs/use by gestation week
- ❖ differences in nurse-to patient ratio

7. center level factors that influence outcome

- ❖ What are the center level factors that influence outcome? (level of specialization, management, number of nurses available, volume of preterm infants/year, difference in approach to active/or palliative care)

Part II: Ethics

- ❖ How do the guideline criteria for deciding between active and palliative treatment translate into reality?
- ❖ Do you have any standard operating procedures (SOPs on process how to invite the parents, who leads the discussion, predefined questions) specific for your institution?
- ❖ How do social factors like educational or socio-economic background of parents influence the decision-making process?
- ❖ What are the key ethical struggles in your experience? What do you think are the key qualities (excellences of character or virtues) of the profession of decision-making in NICU?

6.2 Literature search strategies

Search strategy for Cochrane

Search Name: Extremely Prematurity_Ethics (KH/MS)	
Search Date: 23/06/2017 10:46:19.186	
Description: KH/MS	
ID	Search
#1	MeSH descriptor: [Infant, Extremely Premature] explode all trees
#2	((extreme* or very) near ((prematu* or preterm or early or low-gestational-age) near (newborn* or neonate* or baby or babies or toddler* or infant* or child* or birth* or deliver*)):ti,ab,kw (Word variations have been searched)
#3	perivable birth*:ti,ab,kw (Word variations have been searched)
#4	MeSH descriptor: [Fetal Viability] explode all trees
#5	Periviability:ti,ab,kw (Word variations have been searched)
#6	(limit* or threshold or border*) near viability:ti,ab,kw (Word variations have been searched)
#7	#1 or #2 or #3 or #4 or #5 or #6
#8	MeSH descriptor: [Intensive Care, Neonatal] explode all trees and with qualifier(s): [Ethics – ES]
#9	MeSH descriptor: [Intensive Care Units, Neonatal] explode all trees and with qualifier(s): [Ethics – ES]
#10	((ethic* or decision*) near (neonatal intensive care or NICU)):ti,ab,kw (Word variations have been searched)
#11	MeSH descriptor: [Decision Making] explode all trees and with qualifier(s): [Ethics – ES]
#12	decision*:ti,ab,kw (Word variations have been searched)
#13	deciding:ti,ab,kw (Word variations have been searched)
#14	MeSH descriptor: [Ethics] explode all trees
#15	MeSH descriptor: [Ethics, Medical] explode all trees
#16	ethic*:ti,ab,kw (Word variations have been searched)
#17	moral near (challenge* or dilemma* or issue* or concern* or reservation* or attitude* or judgment*):ti,ab,kw (Word variations have been searched)
#18	MeSH descriptor: [Judgment] explode all trees and with qualifier(s): [Ethics – ES]
#19	practical wisdom*:ti,ab,kw (Word variations have been searched)
#20	phronesis:ti,ab,kw (Word variations have been searched)
#21	#8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20
#22	#7 and #21

Total: 47 Hits

Search strategy for CRD

Search Name: Extreme Prematurity_Ethics (KH/MS)	
Search Date: 22/06/2017	
ID	Search
#1	MeSH DESCRIPTOR Infant, Extremely Premature EXPLODE ALL TREES
#2	((((extremely or very) NEAR ((prematu* or preterm or early) NEAR (newborn* or neonate* or baby or babies or toddler* or infant* or child* or birth* or deliver*))))))
#3	(peri*viable birth*)
#4	MeSH DESCRIPTOR Fetal Viability EXPLODE ALL TREES
#5	(Peri*viability)
#6	#1 OR #2 OR #3 OR #4 OR #5
#7	MeSH DESCRIPTOR Terminal Care EXPLODE ALL TREES
#8	((end-of-life OR terminal OR palliative) NEAR (treatment* OR therap* OR care OR decision*))
#9	MeSH DESCRIPTOR Palliative Care EXPLODE ALL TREES

#10	(palliative)
#11	MeSH DESCRIPTOR Intensive Care, Neonatal EXPLODE ALL TREES WITH QUALIFIER ES
#12	MeSH DESCRIPTOR Intensive Care Units, Neonatal EXPLODE ALL TREES WITH QUALIFIER ES
#13	MeSH DESCRIPTOR Resuscitation Orders EXPLODE ALL TREES
#14	(resuscitat*)
#15	MeSH DESCRIPTOR Withholding Treatment EXPLODE ALL TREES
#16	((ethic* OR decision*) NEAR (neonatal intensive care OR NICU))
#17	MeSH DESCRIPTOR Decision Making EXPLODE ALL TREES
#18	(decision*)
#19	(deciding)
#20	MeSH DESCRIPTOR Ethics EXPLODE ALL TREES
#21	MeSH DESCRIPTOR Ethics, Medical EXPLODE ALL TREES
#22	(ethic*)
#23	(moral NEAR (challenge* OR dilemma* OR issue* OR concern* OR reservation* OR attitude* OR judgment*))
#24	MeSH DESCRIPTOR Judgment EXPLODE ALL TREES
#25	(practical wisdom*)
#26	(phronesis)
#2	#7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26
#28	#6 AND #27

Total: 12 Hits

Search strategy for Embase

Search Name: Extreme Prematurity_Ethics (KH/MS)	
Search Date: 22/06/2017	
ID	Search
#1	((extreme* OR very) NEAR/3 (prematu* OR preterm OR early OR 'low-gestational-age') NEAR/3 (newborn* OR neonate* OR baby OR babies OR toddler* OR infant* OR child* OR birth* OR deliver*)):ti,ab
#2	peri*viability
#3	(peri*viable birth*)
#4	((limit* OR threshold* OR border*) NEAR/1 viability):ti,ab
#5	((extreme* OR very) NEAR/3 (prematu* OR preterm OR early OR 'low-gestational-age') NEAR/3 (newborn* OR neonate* OR baby OR babies OR toddler* OR infant* OR child* OR birth* OR deliver*)):ti,ab OR 'perivable*':ti,ab OR peri*viability OR ((limit* OR threshold* OR border*) NEAR/1 viability):ti,ab
#6	'terminal care'/exp
#7	('end-of-life' OR terminal OR palliative) NEAR/1 (treatment* OR therap* OR care OR decision*)
#8	'palliative therapy'/exp
#9	palliative:ti,ab
#10	'resuscitation'/exp
#11	resuscitat*:ti,ab
#12	'treatment withdrawal'/exp
#13	(ethic* OR decision*) NEAR/5 ('neonatal intensive care' OR nicu)
#14	'terminal care'/exp OR ('end-of-life' OR terminal OR palliative) NEAR/1 (treatment* OR therap* OR care OR decision*) OR 'palliative therapy'/exp OR palliative:ti,ab OR 'resuscitation'/exp OR resuscitat*:ti,ab OR 'treatment withdrawal'/exp OR (ethic* OR decision*) NEAR/5 ('neonatal intensive care' OR nicu)
#15	((extreme* OR very) NEAR/3 (prematu* OR preterm OR early OR 'low-gestational-age') NEAR/3 (newborn* OR neonate* OR baby OR babies OR toddler* OR infant* OR child* OR birth* OR deliver*)):ti,ab OR 'perivable*':ti,ab OR peri*viability OR ((limit* OR threshold* OR border*) NEAR/1 viability):ti,ab AND ('terminal care'/exp OR ('end-of-life' OR terminal OR palliative) NEAR/1 (treatment* OR therap* OR care OR decision*) OR 'palliative therapy'/exp OR palliative:ti,ab OR 'resuscitation'/exp OR resuscitat*:ti,ab OR 'treatment withdrawal'/exp OR (ethic* OR decision*) NEAR/5 ('neonatal intensive care' OR nicu))

#16	'decision making'/exp
#17	decision*:ti,ab
#18	deciding:ti,ab
#19	'ethics'/exp
#20	ethic*:ti,ab
#21	moral NEAR/5 (challenge* OR dilemma* OR issue* OR concern* OR reservation* OR attitude* OR judgment*)
#22	'practical wisdom'
#23	phronesis
#24	'decision making'/exp OR decision*:ti,ab OR deciding:ti,ab OR 'ethics'/exp OR ethic*:ti,ab OR moral NEAR/5 (challenge* OR dilemma* OR issue* OR concern* OR reservation* OR attitude* OR judgment*) OR 'practical wisdom' OR phronesis
#25	((extreme* OR very) NEAR/3 (prematu* OR preterm OR early OR 'low-gestational-age') NEAR/3 (newborn* OR neonate* OR baby OR babies OR toddler* OR infant* OR child* OR birth* OR deliver*)):ti,ab OR 'perivable*':ti,ab OR peri*viability OR ((limit* OR threshold* OR border*) NEAR/1 viability):ti,ab AND ('terminal care'/exp OR 'end-of-life' OR terminal OR palliative) NEAR/1 (treatment* OR therap* OR care OR decision*) OR 'palliative therapy'/exp OR palliative:ti,ab OR 'resuscitation'/exp OR resuscitat*:ti,ab OR 'treatment withdrawal'/exp OR (ethic* OR decision*) NEAR/5 ('neonatal intensive care' OR nicu)) AND ('decision making'/exp OR decision*:ti,ab OR deciding:ti,ab OR 'ethics'/exp OR ethic*:ti,ab OR moral NEAR/5 (challenge* OR dilemma* OR issue* OR concern* OR reservation* OR attitude* OR judgment*) OR 'practical wisdom' OR phronesis)

Total: 263 Hits

Search strategy for Medline

Search Name: Electrostimulation for GERD	
Search Date: 21/06/2017	
ID	Search
#1	exp Infant, Extremely Premature/(1249)
#2	((extremely or very) adj2 ((prematu* or preterm or early or low-gestational-age) adj2 (newborn* or neonate* or baby or babies or toddler* or infant* or child* or birth* or deliver*))).mp. (6884)
#3	peri?viable.mp. (104)
#4	peri?viability.mp. (25)
#5	((limit* or threshold* or border*) adj2 viability).mp. (619)
#6	1 or 2 or 3 or 4 or 5 (7430)
#7	exp Terminal Care/(48257)
#8	((end-of-life or terminal or palliative) adj2 (treatment* or therap* or care or decision*)).mp. (85238)
#9	exp Palliative Care/(49398)
#10	palliative.mp. (77106)
#11	exp *Intensive Care, Neonatal/es [Ethics] (92)
#12	exp *Intensive Care Units, Neonatal/es [Ethics] (53)
#13	exp Resuscitation Orders/(3573)
#14	resuscitat*.ti,ab. (54065)
#15	exp Withholding Treatment/(14169)
#16	((ethic* or decision*) adj5 (neonatal intensive care or NICU)).mp. (217)
#17	7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 (173853)
#18	6 and 17 (435)
#19	exp Decision Making/(172661)
#20	decision*.mp. (364316)
#21	deciding.mp. (14670)
#22	exp Ethics/(139285)
#23	exp Ethics, Medical/(47216)
#24	ethic*.mp. (159080)

#25	(moral adj5 (challenge* or dilemma* or issue* or concern* or reservation* or attitude* or judgment*)).mp. (4258)
#26	exp Judgment/(16593)
#27	practical wisdom*.mp. (145)
#28	phronesis.mp. (109)
#29	19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 (639708)
#30	18 and 29 (257)
#31	remove duplicates from 30 (247)

Total: 247 Hits

Search strategy for PsychInfo

Search Name: Extremely Prematurity_Ethics (KH/MS)	
Search Date: 23/06/2017 10:46:19.186	
Description: KH/MS	
ID	Search
#1	((extremely or very) adj2 ((prematu* or preterm or early or low-gestational-age) adj2 (newborn* or neonate* or baby or babies or toddler* or infant* or child* or birth* or deliver*))).mp. (1245)
#2	peri?viability.mp. (3)
#3	((limit* or threshold* or border*) adj2 viability).mp. (46)
#4	1 or 2 or 3 (1278)
#5	exp Palliative Care/(10110)
#6	(end-of-life or terminal or palliative) adj2 (treatment* or therap* or care or decision*).mp. (13241)
#7	palliative.mp. (12647)
#8	resuscitat*.mp. (1815)
#9	exp Treatment Withholding/(457)
#10	((ethic* or decision*) adj5 (neonatal intensive care or NICU)).mp. (54)
#11	exp Decision Making/(91199)
#12	decision*.mp. (188894)
#13	deciding.mp. (6587)
#14	exp ETHICS/(39675)
#15	ethic*.mp. (73725)
#16	(moral adj5 (challenge* or dilemma* or issue* or concern* or reservation* or attitude* or judgment*)).mp. (9528)
#17	exp judgment/(27792)
#18	practical wisdom*.mp. (333)
#19	exp Wisdom/(1733)
#20	phronesis.mp. (177)
#21	5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 (313873)
#22	4 and 21 (75)

Total: 75 Hits

Search strategy for CINAHL

Search Name: Extreme Prematurity_Ethics (KH/MS)	
Search Date: 22/06/2017	
ID	Search
#1	extreme premature infants
#2	((extremely or very) N1 ((prematu* or preterm or early or low-gestational-age) N1 (newborn* or neonate* or baby or babies or toddler* or infant* or child* or birth* or deliver*)))
#3	perivable
#4	peri-viable
#5	periviability
#6	peri-viability
#7	(limit* or threshold* or border*) N1 viability
#8	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7
#9	(end-of-life or terminal or palliative) N1 (treatment* or therap* or care or decision*)
#10	resuscitation orders
#11	resuscitat
#12	withholding treatment
#13	(ethic* or decision*) N5 (neonatal intensive care or NICU)
#14	S9 OR S10 OR S11 OR S12 OR S13
#15	S8 AND S14

Total: 69 Hits



Ludwig Boltzmann Institut
Health Technology Assessment