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DISSERTATION / DOCTORAL THESIS

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“Neonatology and Nudging: The Case of Professional Ethics“

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Academic Curriculum Vitae

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EDUCATION

2015 -	**PhD candidate in Philosophy, Applied Ethics** University of Vienna, Department of Philosophy
2012 – 2013	**Master of Arts in Politics, Philosophy & Health Economics (MA)** University College London, Department of Philosophy
2009 – 2012	**Bachelor of Honours in Religion, Philosophy and Ethics (BA)** King's College London, Department of Theology & Religious Studies
2009 – 2012	**Associateship King's College London (AKC)** King's College London independent cross-departmental degree in Theology and Religious Studies and its relationships with other unrelated disciplines
2004 – 2009	C.S. Lewis English Bilingual High School Matura: Mathematics (1), History (1), English (1), Slovak (1)
2007 - 2008	Minnehaha Academy Study abroad stipend in Minneapolis, United States
2000 – 2004	Metodova French Bilingual Middle School

WORK EXPERIENCE

2015 -	**Researcher in Health Policy and Bioethics at the Ludwig Boltzmann Institute for Health Technology Assessment,** Vienna, Austria
2014 -	**Slovak Foreign Aid Trainer of Kenya 2014: Innovative Methods in Teaching** Integra Foundation, Bratislava, Slovakia & Project for Beacon of Hope, Rongai, Kenya
2013 - 2015	**Senior Teacher of Philosophy and Civic Studies** C.S.Lewis Bilingual High School, Bratislava, Slovakia

PROFESSIONAL MEMBERSHIP

- Member of the Health Technology Assessment International Ethics Interest Group
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RESEARCH ACTIVITIES DURING THE COURSE OF DOCOTRAL STUDIES (2015-2019)

PUBLICATIONS

Peer reviewed publications making up the doctoral dissertation:

- **Stanak M.** (2019): Neonatology in Austria: ethics to improve practice, Medicine, Health Care and Philosophy. (in review)
- **Stanak M.**, Hawlik K. (2019): Decision-making at the limit of viability: The Austrian neonatal choice context, BMC Pediatrics. (accepted for publication – incoming proofs)
- **Stanak M.** (2019): Nudging in Neonatology: Practical Wisdom and Accountability for Reasonableness. International Journal of Technology Assessment in Health Care, 35(1), 5-9. doi:10.1017/S0266462318003732
- **Stanak M.** (2018): Professional ethics: the case of neonatology. Medicine, Health Care and Philosophy, https://doi.org/10.1007/s11019-018-9863-9.

Further publications related to the doctoral dissertation:

- Hofmann B., **Stanak M.** (2018): Nudging in screening: Literature review and ethical guidance. Patient Education and Counselling, 101:1561–1569, https://doi.org/10.1016/j.pec.2018.03.021.
- **Stanak M.**, Winkler R. (2015): Nudging – Behavioral Sciences applied to the Big Four Public Health issues and health inequalities. LBI-HTA Project No.: 83/Addendum. Vienna: Ludwig Boltzmann Institute for Health Technology Assessment.
- Hawlik K., **Stanak M.** (2017): Perinatal Care at the threshold of viability: Part I Resource planning for Neonatal Care Units: clinical outcomes and resource needs. LBI-HTA Project No.: 97a; Vienna: Ludwig Boltzmann Institute for Health Technology Assessment. (not included in the body of the project for its lack of focus on the goal of the doctoral dissertation and its length)

Further peer-reviewed publications unrelated to the doctoral dissertation:

- **Stanak M** , Wolf S, Jagos H, Zebenholzer K (2018): The impact of external trigeminal nerve stimulator (e-TNS) on prevention and acute treatment of episodic and chronic migraine: A systematic review Journal of Neurological Sciences (in review)
- Wolf S, **Stanak M** (2018): Allogeneic Mesenchymal Stem Cells for Crohn's Disease-associated Complex Perianal Fistulas: A Systematic Review. BMC Systematic Reviews (in Review)
- Rosian K, **Stanak M** (2018): Efficacy and safety assessment of lymphovenous anastomosis in patients with primary and secondary lymphoedema: a systematic review. Microsurgery (in Review)
- Zechmeister-Koss I., **Stanak M.**, Wolf S. (2018): The Status of Health Economic Analyses within the decision-making in Austria. WMW, Wien, https://doi.org/10.1007/s10354-019-0689-8
- Ettinger S, **Stanak M**, Szymański P, Wild C, Tandara Haček R, Erčević D, et al. Reply to: Comments on the authors' reply to the critical appraisal concerning "Wearable cardioverter defibrillators for the prevention of sudden cardiac arrest: a health technology assessment and patient focus group study". Med Devices (Auckl). 2019;12:129-131. DOI: 10.2147/MDER.S202581.
- Emprechtinger R., Fischer S., Hozer L.A., Klimek P., **Stanak M.**, Oikarinen H., Wild C. (2018): Methods to detect inappropriate use of MRI and CT for musculoskeletal conditions: A scoping review. Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen, 137:20-26
- Ettinger S., **Stanak M.**, Szymański P., Wold C., Hacek R.T., Ercevic D., Grenkovic R., Huic M. (2018): Authors' reply. Medical Devices: Evidence and Research, 11:203-2014, http://dx.doi.org/10.2147/MDER.S144048.
- **Stanak M.**, Erdos J., Hawlik K. (2018): Novel Surgical Treatments for GERD: Systematic Review of Magnetic Sphincter Augmentation and Electric Stimulation Therapy. Gastroenterology Research, 11(3):161-173, doi: https://doi.org/10.14740/gr1024w.
- Ettinger S., **Stanak M.**, Szymański P., Wold C., Hacek R.T., Ercevic D., Grenkovic R., Huic M. (2017): Wearable cardioverter defibrillators for the prevention of sudden cardiac arrest: a health

technology assessment and patient focus group study. Medical Devices: Evidence and Research;10:257–271, http://dx.doi.org/10.2147/MDER.S144048.

Further publications unrelated to the doctoral dissertation:

- **Stanak M.**, Grössmann N. Strohmaier C. (2019): 177Lu-PSMA Therapy in Patients with Metastatic Castration-Resistant Prostate Cancer. Decision Support Document No. 118, Vienna: Ludwig Boltzmann Institute for Health Technology Assessment.
- Chiarolla E., Orso M., Goetz G., **Stanak M.**, Perrini M.R., Amicosante A.M.V., Wild C., Jefferson T. (2019): Update on: Wearable cardioverter-defibrillator (WCD) therapy in primary and secondary prevention of sudden cardiac arrest in patients at risk. Decision Support Document No. 103/Update, Vienna: Ludwig Boltzmann Institute for Health Technology Assessment.
- **Stanak M.**, Wolf S., Jagoš H. (2018): External stimulation of the trigeminal nerve for the prevention and treatment of episodic and chronic migraine. Decision Support Document No. 114, Vienna: Ludwig Boltzmann Institute for Health Technology Assessment.
- **Stanak M**., Wolf S. (2018): Externe Stimulation des Trigeminusnervs zur Prävention und akuten Behandlung von episodischer und chronischer Migräne (Cefaly®). HTA-Newsletter September 2018.
- Rosian K, **Stanak M.** (2018): Lymphovenous anastomoses in patients with primary and secondary lymphoedema. Decision Support Document No. 110, Vienna: Ludwig Boltzmann Institute for Health Technology Assessment.
- Wolf S., **Stanak M.** (2018): Allogeneic mesenchymal stem cells for Crohn's Disease-associated complex perianal fistulas. Decision Support Document No. 111, Vienna: Ludwig Boltzmann Institute for Health Technology Assessment.
- Winkler R., **Stanak M.** (2017): HTA und Deliberation – für legitime(re), transparente(re) und gerechte(re) Entscheidungen im Gesundheitswesen. HTA-Newsletter September 2017.
- Fischer S., **Stanak M**. (2017): „Social Return on Investment: Outcomes, Methods and Economic Parameters. LBI-HTA Project No.: 96; Vienna: Ludwig Boltzmann Institute for Health Technology Assessment.
- **Stanak M.,** Hawlik K. (2017): Electric stimulation therapy (EST) in patients with gastroesophageal reflux disease (GERD). Decision Support Document No. 104, Vienna: Ludwig Boltzmann Institute for Health Technology Assessment.
- Ettinger S., **Stanak M.**, Huic M., Hacek R.T., Ercevic D., Grenkovic R., Wild C. (2016): Wearable cardioverter-defibrillator (WCD) therapy in primary and secondary prevention of sudden cardiac arrest in patients at risk, Decision Support Document Nr. 103; Vienna: Ludwig Boltzmann Institute for Health Technology Assessment.
- Erdös J., **Stanak M.** (2016): Magnetic Sphincter Augmentation Device (MSAD) in patients with gastroesophageal reflux disease (GERD). Decision Support Document No. 101; 2016. Vienna: Ludwig Boltzmann Institute for Health Technology Assessment.

ORAL/POSTER PRESENTATIONS

Oral presentations related to the doctoral dissertation:

- **Stanak M.** (2018): Choice architecture, Nudging, and NIPT. NIPT event of LBI-HTA. Vienna: 09.10.2018
- **Stanak M.**, Hawlik K. (2018): Professional Ethics at Neonatal Intensive Care Units, ESPMH 2018, Annual Meeting; Lisbon: 01-05.06.2018.
- **Stanak M.**, Hawlik K. (2018): Professional Ethics at Neonatal Intensive Care Units, HTAi 2018, Annual Meeting; Vancouver: 01-05.06.2018.
- **Stanak M.**, Hofmann B. (2018): Nudging in screening: Literature review and ethical guidance, Theologie und Medizin Konferenz, Vienna 26-27.01.2018.
- **Stanak M.** (2017): Nudging in Public Health: Accountability for Practical Wisdom. PGBC 2017, Oxford, 04.-05.09.2017.

Oral presentations unrelated to the doctoral dissertation:

- Panel: Imaz-Iglesia I., Moga C., **Stanak M.**, (2018): Addressing The Conundrum Of Inclusion And Quality Appraisal Of Case Series Studies, HTAi 2018, Annual Meeting; Vancouver: 01-05.06.2018.
- Fischer S., **Stanak M.** (2018): Lohnt sich die Investition in die Gesundheit von Kindernund Jugendtlichen? 21. Wossenschaftliche Jahrestagung der ÖGPH; Vienna, 23-24.11.2018.
- Ettinger S., Mayer J., **Stanak M.**, Wild C. (2017): Patient Involvement in European HTA: Focus Group with Cardiac Patients. HTAi 2017, Annual Meeting; Rome: 17-21.06.2017.

Poster presentations related to the doctoral dissertation:

- **Stanak M.**, Hawlik K. (2018): Communication with Parents at Neonatal Intensive Care Units, HTAi 2018, Annual Meeting; Vancouver: 01-05.06.2018.
- **Stanak M.** (2017): Nudging in Public Health: Accountability for Practical Wisdom. HTAi 2017, Annual Meeting; Rome: 17-21.06.2017.
- **Stanak M.** (2016): Nudging in the big found and health inequity. 9th European Public Health Conference; Vienna, 09.-12.11.2016.
- **Stanak M.** (2016): Nudging: Behavioural Sciences Applied to the Big Four Public Health Issues and Health Inequalities. ÖGPH Conference; Vienna, 09.-12.11.2016.

Poster presentations unrelated to the doctoral dissertation:

- **Stanak M.**, Hawlik K. (2018): Electric stimulation therapy (EST) in patients with gastroesophageal reflux disease (GERD), EBM Congress, Annual Meeting; Graz: 08-10.03.2018.
- Ettinger S., Mayer J., **Stanak M.**, Wild C. (2016): Piloting patient involvement strategies in European HTA: a focus group approach with cardiac patients. LBG Meeting for Health Sciences; Wien, 28.-29.11.2016.
- Ettinger S., **Stanak M.**, Huic M., Hacek R.T., Ercevic D., Grenkovic R., Wild C. (2016): Wearable cardioverter-defibrillator therapy in primary & secondary prevention of sudden cardiac arrest in patients at risk. EBM Congress; Hamburg, 03.-05.03.2016.

TEACHING ACTIVITIES AND PRIZES

- Lecture series (2019) at the Medical Faculty of the Comenius University, Bratislava, Slovakia on Ethics in Health Technology Assessment.
- Best student poster award for the poster on Nudging in Public Health: Accountability for Practical Wisdom. HTAi 2017, Annual Meeting; Rome: 17-21.06.2017.

LANGUAGES

Slovak - native speaker
English - near native/ fluent
German - basic communication skills
Spanish – very good command
French - good command
Koine Greek - good command

Synopsis of the Publications/Manuscripts

Chapters 1-4 making up the dissertation project:

Chapter 1: *Decision-Making at the Limit of Viability: The Austrian Neonatal Choice Context*

- Stanak M, Hawlik K (2019). Decision-Making at the Limit of Viability: The Austrian Neonatal Choice Context. BMC Pediatrics. http://doi.org/10.1186/s12887-019-1569-5 (accepted for publication –proofs stage) OPEN ACCESS publication
- Michal Stanak drafted the outline of the study, initiated the literature search, and wrote all the drafts of the manuscript. Katharina Hawlik revised the outline of the study, reviewed the included literature, and thus assured quality of the manuscript.

Chapter 2: *Professional Ethics: The Case of Neonatology*

- Stanak M (2018). Professional Ethics: The Case of Neonatology. Medicine, Health Care and Philosophy. 22: 231-238. https://doi.org/10.1007/s11019-018-9863-9. OPEN ACCESS publication
- Michal Stanak drafted the manuscript at its every stage.

Chapter 3: *Nudging in Neonatology: Practical Wisdom and Accountability for Reasonableness*

- Stanak M (2019). Nudging in Neonatology: Practical Wisdom and Accountability for Reasonableness. International Journal of Technology Assessment in Health Care. 35(1):5-9. https://doi.org/10.1017/S0266462318003732. REPRINTED WITH PERMISSION
- Michal Stanak drafted the manuscript at its every stage.

Chapter 4: *Neonatology in Austria: Ethics to Improve Practice*

- Stanak M (2019). Neonatology in Austria: Ethics to Improve Practice. Medicine, Health Care and Philosophy. (in review with the ESPMH journal of Medicine, Health Care and Philosophy)
- Michal Stanak drafted the manuscript at its every stage.

Chapters 5 and 6 representing further publications related to the dissertation project:

Chapter 5: *Nudging: Behavioral Sciences Applied to the Big Four Public Health Issues and Health Inequalities*

- Stanak M, Winkler R (2015). Nudging – Behavioral Sciences Applied to the Big Four Public Health Issues and Health Inequalities. LBI-HTA Project No.: 83/Addendum. Vienna: Ludwig Boltzmann Institute for Health Technology Assessment. OPEN ACCESS REPORT
- Michal Stanak drafted the outline of the study, initiated the literature search, and wrote all the drafts of the manuscript. Roman Winkler revised the outline of the study, reviewed the included literature, and thus assured quality of the manuscript.

Chapter 6: *Nudging in Screening: Literature Review and Ethical Guidance*

- Hofmann B, Stanak M (2018). Nudging in Screening: Literature Review and Ethical Guidance. Patient Education and Counselling. 101:1561–1569, https://doi.org/10.1016/j.pec.2018.03.021. REPRINTED WITH PERMISSION
- Björn Hofmann drafted the outline of the study, initiated the literature search, and wrote all the drafts of the manuscript. Michal Stanak drafted the theoretical section on nudging, revised the outline of the study, reviewed the included literature, revised the draft, and thus assured quality of the manuscript.

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Preamble

The research project at hand is an overlap between three distinct fields: health policy, behavioral sciences, and moral philosophy. Based on a systematic literature search and in-depth interviews, the project aims to analyze the particular clinical reality of the Austrian neonatal context. It examines the ethical challenges present in the neonatal profession, including the challenges related to the notion of nudging. Furthermore, it aims to provide a normative framework of virtue ethics and accountability for reasonableness that are to guide the use of nudging. The project consists of four main publications (one of which is still a manuscript in review) and two further publications that are related to the doctoral dissertation and discuss the topic of nudging in the field of public health. The four core publications attempt to answer the following research questions:

1. What is the neonatal decision-making context at the *limit of viability* in Austria?
2. What ethical challenges do Austrian neonatal professionals encounter at their work around the *limit of viability*?
3. Is there a role for ethics – and virtue ethics in particular - in the neonatal profession?
4. Is there a role for nudging in the decision-making context around the *limit of viability*?
5. What normative framework can guide the use of the tool of nudging?

Chapter one entitled *Decision-making at the Limit of Viability: The Austrian Neonatal Choice Context* aims to answer research question one and thus to set the empirical stage for the analysis that follows. It is published in BMC Pediatrics for the sake of taking a step towards the target audience of the pediatric/neonatal profession. This publication is also part of a larger health technology assessment (HTA) project done at the Ludwig Boltzmann Institute (LBI) for HTA that aimed to provide decision support to the Viennese Hospital Association reporting on outcomes, resource needs, decision-making strategies, and ethical challenges at the *limit of viability* (weeks 22-25 of gestation). Chapter one thus focuses on the behavioral aspects that play a role in the neonatal shared decision-making and it concludes that professional biases, parental understanding, and the process of information giving possibly influence survival and neurodevelopmental impairment (NDI) outcomes. That happens, for instance, via institutions that create self-fulfilling prophecies by recommending intensive/palliative care based upon their institutional statistics, yet those vary considerably among high-income countries. Hence, labelling an extremely preterm infant by the gestational week was shown to skew the estimates for survival while the process of information giving was shown to be subject to framing effect and other cognitive biases.

Chapter two entitled *Professional Ethics: The Case of Neonatology* is an analysis of the explicit ethical dilemmas encountered in a neonatal intensive care unit (NICU) approached through the perspective

of virtue ethics. It is published by the European Society for Philosophy of Medicine and Health Care (ESPMH) in their journal of Medicine, Health Care and Philosophy and it aims to answer research questions two and three. In this publication, it is argued that neonatal professionals encounter many ethical challenges especially when it comes to interventions at the *limit of viability*. Using Martha Nussbaum's distinction between the tragic and the obvious questions, it is argued that at times, these ethical dilemmas in neonatology are tragic (i.e. there is no alternative open to us free from serious moral wrongdoing) and they require a particular set of intellectual and moral virtues. Intellectual virtues of episteme and phronesis, together with moral virtues of courage, compassion, keeping fidelity to trust, and integrity were highlighted as key virtues of the neonatal professional. It is furthermore argued that recognition of the role of ethics requires the recognition that answering the obvious question (what shall we 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 organizational support can help in allowing the team members to recognize the ethical dilemmas, avoid moral distress, and improve team cohesion and the quality of care provided. It is argued that only when the organizational structures allow ethical dilemmas to be recognized, adequate decisions can be made.

Chapter three entitled *Nudging in Neonatology: Practical Wisdom and Accountability for Reasonableness* answers research questions four and five by examining the role of nudging in the shared decision-making in neonatology and it provides a moral framework for nudging. Published in the International Journal of Technology Assessment in Health Care, it is argued in this publication that nudging is not morally neutral. There are two key sources of ethical issues at the heart of nudging where the first one concerns the lack of transparency, while the second concerns the background value judgments that are imminent whenever nudging is used for achieving a particular end. To solve the underlying conflict, a virtue ethics approach combined with the accountability for reasonableness framework is suggested to guide the use of the tool of nudging. It concludes that NICU professionals ought to use nudging transparently in line with their act of profession and their practically wise judgment.

Chapter four entitled *Neonatology in Austria: Ethics to Improve Practice* in an analysis of the implicit ethical dilemmas encountered in the NICU, namely the dilemmas surrounding nudging. This manuscript attempts to answer research questions number three, four, and five and thus to tie the loose ends from the three publications above. It is currently in review in the same ESPMH journal. It attempts to elucidate the less explicit ethical challenges related to the notion of nudging in the neonatal practice. It analyzes the definition of nudging and highlights the complications that nudging

brings to the NICU decision-maker. It questions whether nudging remains to deliver upon its promise of libertarian paternalism by preserving freedom of choice and, at the same time, making people better off. Finally, it argues that the role of ethics needs to be recognized more - with the focus on the role of virtue ethics - in order to improve the practice of neonatal medicine.

Chapters five and six are publications that do not make up the doctoral dissertation, but they are related to it. The two chapters represent my further co-authored work in the general field of nudging in public health and philosophy.

Chapter five entitled *Nudging: Behavioral Sciences Applied to the Big Four Public Health Issues and Health Inequalities* is an Addendum to a LBI-HTA report that critically discusses the definition and the current nudging practices with respect to the public health topic of big four health issues (smoking, alcohol consumption, nutrition, and physical activity). Furthermore, it analyses the links between nudges and health inequalities.

Chapter six entitled *Nudging in Screening: Literature Review and Ethical Guidance* published in Patient Education and Counselling examines the role of nudging in another public health topic, namely screening. Nudging tends to be used to assure high uptake and good outcome of screening programs, but it has been criticized for being paternalistic, undermining free choice, and shared decision-making. Hence, this publication explored a) nudging strategies identified in screening, b) arguments for and against nudging; and on basis of this, it c) suggested a tentative conclusion on how to handle nudging in screening.

Regarding the list of references used, each chapter contains its own list.

Chapter 1

Decision-making at the limit of viability: The Austrian Neonatal Choice Context

OPEN ACCESS PUBLICATION WITH BMC (PART OF SPRINGER NATURE)

Full publication to be found in the journal of BMC Pediatrics (currently awaiting final proofs)

Abstract

Background: We aimed to explore the shared decision-making context at the *limit of viability* (weeks 22-25 of gestation) through analyzing neonatologist's communication strategies with parents and their possible impact on survival and neurodevelopmental impairment (NDI) outcomes.

Methods: A mixed methods approach was applied where a systematic literature search and in-depth semi-structured interviews with five heads of neonatology departments and one clinical ethicist from the Austrian context were integrated into a literature review. The aim was to identify decision practice models and the choice context specific to Austria.

Results: Professional biases, parental understanding, and the process of information giving were identified as aspects possibly influencing survival and NDI outcomes. Institutions create self-fulfilling prophecies by recommending intensive/palliative care based upon their institutional statistics, yet those vary considerably among high-income countries. Labelling an extremely preterm (EP) infant by the gestational week was shown to skew the estimates for survival while the process of information giving was shown to be subject to *framing effect* and other cognitive biases.

Conclusion: Communication strategies of choice options to parents may have an impact on the way parents decide and hence also on the outcomes of EP infants.

Key words: neonatology, NICU, limit of viability, decision-making, choice context, communication strategies

1 Background

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

The ways in which EP births are currently managed include prevention, preparation for the delivery, as well as intensive and palliative (comfort) care treatment options post-delivery. It is particularly between weeks 22 to 25 of gestation - the *limit of viability*, when shared decision-making with parents concerning intensive and comfort care options is at stake. The intensive care options include the application of surfactant therapy, intubation, and supportive ventilation, while comfort care options aim at improving an infant's quality of life (QoL), treating symptoms, and minimizing pain and suffering [5].

Limit of viability is the point in foetal development at which the EP infant has a chance for extra-uterine survival [6]. This definition of the *limit of viability* is changing over time due to improvements in treatment and care. These improvements lead also to better survival and neurodevelopmental impairment (NDI) outcomes that differ between institutions and countries [7]. However, there is a considerable consensus among high income countries that with intensive care, most infants born after 25 weeks and 0 days (25+0) of gestational age (GA) will survive, while there is a little chance for survival and survival without severe impairment in infants born below 22+0 weeks of GA [6]. The probability of survival and survival without impairment increases significantly over these few weeks (22+0 to 25+6) [8]. In the context of intensive and comfort care, determining this point with as much precision as possible is important in order 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 hand.

Finding the agreement during shared decision-making with parents of EP infants before and after the delivery is one of the key tasks of the Neonatal Intensive Care Unit (NICU) team. This decision-making is occurring at the backdrop of a specific cultural, socio-economic, and religious context and because the content that needs to be communicated is highly sensitive, it places even more emphasis on the form of communication. However, neonatologist's communication strategies with parents in preparation for delivery as well as after delivery are not addressed in current guidelines (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 sciences [9] and hence it is assumed that the same applies to the NICU context of choice. The design in which the options of choices are communicated is assumed to have an impact on the way parents decide and hence on the survival and NDI outcomes of EP infants.

In this review, we aimed to explore the shared decision-making context through reviewing the general literature and comparing it to the specific Austrian context in which we conducted qualitative interviews with the heads of NICUs and a clinical ethicist. This paper is a shortened version of one part of a larger health technology assessment (HTA), which particularly focuses on the analysis of the neonatologist's communication strategies with parents and their possible impact on survival and NDI outcomes of EP infants. The HTA was conducted to provide decision support for resource planning of NICUs in Austria and additionally included the assessment of outcomes, resources, and ethical challenges [10, 11].

2 Methods

A mixed methods approach was applied. In the first step, a systematic literature search was conducted to identify the most relevant sources applying the MIP (Methodology, Issue, Participants) question and inclusion criteria as listed in the Table 1. Secondly, interviews with the heads of departments of neonatology of five perinatal care centres and a clinical ethicist working at a NICU were conducted to gather data specific to the Austrian neonatal context. Data from the systematic search as well as the interviews were integrated into a literature review. Each part of the text thus includes data from the literature review that reflects the general state of the neonatal literature and supports it by the context specific data from interviews (presented in the running text or standing alone as quotes).

Table 1: Methodology, Issue, Participants (MIP), and inclusion criteria for systematic search

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

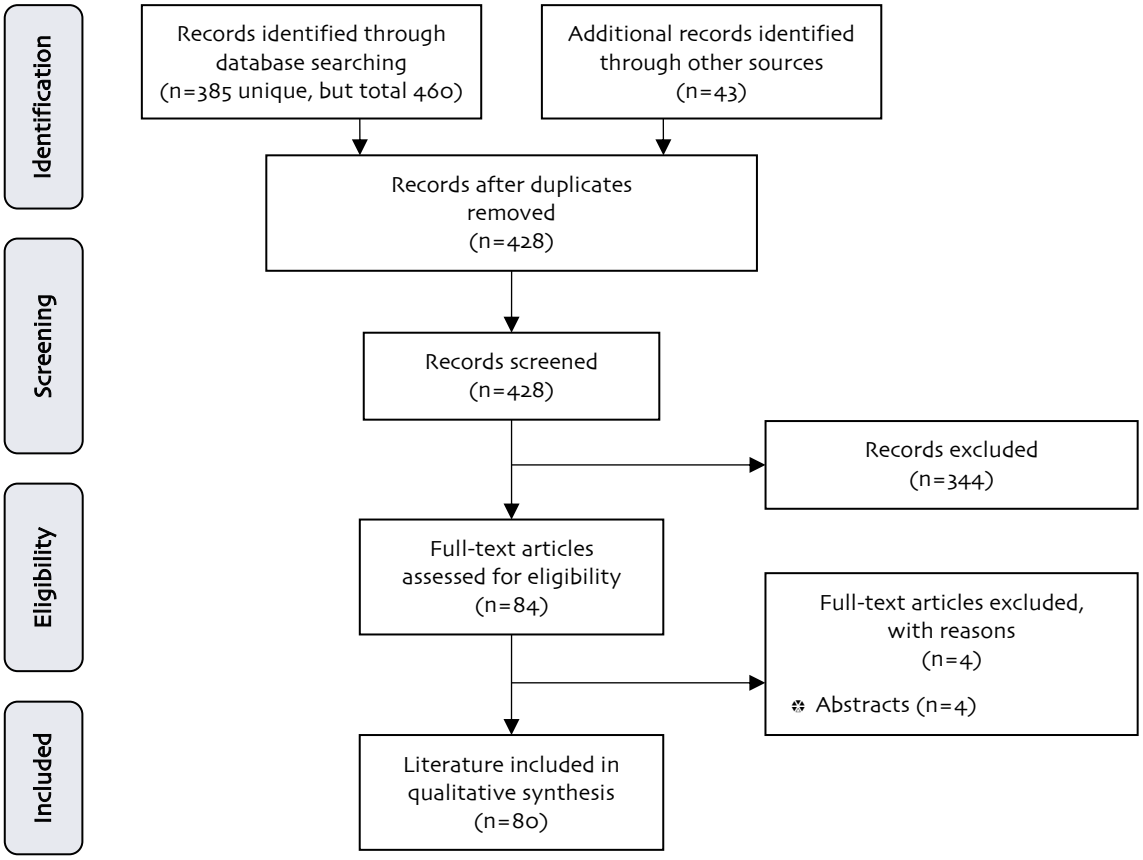
2.1 Systematic literature search

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. The reason for limiting the year of publication to 1990 was to limit the volume of hits and to focus on the most up-to-date decision models in neonatal care. After deduplication, overall 385 citations were included. The specific search strategy employed can be found in the availability of data and materials section. In addition, a hand search of literature (web-search) was performed and yielded additional 43 sources, resulting in overall 428 hits. 80 publications were finally selected for the analysis (see Figure 1: Flow chart of study selection (PRISMA Flow Diagram)).

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



The data retrieved from the 80 publications selected for the analysis were not extracted into extraction tables, but were analysed according to content analysis where all the topics relevant to the theme of biases in neonatal decision-making were included. In terms of literature selection, 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.

2.2 Interviews

Six semi-structured interviews with five heads of neonatal departments (out of the total of seven departments in Austria) and one clinical ethicist working in a NICU were conducted with the aim of exploring the choice context specific to Austria. Ethics approval was not requested for interviewing stakeholders based on section 15b, subsection 3a, of the Viennese Law on health institutions.

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 code tree in Table 2.

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.

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

To analyse the transcripts, a combination of open coding and structured thematic analysis was applied [12]. This analysis was performed beginning with fragmentation and open-coding of each transcript. Thereby, every fragment received a code such as a word or a short sentence to identify themes.

The main codes and themes were organised in a code-tree. In addition, the themes from the interview topic list served as a structural GL 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).

Table 2: Code tree

Overall theme	Code	Sub code	Coding example
Decision-making	Decision models	Guidelines	*"we follow the guidelines ... of the ÖGKJ, uh and uh ... we treat routine- really routinely at 24+0, so there's no question about that if we treat it or not"* (Interviewee 4)

		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."* (Interviewee 6)
		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."* (Interviewee 1)
		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 canmeet immediately and you have a a written m paper afterwards m regarding the discussion and also the decision ..."* (Interviewee 2)
	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."* (Interviewee 2)
		Paternalism	*"we sometimes really have to fall back and make a paternalistic decision."* (Interviewee 5)
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."* (Interviewee 2)
		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) ..."* (Interviewee 1)
		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 ..."* (Interviewee 3)
	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"* (Interviewee 2)
	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"*. (Interviewee 5)
		Moral distress	*"nurses sometimes want to stop therapy. because of futility and futility is a very difficult thing."* (Interviewee 1)
		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'."* (Interviewee 3)

3 Results: Communication with parents - Biases influencing outcomes

The following section is structured in categories of professional biases, parental understanding, and information-giving and choice.

3.1 Professional biases

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. Parents have to decide based on the content – information provided by the NICU professionals, and the form – the way 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 bias [13].

3.1.1 Institutional bias

There are differences in results of neonates between countries and more importantly between institutions (see Table 3) [14]. One of the explanations comes down to the role of social norms and institutional biases. 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" [15]. Such a path creates self-fulfilling prophecies because such defaults both reflect on the social norms as well as create them [16].

With respect to the institutional differences as well as the differences in social norms, Interviewee 5 describes a situation of a Swiss couple delivering an EP infant in Austria. While there is a consensus among all NICUs in Austria that intensive care starts by default in 24th week of gestation and if parents decide so, intensive care is also routinely delivered in 23rd week [17], Interviewee 5 states that in Switzerland and the Netherlands, by default, comfort care is delivered in 23rd week of gestation, because

> *"they are really more conservative… I remember we had a Swiss couple travelling through who did not want to deliver their baby here, but then she had a premature rapture of membranes at 23 weeks plus something…and for her, it was completely normal not to go for this baby. Then we talked a lot with this family and at the end, we convinced them to actively go for this baby and they had a wonderful outcome."*

The presence of such default bias 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 [18]. The default option created a norm that the participants had the tendency to follow.

Table 3: Recommendations According to Week of Gestation as of 2015 (German speaking countries update) [14]

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 (Updated according to Austrian GL) [17]	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 (Updated according to German GL) [43]	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
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 (Updated according to Swiss GL) [29]	2011	CC	CC	PW	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.

3.1.2 Personal bias

Not only institutional, but also personal biases may have an impact on the assessment of viability by the NICU professionals and subsequently, on the survival and NDI outcomes. This can be observed on surveys and assessments of hypothetical scenarios, where the variety of conclusions points to the presence of personal attitudes and biases. While NICU professionals in one Australian narrative review underestimated survival and positive outcomes of infants between weeks 22 and 26 of GA [19], in other Australian and US surveys, they also overestimated major neurosensory disability at both week 24 and 28 of GA [20] and long term disability [21]. To the contrary, however, UK NICU professionals in a questionnaire survey overestimated infant survival and underestimated intact infant survival rate [22]. Also, 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 to speed up the process of development of the infant [23]. Furthermore, 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 [24]. In this way, personal biases influence the chances for survival of extremely premature infants.

3.1.3 Informational bias

NICU professionals make their decisions also based upon their own informational 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."* (*Interviewee 2*)

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 ten EP infants were shown to 17 neonatal fellows at 20 seconds, two minutes, and five 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 [25].

Secondly, labelling a periviable infant by the gestational week was shown to skew the estimates for survival and uncover the informational bias of the NICU teams. 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 [26]. Furthermore, in a US survey among obstetrician-gynaecologists, GA was weighted more heavily than parental resuscitation preferences [24], even though the ultrasound evidence of GA may vary by 15% and the gestational weight estimate by two weeks [27].

Reliance of on very early ultrasound evidence for GA measurement was also reported in the interviews. Interviewee 5 states that they have confidence in the GA measurement if it comes from the obstetricians within the hospital, because

> *"…with our obstetricians…normally, we know very well the exact date of birth because most of our NICU patients have a very early ultrasound…So, normally, we have very good data there."*

Furthermore, 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 [28]. Another survey with hypothetical case scenarios showed that after the educational intervention, respondents improved significantly in the accuracy of their survival and disability estimates [21]. The presence of professional biases – institutional, personal, or informational – thus needs to be acknowledged as it unavoidably influences the survival and NDI outcomes of EP infants in respective institutions.

3.2 Parental understanding

Because preterm infants cannot communicate their preferences autonomously, decisions must be made by proxy [29]. 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 [30]. In the Austrian NICU decision-making context, ethics committees are in place in all the centres included in the analysis and while some are organized *ad hoc* by the head of the respective NICU in challenging cases (as stated by Interviewee 5), others have established standard operating procedures that are being followed (as stated by Interviewees 4 and 6). 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. Parental decision-making is, however challenging, as Interviewee 4 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."*

At the same time, the NICU team needs to work in accordance with the parents to the extent possible, as Interviewee 1 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."*

When communicating with parents, however, one size does not fit all as 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 [13, 31]. Parents,

however, seem to have needs that are so heterogeneous that acting by the principle is not sufficient. As stated by the Interviewee 5 and suggested in the literature, some parents require all the detail possible [13], while others would not be influenced at all by the information provided because of their own value frameworks in place [32].

When making a decision, parents are put under extreme stress [33] and some prefer that the competent NICU professional decides on their behalf [9, 19]. Also, due to the recent dramatic demographic change and the rise in the migrant population, the Austrian NICU professionals face families who have never encountered the idea of *shared decision-making* and so as Interviewee 5 puts it,

> *"…we sometimes really have to fall back and make a paternalistic decision."*

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.

> *"We need to develop a sense of who these parents are in order to ensure effective communication for both sides."* (Interviewee 5)

Interviewee 2 further states that if the communication from the side of NICU professionals is personal and empathetic, it is nearly always possible to work 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...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…"*

As supported by both the literature and the interviews, the data communicated to the parents need to be personalized because parents have different information needs to be begin with.

3.2.1 Real life data and psychological support

There is, however, also a discrepancy between the information that parents can be provided in the NICU and the 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 QoL their child would have, or whether their child would be happy [13].

In case of EP infants, the term QoL is particularly debatable. While there are generic QoL measures (such as 36-Item Short Form (SF-36) or EuroQol five dimension scale (EQ-5D) [34]) and health-related quality of life (HRQoL) measures developed for adults, and older children, there are no established measures for EP infants [35]. There are even family QoL measures in place such as the Family Quality of Life Scale (FQOL) [36]. For EP infants, Boss, Kinsman, and Donohue 2012 suggest that HRQoL

metrics on emotional and social functioning for adults and paediatric patients "could be adapted to focus on the role of a neonate in the context of a family unit, as with caregiver ratings of their ability to bond with infant" [35]. Furthermore, they suggest that physical domains such as "pain, energy/neurobehavior, sleep and physical symptoms could be adapted from existing NICU metrics" for instance, the Neonatal Infant Pain Scale, Neonatal Care Unit Network Neurobehavioral Scale, Polysomnography, or Nursing-Child Assessment Feeding Scale [35]. Standardizing the EP infant's QoL or HRQoL measures could prove beneficial in preventing the neonatal QoL discussion to be narrowed down to analysing only the infant's physical and cognitive impairments.

Janvier, Barrington, and Farlow 2014 further 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 [13]. 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 [13]. 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 [13].

The content of psychological support was not discussed in the interviews, but with respect to psychological support for families with EP infants, the Interviewees reported a homogenous use across all five perinatal care centres. All centres reported that there was a psychological support for parents. In the centre of Interviewee 5, one psychologist supported the family through the entire hospital stay, whereas in the centre of Interviewee 1, the family was transferred from the obstetrics psychologist to the NICU psychologist. Furthermore, Interviewee 3 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, Interviewee 5 reminded that counselling also comes from nurses, who spend a lot of time with parents at the bedside.

Because parents come from different backgrounds and have different information needs, the communication from the side of NICU professionals needs to adjust. Moreover, apart from medical data about outcomes, psychological support and real life psychological data about the impact of having an EP infant need to be communicated to the parents [13].

3.3 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. As the Interviewee 5 puts it that is their NICU,

"parents get an idea of the medical 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 the process of passing the information to parents, however, different cognitive biases are at play (see Table 4), in particular, a *framing effect*.

3.3.1 Framing effect

Framing effect 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 revealed 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 [37].

When communicating with parents, *framing effect* of how the data is presented is inevitable. Communicating proportional outcomes constitutes the majority of information that is being given to parents, however, many individuals do not understand percentages [13]. Patients tend to 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. Even though the risk is smaller in the latter, patients presumably tend not to choose that procedure because 120 is a larger number than 24 [13].

The question of *framing effect* did not come up in any of the interviews, but for the sake of better communication with parents, an instant translating system called Videodolmotsch that interacts with a real interpreter via a screen was used in the centre of Interviewees 5 and 6.

„„we always discuss with parents, of course, which is difficult if you are confronted with families who do not have the cultural, religious, or intellectual basis to decide. We still discuss it with them. We have a Videodolmetsch system where we at least try to show those parents, or pregnant women, what the odds of complications and NDIs are. But normally, it is like "Please do everything for our baby"." (Interviewee 5)

The attitude of parents to save the EP infant at all costs is, as shown above, context specific as it is subject to the respective societal norms. The impact of framing seems to persist nonetheless as a randomized survey found a trend towards a *framing effect* on the treatment preference in NICU decision-making. 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 [38, 39]. *Framing effect* can also be seen when presenting a list of complications of an intervention, although there is also evidence against it [40]. 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 [13]. Other cognitive biases that have an impact on the decision-making at the *limit of viability* are described in Table 4.

Table 4: Cognitive biases and their influence on decision-making [13]

Cognitive biases	**The possible influence of the bias on the communication between NICU professionals and parents**
Anchoring effect: 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.
Focusing effect: 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.
Availability effect: estimation of a probability of an event that 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.
Effective forecasting: 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.
Loss aversion: tendency to strongly prefer avoiding losses to acquiring gains (the loss of 100 EURO causes more loss of satisfaction that 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.

4 Discussion

This literature review outlined the current evidence on decision-making practices, especially on neonatologist's communication strategies at the *limit of viability*. Data from the systematic literature search were supported by specific data from the interviews with Austrian heads of NICUs and a clinical ethicist. The overlap between the literature reviewed and the content of the semi-structured interviews is the main advance that this paper adds on the existing literature. The categories of biases found in the literature were also found to be present in the Austrian neonatal context, namely professional biases, parental understanding, and the process of information giving were identified as aspects possibly influencing survival and NDI outcomes.

Outcomes and biases

Especially within the *grey zone*, the difference in practices may lead 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 infants [29]. These outcomes then become part of institutional statistics that further influence counselling and so the outcomes based on historical data influence the present 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 4) are understood to be in part responsible for the variation in outcomes between hospitals.

As behavioural sciences argue, 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 [41]. 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 [13]. 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 for neonatologists in terms of communication strategies with parents as those may influence outcomes as well [42]. It is argued here that there is a need for trainings 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.

4.1 Limitations

In terms of limitations to this literature review, we acknowledge, firstly, that we limited the search language to German and English, which presumably led to leaving out of some literature. Nonetheless, we consider the literature that we used to be robust enough to provide a good overview of the decision-making models in place.

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 we could not find a common denominator that would allow for comparison between the variety of studies. Hence, also no quality assessment or risk of bias tools were used.

5 Conclusion

Communication strategies of choice options to parents may have an impact on the way parents decide and hence also on the survival and NDI outcomes of EP infants. Professional biases, parental understanding, and the process of information giving were identified as aspects possibly influencing outcomes. For these reasons, it is important to address the impact of communication in the management GLs of EP infants as well as in in-house trainings for NICU professionals.

6 List of abbreviations

CRD – Centre for Reviews and Dissemination

EP – extremely preterm

EQ-5D – EuroQol five dimension scale

GA – gestational age

GL – guideline

HRQoL – health-related quality of life

HTA – health technology assessment

MIP – methodology, issue, participants

NDI – neurodevelopmental impairment

NICU – neonatal intensive care unit

QoL – quality of life

SF-36 – medical outcomes study 36-item short form

7 Declarations

7.1 Ethics approval and consent to participate

Ethics approval was not requested for interviewing stakeholders based on section 15b, subsection 3a, of the Viennese Law on health institutions. Verbal consent was given by all interview participants prior to recording, audio proof of verbal consent has been collected.

7.2 Consent for publication

No consent for publication was needed as all interview participants we anonymized.

7.3 Availability of data and materials

Search strategies as well as all data generated or analyzed during this study are included in this published report:

Stanak M, Hawlik K. Perinatal Care at the threshold of viability: Decision-making at the threshold of viability and ethical challenges at Neonatal Intensive Care Units (NICUs). LBI-HTA Project No.: 97b; 2017. Wien: Ludwig Boltzmann Institute for Health Technology Assessment.

7.4 Competing interests

Both authors declare no conflict of interests.

7.5 Funding

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Chapter 2

Professional Ethics: The Case of Neonatology

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Abstract

Neonatal professionals encounter many ethical challenges especially when it comes to interventions at the *limit of viability* (weeks 22 to 25 of gestation). At times, these challenges make the moral dilemmas in neonatology tragic and they require a particular set of intellectual and moral virtues. Intellectual virtues of *episteme* and *phronesis*, together with moral virtues of *courage*, *compassion*, *keeping fidelity to trust*, and *integrity* were highlighted as key virtues of the neonatal professional. Recognition of the role of ethics requires a recognition that answering the obvious question (what shall we do?) does not always suffice. Acknowledging the tragic question (is any of the alternatives open to us free from serious moral wrongdoing) 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 neonatology units, such organizational support can help in allowing the team members to recognize the ethical dilemmas, avoid moral distress, and improve team cohesion and the quality of care provided. Only when the organizational structure allows ethical dilemmas to be recognized, adequate decisions can be made.

Keywords

Neonatology, NICU, virtues, ethics support, organization, ethics committees

1 Introduction

In all situations of choice, we face what M. Nussbaum calls the *obvious question*: what shall we do? Sometimes, however, we also face, or should face, what she calls the *tragic question*: is any of the alternatives open to us free from serious moral wrongdoing (Nussbaum 2000)? The mere consideration of costs and benefits – as in a cost-benefit analysis (CBA) – helps answer the obvious question, but it often obscures the presence of the tragic one 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 (Nussbaum 2000). This distinction, however, is important as it makes us engage in a form of ethical reasoning that is distinct from the mere CBA. In the situations of neonatal intensive care unit (NICU) decision-making, it does not always suffice to find the answer to the obvious question only. At times, particularly in the ethically intense situations around the *limit of viability*, the tragic question concerning transgression of the moral law is at stake.

This experience of the tragic moral dilemma to which there is no clear solution poses a particular challenge to professional ethics of NICU teams. Of course, the ethics related aspects of the work in a NICU are by no means confined to the experience with the *limit of viability*, but the presence of ethics is more pronounced in the situations of tragedy that sometimes occur around this limit. The experience of the tragic is, however, not exclusive to the work in the department of neonatology or to clinical medicine at large. I want to suggest, however, that in neonatology, the experience of tragedy requires special attention. The reason is that NICU professionals operate around the *limit of viability* with vulnerable infants and parents as surrogate decision-makers. They make decisions about end of life right at its beginning at the age when technologies can prolong life without guaranteeing its quality. Hence, the main reasons that bring about tragedy are clinical uncertainty and ambiguity about best interest.

I believe that virtue ethics has a role to play in addressing the experience of tragedy and so in the following discussion, I explore the applicability of the virtue ethics framework to professional ethics using the case of neonatology. Having a virtues character has been argued to be a requisite for ethical medical practice in general (Pellegrino 2009). Pellegrino puts forth a particular set of virtues for the clinical profession as such, which are compatible also with the case of neonatology. However, I want to argue that for a NICU professional to develop as a moral agent, the organizational culture providing ethics support when the experience of tragedy is imminent is a prerequisite. In terms of the structure of this essay, I am going to explain the challenges that make the moral dilemmas at NICUs tragic, elaborate on the set of virtues required from the NICU professional, and conclude with stressing the need for the organizational culture to recognize the presence of tragedy.

2 Ethical challenges at NICUs

2.1 Background

The *limit of viability*, the issue at heart of this essay, is defined as the point in foetal development at which the infant has a reasonable chance of extra-uterine survival [3]. This definition of the limit changes over time due to improvements in treatment and the resulting improvements in outcomes that differ between countries [4]. Currently in high-income countries, there is a considerable consensus that with an active intervention, most infants born after 25 weeks and 0 days (25+0) of gestational age (GA) will survive, while there is little chance for survival and survival without severe impairment in infants born below 22+0 weeks of GA [3]. Around the limit, particularly in the *grey zone* of weeks 23+0 and 24+6, shared decision-making with parents is the strategy of choice. 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 burden on the infant and the family on the one hand (*non-maleficence*), yet to give sufficient chances for survival to the infant on the other hand (*beneficence*). Stratification of decision-making is outlined in Table 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.

Table 1: Stratification of decision-making at the limit of viability (Berger 2011)

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

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. That is not true in the *grey zone* (zones B and C). At this point, issues concerning uncertainty and best interest are the main sources of tragic moral dilemmas for NICU professionals.

2.2 Uncertainty

2.2.1 Assessment of baseline and outcome data

It is the knowledge of baseline and outcome data that provides the frame for discussions about active care versus comfort (palliative) care of NICU infants. The assessment of baseline data, however, is

marked with serious uncertainty. Foetal weight can vary as much as 15% and GA estimates vary depending on the assessment tools used (Kett 2015). 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 (Leuthner 2014). Also, the neonatologist's ability to predict survival based on baseline appearance data and early response is argued to be poor (Brett 2010). And, the assessment of outcome data is subject to gaps in knowledge as, after an educational intervention, NICU professional were more prone to resuscitate regardless of GA (Doucette et al. 2015).

2.2.2 Empirical and ethical uncertainty

Uncertainties about baseline and outcome data couple with the empirical uncertainly. It is unclear what it is like to live through the experience of comfort care, active treatment that leads to death, or active treatment that leads to neurodevelopmental impairment (NDI) (Leuthner 2014). This is further coupled with ethical uncertainty. The lack of clarity in these three categories of data (baseline, outcome, and empirical) invites value judgments to be made by NICU professionals.

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* (Dupont-Thibodeau et al. 2014). At times, NICU professionals seem to conflate these two meanings into one and they 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 quality of life (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+0 weeks of GA, an intervention can be considered qualitatively futile (Dupont-Thibodeau et al. 2014), but, depending on the GA estimate, the *grey zone* examples of weeks 23+0 and 24+6 of GA remain to be hard to discern. The baseline, outcome, and empirical uncertainties invite ethical uncertainty and respective value judgments to decide what is worth and what is not making the decision-making around the *limit of viability* tragic.

2.3 Best interest

Ambiguity about best interest of the infant is one of the key aspects of moral dilemmas encountered at NICUs. It is not clear what exactly 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 NICU teams as well as between the NICU teams and parents.

2.3.1 What is best interest?

The best interest principle is grounded in the idea of *beneficence*. The aim is to find out, lacking the opinion of those concerned, what would the given individuals choose themselves. Yet, due to the empirical uncertainly of what it is like to be a patient at a NICU, it is not fully knowable what is beneficial to a vulnerable infant. For instance, a Canadian study points to the lack of understanding of pain that extremely preterm infants go through while at NICUs. 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 (Gibbins et al. 2015). Hence, the lack of clear clinical facts on the experience in NICUs makes the best interest principle ambiguous.

Not only are the clinical facts about what exactly is beneficial in part unknowable, but the meaning of the word *best* is also inevitably connected to the person who evaluates the case. Different people may interpret the best interest of the extremely preterm infant differently at different times in history. While almost three decades ago, Down syndrome children were left to die because of their *unacceptable* outcomes, today, life-sustaining interventions are no longer considered optional in this segment of the population. The understanding of disability has changed with respect to Down syndrome and so the doctor's judgment of what the best interest for a Down syndrome infant is has changed as well. This is the case regardless of the fact that if children with Down syndrome were categorized according to the 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 (Dupont-Thibodeau et al. 2014). Thus, putting the NICU challenges into perspective, the future understanding of disability may change and hence influence the today's judgment of NICU professionals concerning best interest. Therefore, in order to prevent moral wrongdoing, as Berger suggests, the decision to withhold or withdraw life-sustaining therapies needs to be motivated by the desire not to inflict unnecessary suffering on the extremely preterm infant and not by the wish to prevent survival with disabilities (Berger 2011).

2.3.2 Whose best interest?

When deciding within the *grey zone*, parents as well as NICU professionals are expected to regard the best interest of their newborn child in the first place. But, this distinction between the best interest of the newborn and the best interest of the family is overly individualistic and hence questionable (Leuthner 2014). The best interest principle calls for negating all other interests except for the infant's self-regarding interest. However, when focusing on the infant's best interest individually, one tends to put it into contrast with best interests of the family (Leuthner 2014). Those, however, are interrelated and so what is best for the family has the tendency to be also best for the infant. Also for this reason, decisions within the *grey zone* tend to be left within the *zone of parental discretion* as the non-individualistic nature of the best interest principle puts the objective appeal to it into question (Gillam et al. 2017).

The above outlined two challenges make the experience of NICU professionals at the *limit of viability* fall under the category of tragedy because at times, none of the options available is free from serious moral wrongdoing.

3 Professional ethics

The professional ethics approach for analysing the normatively sensitive topic of NICU decision-making was chosen for the following reasons. Firstly, the NICU context very clearly highlights the role of agents, NICU professionals, in the value-laden process of decision-making. Particularly, the cases around the *limit of viability* show the need for prompt and tailored decisions that must be made on the spot against the backdrop of the list of above outlined uncertainties and ambiguities. NICU professionals thus must take a value stand when facing these challenges and discern what moral principles to follow and what moral principles to forgo in what situations. This puts their character into focus. Secondly, in the body of literature on ethics of NICUs, almost no mention of the role of virtues was found. Rights-based, utilitarian, or principlistic approaches dominate the field and none of them puts enough focus on agents who make moral decisions on the spot against the backdrop of their specific context. And thirdly, following the conviction of A.MacIntyre that virtues develop in practices (MacIntyre 2007), I want to suggest that it is not only clinical judgment, but also moral judgment that should come with expertise and that is required for acting well in the clinical practice of neonatology. There are character traits, virtues, that are at stake here and those are intellectual virtues of *episteme* and *phronesis* and moral virtues of *courage, compassion, fidelity to trust,* and *integrity*.

3.1 Intellectual virtues

The inevitability of uncertainty that NICU professionals at times experience further complicates the above outlined issues with discerning the best interest. For that reason, possessing the intellectual virtues of *episteme* and *phronesis* is key. Only the professional with quality understanding of the scientific, *epistemic*, data can build on this factual knowledge and work towards the goal of clinical practice in general and neonatology in particular - the good of the patient (MacIntyre 2007). Furthermore, because *phronesis* links intellectual and moral virtues, it is essential for the NICU professional for discerning the right course of action with regards to both scientific data as well as moral principles. It refers "to the reasoned capacity to act with regard to the things good for the patient—both technical and moral" (Pellegrino 2009). 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 [*phronetic*] judgment of the people on the spot." (President's Council on Bioethics 2005). The *phronetic* judgment is key also in the use of the following set of moral virtues particularly required in the practice of neonatology.

3.2 Moral virtues

Ambiguity about what the best interest is, combined with the unavoidability of surrogate decision-making bring about challenges to the professional ethics of the members of NICU teams. In the *grey zone*, these challenges occur at the backdrop of parental decision-making preferences. As a US qualitative study suggests, parents identified two factors that influence their preference to delegate decisions to the NICU team: high level of urgency and high level of medical expertise required (Weiss et al. 2016). Parents also identified four factors associated with their preference to retain control over decisions: high-perceived risk, high personal experience with the decision, involvement of foreign bodily fluids, and similarity to decisions that they perceived as part of the normal parental role (Weiss et al. 2016). Furthermore, according to an Austrian qualitative study, parents sometimes 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 infant's chances for meaningful survival) (Stanak and Hawlik 2017). Complications arise when there is a conflict between what the NICU team thinks is the best interest for the infant and what parents think. Rarely do parents want to stop the treatment and the team thinks the infant has good chances for meaningful survival (Stanak and Hawlik 2017). Parents tend to want to prolong life, but the professional conflict also arises when it comes to prolonging life that has little chances for meaningful survival (that is now possible thanks to advances in the technology) (Stanak and Hawlik 2017). Thus, as the aim of the NICU team is the best interest of the child, which may get in conflict with parental wishes or which may cause a disagreement within NICU teams, it is in these particularly heated situations that the character of NICU professionals is put at stake.

When such situations of disagreement 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 (Gillam et al. 2017), while on the other hand, the NICU professionals face the demand of their own *act of profession* that commits them to serve the best interest of the infant (Pellegrino 2009). As infants at NICUs cannot make autonomous decisions for themselves (Doroshow et al. 2000), the legal guardians are expected to be the surrogate decision-makers and decide on their behalf (Berger 2015).

In practice, doctors seem to have the tendency to accept family's refusal of resuscitation of an extremely preterm infant even if they think that resuscitation is in the infant's best interest (Janvier et al. 2008). 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 infant's best interest (Mills et al. 2015). This poses a challenge to the NICU profession. Because parents are not always in the right to decide (Leuthner 2001), as they face a decision they presumably never anticipated and so they may be ill prepared to make such a decision about their infant (Weir et al. 2011), the clinicians may be arguably more competent to make the decision amidst the tragic moral dilemma. Knowing when to step in and when

to override parental decision, however, presents a professional conflict that requires the virtue of *courage* to challenge the parents and the virtue of *phronesis* to discern when to apply what course of action.

Knowing when to step in to decide is made even more complicated by the fact that the virtue of *compassion* is reported to be the distinguishable character trait of NICU professionals. Compared to the obstetric personnel, neonatologists are in general more prone to be interventional within the *grey zone* in weeks 23+0 to 24+6 of GA (Chan et al. 2006). It is a reoccurring topic in the literature that neonatologists are different from obstetricians in their approach (Chan et al. 2006). The basic difference is that neonatologists seem more pro-life, pro-caring for infants 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 (Stanak and Hawlik 2017).

A further complication arises from the fact that infants and their families tend to spend months at the NICUs, which makes the relationship with the NICU professionals more individual and personal. It is particularly the case with the NICU nurses who spend a considerable amount of time with parents at the infant's bedside and thus often act as family advocates (Green et al. 2015). An Australian study found that NICU nurses often find themselves in challenging situations where they have to *keep secrets* from the parents. Due to the challenge created by the trust given to them by the parents and the nurses' up-to-date knowledge about the health state of the infant, the nurses reported the experience of 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 the trust between them and the parents (Green et al. 2015). These situations pose a challenge for the character of NICU nurses with respect to *keeping fidelity to trust* given to them by parents and their own *integrity*.

3.3 Organizational culture

Discerning the right course of action in the NICU is predicated by a certain degree of freedom to act in accordance with one's decision. Understanding virtues as character traits that manifest themselves in professions and that dispose the NICU professionals to habitually act well puts an emphasis on the organizational structures. I want to suggest that the organizational structures play a vital role in allowing the NICU professionals to develop in their professional virtues. For that reason, the organizational structures ought to recognize the role of tragedy in the NICU decision-making and hence recognize the ethics-related aspects of the work in NICUs.

Recognizing the presence of the tragic question can have impact on both the team as well as the individual. In terms of the individual NICU professional, recognizing the tragic question may help with the experience of moral dilemmas and, at times, moral distress and thus allow the members of the NICU team to acknowledge and work with the dilemmas individually. In case of NICU teams, 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.

3.3.1 NICU individuals

A reoccurring theme in the literature is that the bedside experience of the NICU nurses leads to the experience of futility (Stanak and Hawlik 2017). Nurses are close to the suffering of vulnerable infants and thus see the futility of intensive care. It is partly due to the fact that 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, not withheld (Mills et al. 2015). As reported in a UK qualitative study among NICU nurses, the use of advanced technology brought with it an increased number of moral dilemmas (Gallagher et al. 2011).

Furthermore, being so close to suffering and thus going through the normative tension inherent to the situation may make the nurses experience moral distress (Catlin 2008). One of the most common causes of distress in other areas of medicine lies in supporting patients at the end of their lives when comfort care would be more humane. The same is the case for NICU nurses as well. Nurses report that they struggle with causing suffering through carrying out active treatment when they could comfort instead and so they are more prone to withhold resuscitation altogether (Catlin 2008). The experience of moral distress, however, differs from the experience of a moral dilemma in that the nurses think they 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 (Jameton 1993). The fact that NICU doctors tend to be more hopeful and thus interventional while the NICU nurses tend to want to withhold active interventions creates a tension point. This tendency is confirmed by a Swiss survey among NICUs that indicates that 35% of doctors and 64% of nurses stated that some infants were treated too intensively (Klein 2016). Such a tension points to the presence of tragedy and hence to the need to explicitly recognize the role of ethics in NICU decision-making.

3.3.2 NICU teams

Discussing the virtues of NICU professionals is secondary to allowing NICU professionals to be open about the role of ethics in their profession. I want to suggest that insofar as the role of moral enquiry is recognized by the respective organization, the normative tension can be eased via the use of mechanisms of ethics support. The same Swiss survey mentioned above further states that 50% of doctors and 78% of nurses wished for more group discussions about ethics-related issues (Klein 2016). It suggests that the topic of ethics receives less attention than it is supposed to. However, to speak openly about ethics in the NICU teams, the organizational set up must be such that it is allowed. The challenges with such openness to ethics can be manifold. Starting from the background legal context that sets the broad boundaries of the ethics debate, to the general societal recognition of the role of ethics, and individual attitudes of clinical professionals to the field of ethics. An Austrian qualitative study further states that bringing the conflicts from the personal to the value level poses a challenge, as well as the individualized and competitive nature of the medical profession that, compared to other professions, sometime lacks the recognition of the need for building of a team culture (Stanak and Hawlik 2017).

Support from ethics committees, in-house supervision, and ethics moderation of team discussions are the current good practice mechanisms that help bring the ethics related aspects of the work in NICUs to be explicit. While the practice of ethics committees that support NICU decision-making (formally or informally) is fairly common (Nuffield Council on Bioethics 2006; Stanak and Hawlik 2017), in-house supervision structures depend on the particular hospital set-up. In the Austrian context, ethics committees at times serve as a moderation mechanism that helps resolve the NICU team tensions via moderating team discussions. In this way, members of ethics committees are send to the neonatal departments with the aim of bringing the issue from a personal conflict to a conflict at the value level for the sake of improving the decision (Stanak and Hawlik 2017). Such moderation helps minimize the variety of opinions in the team and thus allows the team to go with one opinion to support parents in the process of ethics consultation. An Italian qualitative study further states that there is a need for formal ethics consultation and ethics training programmes for neonatal professionals for the sake of improving the quality of care delivered (De Panfilis et al. 2018).

The correlation between ethics consultation and quality of care provided is also the result of a US survey among neonatologists (Weiss et al. 2007). A similar point is also supported by a Canadian survey that suggests that organizational culture has an impact on the improvement of quality of care at a NICU (Mahl 2015). 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. The survey concludes that group oriented culture leads to better outcomes, however particularly in Canadian NICUs, hierarchical culture is associated with even better patient outcomes (Mahl 2015). For that reason, ethics consultations from the outside, but also the need of team buildings for NICU professionals within teams are necessary to support the team cohesion for the sake of improved decisions.

If the NICU management openly recognizes the tragic moral dilemmas that are at times experienced by NICU professionals, it makes it easier for individuals to progress not only as professionals, but also as moral agents. It may have an 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 the NICU professional within it.

4 Conclusion

Distinguishing between the obvious and the tragic questions is important because it allows us to engage in a form of ethical reasoning that would otherwise be obscured by the presence of the mere CBA. In NICUs, I focused on the experience of tragedy, that is when there is no option that would be free from serious moral wrongdoing, which can occur when deciding around the *limit of viability*. Due to this experience of tragedy that is caused by the high level of uncertainty and ambiguity of the best interest principle, I argued that the case of neonatology requires special attention. In line with the virtue ethics

literature, I identified the intellectual virtues of *episteme* and *phronesis* and moral virtues of *courage, compassion, fidelity to trust,* and *integrity* as key. However, I argued that the discussion about virtues can only take place once the organizational structures acknowledge the distinction between the obvious and the tragic and so allow the NICU professionals to engage in the moral enquiry. With this freedom and, ideally, with some form of ethics support, NICU professionals as well as NICU teams can grow as moral agents. Virtue ethics thus has a role to play in addressing tragedy through focusing on the individual agent, the NICU professional, who needs to decide on the spot on how to solve the complicated dilemmas encountered in the NICU profession and who needs ethics support in the process. Only when the organizational structure allows ethical dilemmas to be recognized, adequate decisions can be made.

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Conflict of interests
None

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Chapter 3

Nudging in Neonatology: Practical Wisdom and Accountability for Reasonableness

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Abstract

Objective: The way choice is presented has an impact on decision-making. This is the case also in the context of neonatal intensive case units (NICUs), particularly in the challenging cases that concern the *limit of viability*. The objective of this article is to examine the role of nudging in the shared decision-making in neonatology and elaborate on the respective moral challenges.

Results: Nudging is not morally neutral. There are two key sources of ethical issues at the heart of nudging. The first one concerns the lack of transparency, while the second concerns the background value judgments that are imminent whenever nudging is used for achieving a particular end. To solve the underlying conflict, a virtue ethics approach combined with the accountability for reasonableness framework is suggested to guide the use of the tool of nudging.

Conclusion: NICU professionals ought to use the tool of nudging transparently in line with their act of profession and their practically wise judgment.

Keywords
nudging, neonatology, NICU, accountability, practical wisdom

1 Background

The way choice is presented has an impact on decision-making. This is the case also in the clinical context of Neonatal Intensive Care Units (NICUs). Particularly, in the challenging cases that concern the *limit of viability*, which is the point in fetal development at which the infant has a reasonable chance of extra-uterine survival (1). There, between the beginning of week 22 and the end of week 25 of gestational age, shared decision-making with parents takes place (2). According to a systematic review from decision-making in high-income countries, weeks 23 and 24, in particular, are the *zone of parental* discretion where the parents ultimately make the decision between comfort (palliative) care and active care based upon the portrayal of choices by NICU professionals (2). This situation is of extreme gravity because it requires the surrogate decision-makers, the parents or NICU professionals, to operate at the border of beginning of life as well as end of life. The main aim is thus to minimize undertreatment as well as overtreatment by attempting to save each infant that has reasonable chances for meaningful survival and let go the one that does not in order to prevent unnecessary harm (3).

This paper is set against the backdrop of our research of the Austrian context where a limited number of intensive care beds, limited number of NICU professionals, and scarce financial resources make the decision-making in NICUs a matter of resource prioritization (4, 5).

In this paper, I want to examine the use of the tool of nudging using the NICU as the paradigm case. In doing so, I am going explain what nudging is, suggest that we should understand it as a tool, and elaborate on the moral challenges that come along in the context of NICUs. Furthermore, I am going argue that the democratic framework of *accountability for reasonableness* together with the virtue of practical wisdom (*phronesis*) can guide the right use of nudging in the NICU profession.

2 Nudging definition and theory

In the following section, I try to establish that in any situation of decision-making – whenever one chooses between alternative options, choice architecture is present. Choice architecture refers to the particular way the options are laid out in front of the decision-maker without anybody intentionally guiding the choices. The way the options are presented triggers a spectrum of cognitive biases, where some are avoidable while others less so. Intentional alteration of choices based on the knowledge of these biases is what it means to nudge. Hence, when decision-makers intentionally decide to work with choice architecture, they become responsible for nudging.

Nudges operate on two main premises. The first premise is that people are not *econs* – rational economic optimizers, but that they exhibit *bounded rationality (6).* They do not always rationally weigh all the options at hand in the limited time available to them, but they follow their cognitive biases and decide

by following the principles such as rule of thumb, common sense, or educated guess (6, 7). Irrational as it may be, such decision-making is predictable. The cognitive biases (see table 1) are shared among many and they make people deviate from the *optimal* decision they would have made on the basis of their rationality alone (8).

The second premise is that institutions unavoidably influence the choice presented to people and thus push people one way or the other without having to be intentional about it (6). Being intentional about the way choice is architected is what it means to nudge. In daily life, default setting on a mobile phone are a nudge, so is a GPS, or the size of glasses and plates (9). The decision-makers thus have two options. They can either not use the tool of nudging, but leave the unintentional choice architecture in place to guide the decision-making, essentially, closing their eyes and hoping for the best (10). Or they can use to tool of nudging, which, however, requires them to take a stand on the background issues on the value level and thus be paternalistic. There is no neutral solution, either closing the eyes and hoping for the best or some level of paternalism.

2.1 Cognitive biases

In the context of NICUs, there is a list of cognitive biases that are at play when the decision between active and comfort care is taking place. When NICU professionals (neonatal doctors, nurses, psychologists, or other professionals – depending on the hospital (4)) communicate with parents as part of the shared decision-making procedure, some of the biases on the side of parents as well as NICU professionals are unavoidable. Avoidability is defined here as the freedom to communicate a specific message to the parent without tapping into a cognitive bias. While it is possible to communicate the data without referring to how other parents decided in that position (*bandwagon effect*), the use of the *framing effect* is unavoidable. There is no neutral framing NICU professionals may use as they simply must use words such as survival or mortality (or words conveying similar meaning) and their positive or negative connotation may have an impact on the parents' choice (see table 1 for a list of examples of cognitive biases potentially present in NICUs). The more unavoidable the bias is, the less neutrality in the process of communication is possible.

It needs to be noted that communication trainings for NICU professionals can help avoid the misusing of the more avoidable cognitive biases or, alternatively, can help in nudging parents towards the use of rational thinking in the decision-making processes. Indeed, improving parental decision-making competences should be the first step, however, that does not avoid the issue of biases in the shared decision-making procedure.

Table 1: Avoidable and unavoidable cognitive biases in NICUs (11, 12)

Unavoidable cognitive biases	**The possible influence of the bias on the communication between NICU professionals and parents**
Anchoring/order effect: the tendency to rely on the first piece of information received (the anchor) that is used to make subsequent judgments.	When doctors communicate benefits before risks, it may create a positive anchor on parents' perception (or the other way around).
Authority bias: the tendency to attribute more importance to the opinion of a person with authority and follow the opinion.	When NICU professionals recommend parents to go for active or comfort care, parents may have the tendency to follow the opinion of the NICU authority figures.
Availability effect: the tendency to base the likelyhood of an event on how easily the event comes to mind.	When doctors tell the parents that their child may pass away three times, but it survives nonetheless, parents overestimate the chances for survival in case of another event.
Confirmation bias: the tendency to notice that information, which confirms our pre-existing point of view.	When doctors may judge the likelihood of survival of the EP infant based on their subjective assessment of its appearance.
Default effect: the tendency to go with the option that is designated as the default.	When doctors present to parents that their institution generally does not provide active treatment to children born in 23rd week of gestation, that makes parents choose comfort care.
Effective forecasting: the tendency to predict future states inaccurately.	When parents may find it difficult to imagine living with a disabled child, but manage it better than they anticipated nonetheless.
Framing effect: the tendency of different descriptions of the same problem to lead to different responses.	When phrasing the prognosis by means of survival and non-disability rates (positive frame) makes parents more likely to choose resuscitation than when framed as mortality and disability rates (negative frame).
Illusory corrolation: the tendency to establish a causal relationship when the connection may be coincidental or non-existent.	When parents assume that a random event caused the EP birth.
Omission bias: the tendency to prefer inaction (omission) against action (commission).	When prefering comfort care over interventional active care of EP infants as if dealth following an intervention was worse than natural death.
Representativeness bias: the tendency to make judgments about probability of an event around the category prototype.	When in the context of individual conversations, doctors may judge wrongly what level of language to use when talking to the parents if, for instance, they judge them by appearance.
Sunk-cost bias: the tendency to pursue the course of action that includes already irretrievable expenditure of time, effort, or money.	When parents who have conceived after repeated IVF interventions may prefer active care even in situations when comfort care would be more appropriate.

Avoidable cognitive biases	**The possible influence of the bias on the communication between NICU professionals and parents**
Bandwagon effect: the tendency to be influenced by what others are doing or saying.	When doctors provide the information to parents on how other parents decided in their situation.
Focusing effect: the tendency to place too much emphasis on one aspect of the situation thus falsifying the prediction of a future outcome.	When communicating about the infant's likely abilities for an extended period of time and not about the likely disabilities (and the other way around).
Hinsight bias: the tendency to believe after an event that the event could have been predicted.	When parents assume that the event of emergency EP birth could have been predicted.
Institutional bias: the tendency of institutions to present their practices as the official correct ones.	When institutional statistics influence counselling that further influences the decision-making of parents and thus the future outcomes.
Loss aversion: the tendency of people to prefere avoiding losses to acquiring gains.	When framing the information via losses and gains may have an impact on parents, i.e., losing a child vs getting a child.
Overconfidence bias: the tendency to overestimate how much we know and how reliably we know it.	When doctors overestimate the correctness of their judgment and hence the right course of action.

3 The tool of nudging and values

3.1 Nudging as a tool requiring an end

No longer is it the case then that the arsenal of decision-makers consists only of restrictions and incentives, sticks and carrots, but, in this way, nudging can be approached as another tool that the decision-makers have at hand. The Nuffield ladder of intervention for public health understands nudging strategies to precede the use of incentives and choice restriction, or elimination (13). When taken in the way as a tool, however, nudging requires an end toward which it can be used. Nudging is at disposal of the agent, the person in the position of authority, who can use it for whatever ends deemed appropriate. Against this backdrop, nudging is criticized for being implemented without being scrutinized the same way other government restrictions are. Nudging often bypasses the principle of informed consent and, due to the lacking transparency, allows for paternalistic manipulation (6).

Also, nudging is by no means a morally neutral tool that the decision-maker is automatically an expert on. When decision-makers choose to intentionally alter the choice architecture at their disposal, they automatically need to take a stand on what the good for the given individual or population is. Using of the tool of nudging brings about a conflict on the level of values as taking a stand is inevitably value laden. For instance, when NICU professionals communicate to parents that active care is the default option already at week 24 of gestation, they take a value stand that saving a child at this point of prematurity is already worth it.

The two points above highlight the need for making a distinction between two key sources of ethical issues at the heart of nudging. The first issue concerns the lack of transparency in the use of the tool of nudging, especially when compared with explicit government regulations that restrict of eliminate choice. While the second issue concerns the background value judgments that are imminent whenever nudging is used for achieving a particular end. Nudging in the latter case merely highlights those conflicts that are rooted deeper in the topics at stake and hence the value clashes vary with interventions.

3.2 Conflicts on the value level

The need for this distinction applies also to the context of NICUs. In the extreme cases around the *limit of viability*, not only are there conflicts between NICU professionals and parents, but there are also conflicts on the value level within particular NICU teams (elaborated on in (14)). It is especially so because of the advances in technology that allow to keep most infants alive and by the prioritization challenges caused by the limited resources that force NICU professionals to participate in ethics (15). Such conflicts in the background will inevitably lead to different positions with regard to the use of nudging. In order to come up with ethical guidance for nudging, the issues of lacking transparency and the underlying conflicts on the value level need to be addressed.

4 Solution to normative issues with nudging

In the following section, I am going to argue that the *accountability for reasonableness* (A4R) framework can be a step toward the solution for the first issue with nudging (the lack of transparency) on the level of institutional and national formulation of guidelines (GLs) on the management of extremely preterm (EP) infants (16).

4.1 Procedural justice as a solution

At the beginning, it is important to establish the similarities between the private insurance rationing context where Daniels and Sabin apply the A4R (16) and the bedside rationing context at the *limit of viability*. The following core aspects are the same. NICUs face the problem that intersects the fields of medical ethics as well as political philosophy. They must ration due to shortage in staff counts or NICU beds (4), their legitimacy to decide on behalf of the EP infant is in question as their view of the best interest for the infant may differ from the one of the parents (14), and their fair treatment of similar cases similarly cannot be discerned as the outcome data is hard to access. Moreover, the A4R framework can, in essence, be understood as a large shared decision-making procedure in which – just like in the NICU context – decisions are made by the decision-makers, evaluated and reviewed by the public or patients, and adjusted if unreasonable. The same process occurs in person with the parents of EP infants with the only difference that between weeks 23 and 24, the deliberation goes a step further as it is the parent who makes the ultimate decision based on the doctor's portrayal of the choices. It is important to note that there is a major difference in the nature of the two rationing context as the US private insurance context is for profit, while the clinical NICU context is not.

Even though the A4R framework was developed for the macro decision-making context, I want to suggest that because of the major similarities, the A4R framework can be also used in the clinical context of NICUs. When applying it to the NICU context, the A4R conditions (see Table 2) are hard to be envisaged in the bedside clinical encounter, but their role can be played in the formation of GLs on the management of EP infants. Currently, there is an agreement in the GLs of high income countries that within weeks 22 and 25 of gestational age, shared decision-making with parents ought to be in place (2). These GLs on decision-making in NICUs in high income countries are already to a large extent transparent. The roles of parents and NICU professionals are clearly defined, but the GLs do not include the issue of the *form* of communication with parents. Applying the above outlined conditions of A4R in setting up of institutional and national GLs makes the use of the tool of nudging transparent, revisable, and able to be reflected upon, and thus, it is a first step towards addressing the first issue with nudging, the lack of transparency.

Table 2: A4R conditions (17)

(i) Publicity condition	Limit-setting decisions, both direct and indirect, as well as their rationales must be publicly accessible.
(ii) Relevance condition	The rationales for limit-setting decisions must provide a reasonable explanation of how a health provider seeks to meet the health needs of a population under resource constraints. Those rationales are considered reasonable which appeal to "evidence, reasons, and principles that are accepted as relevant by fair-minded people" who are disposed to cooperate.
(iii) Appeals and revision condition	A set of "mechanism for challenge and dispute resolution regarding limit-setting decisions."
(iv) Regulative (enforcement) condition	"There is either voluntary or public regulation of the process to ensure that conditions 1-3 are met"

I want to argue that even though the A4R framework is in theory a valuable procedural step towards more accountability, it does not address the *how* of the way rationales are communicated. The decision-makers in both macro and micro worlds can thus influence the process through their value-laden communication that can constitute paternalism and that undermines the main goal of A4R, namely, the provision of legitimacy and fairness (16). The A4R hence only pushes paternalism one step farther as even a good deliberative shared decision-making procedure remains paternalistic. For that reason, relying on the professional virtue of practical wisdom should guide the use of nudging in the bedside NICU context.

4.2 Virtue ethics as a solution

Looking for the solution to the second issue with nudging, namely the value conflicts in the background that also penetrate into the decision-making procedures, I want to suggest an agent-centered solution in line with the virtue ethics tradition. As argued by MacIntyre (18), the modern moral conflicts are interminable as they lack a teleological, goal oriented, essence. The goal (*telos*) can be found in the professions and the solution to the moral conflicts in the virtue ethics tradition. The reason being that it is the virtues of the individual that help one discern what course of action to take and how to decide between competing moral principles in practice. Hence, I want argue that virtues as character traits are necessary for the professional in pursuing the *act of profession* (the good of the patient). I want to suggest that we should look for the solution on how to use the tool of nudging in the moral structures of professionalism by placing trust in the NICU professionals (19).

What makes professions distinct from mere occupations is the commitment to the profession's particular moral template (19). A lawyer commits to protect the good of the client and pursues the value of justice,

the teacher commits to protect the good of the student and pursues the value of knowledge, and the medical professional commits to protect the best interest of the patient and pursues the value of health. It is the *act of profession* where respective professionals commit to serve the good of their professions.

Furthermore, I want to link being a professional to a theory of moral virtues and suggest that the act of profession entails specific character traits in the person pursuing the respective profession. When giving the Hippocratic oath, medical professionals commit to using their special knowledge for the sake of patient's good (19). On the way towards the good, certain character traits – virtues - enable one to attain it best. Virtue is understood here as a character trait that disposes the physician habitually to act well and wisely in medicine (19). In case of clinical medicine, those virtues that dispose the physician to act well that have been debated in the literature range from benevolence, to intellectual honesty, courage, compassion, or humility (19). The application of these virtues (elaborated on in (14)) puts the act of profession into clinical reality.

4.3 Phronesis – Practical wisdom

Because the topic in question concerns the right use of the tool of nudging, I want to focus on the intellectual virtue of *phronesis*, practical wisdom, that has a key role in discerning what the right course of action is. In the context of professional ethics of NICUs, practical wisdom refers to the capacity to act in line with the good of the profession. Practical wisdom is the virtue that allows the NICU professional to correctly evaluate the value related issues at stake against the backdrop of the particular clinical facts and to make the morally right decision. Just as the clinical setting refers to *clinical judgment* that helps the clinician evaluate the factual data, practical wisdom is its analogue in the moral sphere (19).

The clinical judgment represents a technical mastery of principles of diagnosis, prognosis, and therapeutics that serve the good of the patient (19). In the profession of medicine, the clinical and the moral are inevitably fused. The clinical judgment requires the medical professional to apply the general medical knowledge to a particular patient, while practical wisdom involves complicated interactions between the general moral principles, clinical data, and the particular moral challenge. Practical wisdom, in the sense, is to be taken not as a moral judgment deduced from principles, as it is not an attempt to produce law-like relationships, but a situated context specific knowledge (20). Practical wisdom is not logically simple, in a way that it would provide self-evident clarity, and so it is not a kind of comfortable scientific approach applied to morality. It leaves the weight on the individual to, upon reflection, act correctly, according to right reason. Practical wisdom is not a theoretical wisdom, but wisdom based on making one's hands dirty in practice.

Deciding around the *limit of viability* is precisely the situation of making one's hands dirty. When NICU professionals communicate with parents of an EP infant that is to be born in week 23 of gestation,

through dialogues, they attempt to work out from the bottom-up what the best course of action is. Their decision in the actual situation of birth will thus be context specific. Aware of the general moral principles, the NICU professionals will have to decide in the particular case if active or comfort care ought to be pursued. They will have to use their practical wisdom together with their clinical judgment and parental consultation to discern the right course of action. The pitfall, however, that comes with leaving the NICU professionals decide exclusively on their own judgment is that if this position of authority is misused, also the tool of nudging will be used for the manipulation of the parents. For that reason, merging the A4R framework with the virtue of practical wisdom could be a step towards safeguarding the right use of nudging.

4.4 Practical Wisdom and Accountability for Reasonableness

I want to argue that merging the modern democratic framework of A4R with the ancient Greek virtue of practical wisdom can be seen as a guide to nudging. Through the application of transparency, the A4R framework may bring a solution on the level of GL formation, while the virtue of practical wisdom puts the emphasis on the agent trained in the qualities required for the correct pursuit of its profession to know how one ought to use the tool of nudging in practice. Hence, I want to suggest a framework merging accountability for reasonableness and practical wisdom.

The tool of nudging in the field of NICUs falls at hands of the NICU professionals. They pursue conversations that require reflection and judgment with parents as part of the shared decision-making procedures on daily basis. It is in these conversations where NICU professionals need to adjust their judgment on how to nudge to the specific situation and specific parents. Their aim ought to be improving parental decision-making capacity, reducing the impact of biases, as well as being in line with their professional commitment to the good of the patient. Intentional nudging is easier to justify outside of this morally ambiguous zone around the *limit of viability*, but the role of nudging is present also in these grey zone cases nonetheless. Even though this model remains to be paternalistic, compared to the current practice, it is a step forward that calls for the recognition of the impact of communication strategies (nudges) at the level of GL formation, as well as it calls for the professionals to recognize the role of ethics in the decision-making processes. The quest to eliminate paternalism in NICUs, however, is debatable as, depending on the context, there seem to situations in which explicitly parents want a competent professional to decide on their behalf (21).

Even in a shared decision-making procedure, the form of communication (of rationales) around the *limit of viability* cannot be neutral. Transparency and reflexivity can improve the process, but they do not eliminate paternalism and the related challenges with fairness, or legitimacy. In the everyday practice at NICUs, the decision-making must rely on the character of the NICU professional to discern what principle to follow when. Same as with clinical judgment, practical wisdom is largely invisible in action and hence hard to be accounted for. But as clinicians are held liable for the clinical judgment, they

should also be held accountable for their moral judgment at least on the grounds of GLs. The role of ethics committees and ethics moderation, however, is crucial in supporting the NICU professionals in such normatively intense situations (elaborated upon in (14)).

5 Conclusion

I have argued that rather than ignoring the impact of choice architecture on the outcome and thus closing our eyes and hoping for the best, the NICU professionals should use the tool of nudging. Transparency about nudging at the level of GLs combined with professional virtues guiding the bedside rationing is the position suggested here. Nudging in this sense is nothing else, but using of another tool that is at disposal of the NICU professional towards the end of medicine, the good of the patient (19). For that reason, NICU professionals ought to use the tool of nudging transparently in line with their act of profession and their practically wise judgment.

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Chapter 4

Neonatology in Austria: Ethics to Improve Practice

CURRENTLY IN REVIEW IN SPRINGER (Journal of Medicine, Health Care and Philosophy)

Abstract

In the world of Austrian neonatal intensive care units, the role of ethics is recognized only partially. The normatively tense cases that are at the backdrop of this essay concern the situations around the *limit of viability* (weeks 22+0 days to 25+6 days of gestation), which is the point in the development of an extremely preterm infant at which there are chances of extra-uterine survival. This essay first outlines the key explicit ethical challenges that are mainly concerned with notions of uncertainty and best interest. Then, it attempts to elucidate the less explicit ethical challenges related to the notion of nudging in the neonatal practice and argue that the role of ethics needs to be recognized more - with the focus on the role of virtue ethics - in order to improve the practice of neonatal medicine.

Keywords:

Neonatology, limit of viability, ethics, virtue ethics

1 Background

In the world of Austrian neonatal intensive care units (NICUs), the role of ethics is recognized only partially. The designated place for ethics is mainly outsourced to ethics committees that sometimes include the treating NICU professionals and sometimes consist of independent experts and heads of neonatal units [1]. Depending on the hospital, these committees are established either formally or informally and their function is to support the decision-making process especially in the normatively tense cases [1]. It is rarely so that a form of ethics moderation supporting the NICU team as such is present [1]. The normatively tense cases that are at the backdrop of this essay concern the situations around the *limit of viability* (weeks 22+0 days to 25+6 days of gestation), which is the point in the development of an extremely preterm (EP) infant at which there are chances of extra-uterine survival [2]. Currently, according to the Austrian guideline on the management of EP infants, comfort (palliative) care is recommended in 22nd week, shared decision-making with parents in the *grey zone* in 23rd week, and active care interventions from 24th week onwards [3]. This essay first outlines the key explicit ethical challenges present at the *limit of viability*. Then, it attempts to elucidate the more subtle (less explicit) ethical challenges related to the notion of nudging in the neonatal practice and argue that the role of ethics needs to be recognized more - with the focus on the role of virtue ethics - in order to improve the practice of neonatal medicine.

2 Explicit moral challenges in the neonatal practice

2.1 Uncertainty of data

The moral challenges discussed in the neonatal literature take their shape and form at the backdrop of their specific social, cultural, religious, and legal contexts. For the most part, however, the key challenges stem from the uncertainty of data and the ambiguity of the notion of best interest. Because the probability of healthy survival increases along with the weeks of gestation [4], precision of the baseline data indicating the infant's stage of development is of the utmost importance. The exact data, however, is covered with a veil of uncertainty that is represented by a probability range. The baseline data measurement of the infant's stage of development can vary with the assessment tool used: while crown to rump measurements can vary ± three days, the New Ballard Exam by as much as two weeks [5].

The same lack of certainty plays its role also in the assessment of outcome data. Different countries and different hospitals within countries produce different outcomes [6]. The differences in approach seem to be connected to expertise [6], regionalization of care [7], resource capacities as well as to values and norms of particular societies [8]. For instance, when a policy limits "treatment for infants born at 24 weeks of gestation", it will inevitably 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" [8].

Uncertainties about baseline and outcome data further 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 neurodevelopmental impairment (NDI) [9]. That, in turn, leads to further ethical uncertainty. The lack of clarity in these three categories of data (baseline, outcome, and empirical) invites value judgments to be made by the NICU professionals [5].

2.2 Best interest

Another key moral challenge stems from the ambiguity about the best interest of the EP infant [10]. Because deciding in the grey zone of gestation is a matter of surrogate decision-making the rightness or wrongness of which cannot be verified with the EP infant until considerably later, the question of surrogate consent and the connected question of best interest are at stake. The challenges are that it is unclear whose best interest is to be taken into account (family vs infant) and what that EP infant's best interest looks like amidst the prospects of low quality of life (QoL) and long-term NDI [5].

The above outlined moral challenges connected to uncertainty of data and the notion of best interest are much discussed the literature. More implicit challenges that are given much less attention to are discussed below. They revolve around the notion of nudging in the decision-making process surrounding the *limit of viability* and the related notions of paternalism, freedom of choice, and coercion.

3 Implicit moral challenges in the neonatal practice

3.1 Paternalism and choice architecture

In the decision-making around the *limit of viability* in Austria, shared procedures have been long established in the morally ambiguous grey zone (now, the 23rd week of gestation [3]) where it is ultimately the parents who act as surrogate decision-makers on behalf of the EP infant. It is the so called *zone of parental discretion* [11]. As parents participate in arriving at the decision, paternalism in its traditional negative meaning associated with coercion is seemingly not an imminent matter of concern. However, particularly because of the challenge of surrogate consent, I want to suggest that there is a need to consider a more implicit (and thus potentially also coercive) aspect of paternalism, namely that of nudging in doctor patient communication that may occur due to the presence of professional as well as parental biases in the decision-making process [12].

3.2 Default bias example

With respect to behavioural psychology, there is a spectrum of cognitive biases present in any case of decision-making - including the decision-making at the *limit of viability*. For instance, the option presented as default seems to be the one that people tend to follow as deciding against the default often involves extra effort termed as *friction cost* or *hassle factor* [13]. In case of NICUs, hypothetical case scenarios confirm the same trend. When lay volunteers were randomized to receive either resuscitation or comfort care as the default option for an EP infant born at 23rd week of gestation, participants had the significant tendency to follow the default [14]. The *default bias* (as well as other biases such as *framing effect* or *bandwagon effect*) are potentially present in the decision-making around the *limit of viability*. The intentional work with these biases is what it means to nudge [15]. A more exhaustive list of biases present in the NICU decision-making can be found another work of mine [15].

The two key moral challenges with nudging are going to be examined below. The locus of the first one concerns agency of the nudger, while locus of the second concerns the challenge of coercion of the nudged. Also, due to the ongoing confusion regarding the use of the term nudging, the key distinctions will be made explicit.

4 Analysis of nudging in NICUs: definitions and moral challenges

4.1 Definition of nudging and choice architecture

It is necessary to clarify the terms used in this essay and distinguish between choice architecture and nudging. As Sunstein and Thaler define it, nudging is "any aspect of the choice architecture that alters people's behaviour in a predictable way without forbidding any options or significantly changing their economic incentives" [16]. What this distinction means in the situation of shared decision-making with parents in the NICU is the following. In conversations with NICU professionals, parents get a particular set of choices laid out in front of them. On one level, parents choose between active and comfort care. On another level, these two options can be presented in many different ways: with the use of a default, with a positive or a negative frame, with the use of peer-pressure or without, etc. Choice architecture refers not only to *what* is being presented, but also to *how* that thing is presented [16]. I use the term choice architecture to depict the state of things in which nobody wilfully interacts with the way the choice setting is architected. Nudging, to the contrary, refers to the wilful interaction with the setting – the *architecting* of *what* choices are presented and *how* they are presented.

4.2 Definition of agency

When talking about the "wilful interaction with the choice setting", it is important to distinguish between different dimensions of will, or agency, that are at play in nudging - particularly the psychological and the ethical [17]. The two dimensions of agency that are in use here are *intention* and *voluntariness*.

On the one hand, intention, as a psychological concept, refers to the expression of purpose or desire [17]. Nudging requires intentional use of choice architecture where the decision-makers use the tool for a particular purpose. For instance, the intentional use of the *framing effect* in presenting the options in a positive or a negative frame (in the frame of survival vs mortality) aims to make the parents decide in one way or another. This is supported by a randomized survey that 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 [14].

On the other hand, the dimension of voluntariness, as an ethical concept, refers to the related responsibility for nudging [17]. Nudging requires the voluntary use of choice architecture where the decision-makers use the tool of nudging out of their own volition. An act is understood here as "voluntary if it is not due to ignorance or compulsion" [17, 18]. Hence, one ought not to bear the responsibility if compelled or forced to nudge because such an act can be categorized as done under duress [17]. Equally, if one does not know of the fact that, for instance, negative framing of information nudges parents to choose comfort care for their EP infant (the case of ignorance), one does not bear full the responsibility for it either. Both ignorance and compulsion thus serve as exculpations.

4.3 Moral challenges with agency of the nudger

Concerning compulsion and nudging in the context of NICUs, one needs to distinguish between two categories of situations. There are some situations when nudging can be avoided and others when it cannot. While the NICU professional can avoid using the *bandwagon effect* (by not telling parents how others decided in the specific situation), the above mentioned *framing effect* is hard to be avoided (see table in [15]). What is meant here is that the NICU professional simply has to communicate the message in one way or another (in a positive frame of survival or in the negative frame of morbidity) and thus nudge the parents. There is thus an extent to which nudging is considered inevitable and hence, at times, nudging parents in the decision-making process at the *limit of viability* may present a moral challenge for the NICU professionals as it can be seen as done under duress.

Concerning ignorance and nudging, NICU professionals are exculpated from ignoring the tool of nudging only as long as they lack the knowledge of it. They are thus to be held responsible once they know of the tool, but do not use it intentionally. What adds complexity to this debate is the controversial

nature of what epistemic conditions on responsibility are [19]. While some argue that agents can be held responsible only for what they actually know [20], others suggest that agents can be responsible for ignorant choices as long as they could have been reasonably expected to know the required facts about their choice [21]. Along the lines of the latter, it is suggested here that as long as NICU professionals are aware that nudging may play a role in the communication with parents of EP infants, the only options that they are left with are either to nudge or to close their eyes and hope for the best - yet bear the responsibility nonetheless [22]. Another aspect of the moral challenge with respect to agency thus concerns the question of ignorance of the tool of nudging and the related question of responsibility.

It needs to be stressed that if no intention is in place, we do not talk about nudging, but merely about unguided choice architecture. The moment, however, that NICU professionals get to be aware of the tool of nudging, they are presented with a moral challenge of having to decide whether or not to use it. Also, nudging can happen voluntarily as well as against the will of the nudger. If NICU professionals cannot avoid nudging and thus they do not nudge (strictly speaking) out of their own volition, compulsion serves as an exculpation.

4.4 Moral challenges with coercion of the nudged

Another set of moral challenges with respect to nudging in NICUs concerns paternalism and the related notion of coercion. The key proponents of nudging, Sunstein and Thaler, place nudging into the category of libertarian paternalism [16]. While the traditional view of paternalism refers to the situation when individuals are interfered with against their will with the motivation of preventing harm or making them better-off [23], libertarian paternalism aims to preserve the freedom of choice, yet still make people better-off. Sunstein and Thaler suggest that that can be done via orchestrating choices that promote the good of the agents nudged and that are in line with their own desires [16]. While avoiding significant incentives and choice restriction or elimination, they claim that the sheer alteration of the choice architecture does not constitute coercion – as the agent is free to choose after all [24]. What is true then about the criticism that nudges are coercive especially when considering the neonatal clinical context?

4.5 Coercion and agency

The first premise of libertarian paternalism that needs to be examined is whether nudges really preserve freedom of choice – while freedom is understood here as the capacity to react to reasons [25]. Here, it is important to introduce a distinction between those nudges that preserve freedom in, what Saghai calls, a basic sense and those that do so in a substantive sense [26]. Nudges clearly preserve freedom in the basic sense in that they do not foreclose options. The point of concern is, however, whether nudges preserve freedom in the substantive sense, i.e. whether they bypass an agent's capacity for deliberation [27]. The heart of the problem is that nudges often "take advantage of non-rational features of our

nature…to produce their effect" [27]. Hence, to the extent that nudges do not preserve freedom in the substantive sense, they are to be seen here as coercive.

Critics of nudging argue that by bypassing our deliberative reasoning, nudging undermines responsible agency [27]. As discussed above, the elements of agency that are particularly relevant with respect to nudging are intentionality and voluntariness. When using the tool of nudging in the NICUs, the question is whether the agents nudged can decide intentionally (or purposefully) and voluntarily (bearing the responsibility for their decision). What stands in the way of intentional and voluntary decision is the obstacle of epistemic pollution and the challenge with nudges that merely aims to change the behaviour as opposed to changing the mind.

Levy suggests that we live in an environment that is epistemically polluted [19]. What he means is that there are "agents who use mimicry and other methods as a means of inflating their pretence to expertise", which in turn makes it hard to distinguish between a genuine expert and a charlatan [19]. This may be problematic for parents of an EP infant in the shared decision-making procedure who have to rely on information from neonatologists when making their decision about active or comfort treatment. Assuming that neonatologists are the genuine experts, epistemic pollutant googled on the internet may mislead parents in their decision-making procedure. For instance, finding an information taken out of its context about the exaggerated burden of NDIs or, to the contrary, about the hopeful chances of EP infant's survival below the *limit of viability* may serve as an epistemic pollutant.

Epistemic pollution is not a source of coercion. It is merely another obstacle on the way towards deliberative reasoning and decision-making that is intentional and voluntary. Sources of coercion, however, are all the nudges that make use of the non-rational features of our nature such as those that make use of the above mentioned *bandwagon effect* or *framing effect*. It is all those nudges that do not fall into the category of what Levy calls "nudges to reason" [27]. Nudges to reason are those nudges that "increase our responsiveness to evidence" [27]. Their aim is not to directly affect behaviour, but to "affect behaviour in ways that are mediated by beliefs. They change behaviour by changing minds"- just like rational arguments do [27]. A nudge to reason must make the agent's mind more responsive to genuine evidence [27].

In the case of NICUs, a nudge that could qualify as a nudge to reason would be, for instance, making use of the *salience bias* in decision aids used in the shared decision-making procedures. Decision aids are, for instance, visual tools with short messages and graphics that depict chances of survival, situation in the delivery room resuscitation, or the risks for neurodevelopmental disabilities [28]. The aim of decision aids is to improve health literacy and not harness bad reasoning such as in situations of communication of proportional data. The aim is to prevent situations such as when 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. It is the case even though the first one presents the risk of 24%, while the second just 12%, yet the number 120 is greater than 24 [29]. Working

with salience, in this context, would mean making the key data noticeable with the aim of helping the parent to decide on genuine evidence. Deciding on genuine evidence would allow parents to make an intentional and voluntary decision. Hence, altering the choice architecture with any aim other than the one that aims to nudge parent to reason is seen here as coercive. What constitutes coercion then are all the influences that aim at change in behaviour and not at change of mind. Of all the nudges, it is only those that attempt to change the mind that lead the parents to make an intentional and voluntary decision. Surely, decision aids also need to be subject to quality control as they too can present the developer's bias and steer the parental decision towards active or comfort care [30].

4.6 Coercion and agent's good

The second premise of libertarian paternalism is that preserving the freedom of choice, it still makes people better-off. In case of NICUs, to know this would require the nudger to know what the best interest of the EP infant and the family is. However, not only are the clinical facts about what exactly is beneficial in part unknowable, but also the meaning of the word *best* is inevitably connected to the subject who evaluates the case. Different subjects, different stakeholders, may interpret the best interest of the EP infant differently.

This can be illustrated on the case of cochlear implants for children. 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 brought 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 [31]. In case of NICUs, the evaluation of both best interest as well as QoL of the infant and the family is subject to individual judgment [32]. 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 EP infants at NICUs. For that reason, nudgers cannot know what, in fact, makes the agents nudged better-off and hence all other nudging in NICUs than nudging to reason constitutes coercion.

As Mill puts it "a man's mode of laying out his existence is the best, not because it is the best in itself, but because it is his own mode" [33]. Scrutinized as this Mill's statement may be, it contributes well to our discussion. In the process of finding out their (and their infant's) own best interest, parents should be nudged to deliberate (via nudges to reason) rather than nudged to act in ways the NICU professional perceives as best. This is particularly at stake in situations when the parents are uncertain about their decision (and so they do not know themselves what contributes to their and the infant's best interest). In these situations, the promise of making the nudged better-off gets to be particularly ambiguous. In these vulnerable situations when the subtle use of nudging may steer the parental decision, nudging to change behaviour constitutes coercion.

To sum up, even if the choice is *just* guided by choice alteration, in the context of neonatology, all the nudging that aims merely at change in behaviour remains coercive. Even the libertarian form of paternalism interferes with the parents' intention and voluntariness as well as their understanding of the good.

4.7 A way forward

Taken into account all the above, the current situation appears to be particularly problematic. On the one hand, there seem to be situations when nudges are inevitable, while on the other hand, making use of the tool of nudging seems to constitute coercive paternalism. Nudges seem not to deliver upon the libertarian promise of being freedom preserving while making the nudged better-off. And, as they tend to fail in preserving freedom in a substantive sense, except for nudges to reason, the NICU professionals are, so to speak, stuck between the rock and a hard place. In other words, NICU professional must, at time, be inevitably coercive. They may want ignore the tool of nudging altogether, but thanks to epistemic conditions on responsibility, they can be arguably held responsible as they could have been reasonably expected to know about nudging in the first place. What is then the possible way out of this? Apart from using nudging for the purpose of supporting deliberative reasoning (as outline above) [27], I want to suggest that nudges should be dealt with transparently on the grounds of the respective professions.

Firstly, transparency should serve as a tool of quality control in order to limit the coercive threat of nudging. In case of NICUs, applying the condition of transparency would mean that in the process of antenatal counselling, NICU professionals would communicate openly about, for instance, the possible impact of the *framing effect* or the *default bias* (even though there is evidence suggesting that the impact of a default tends to persist even if the patients are aware of it [34]). The agents who are nudged ought to know that they are being nudged, especially in the vulnerable context of shared decision-making procedures at the *limit of viability*, even if we run the risk of the nudge potentially losing its effect. Focusing on the meso-level of neonatal guidelines, I want to suggest that the impact of the form of communication on parental decision-making needs to be explicitly recognized on this ground. I have also argued elsewhere that this should be done along the line of Norman Daniels' *accountability for reasonableness* framework [15].

Secondly, under the above condition of transparency, I want to suggest that the tool of nudging should rest in the hands of professions that, in case of clinical medicine, use it in line with their professional commitment to serve the good of the patient. The work of NICU professionals is not only clinical in its nature, but it is also normative. Because of the above reasons of moral challenges as well as the issue of coercion and values related to paternalistic communication with parents, NICU professionals have to participate in ethics. They need to make judgments that are concerned with rightness and wrongness that stand separate to their clinical decisions. This constitutes the *moral sphere* of their profession [10]. For

instance, in communication with parents, they need to make judgments about the threshold QoL of the EP infant and hence its best interest. These are essentially value judgments and once the NICU professionals are aware of it (and hence the exculpation based on ignorance cannot be applied [17]), they ought to recognize the role of ethics in their profession.

I want to further argue that there is a need to recognize the role of ethics in the NICU profession more not only because of the theoretical argument above, but also because of the practical argument that recognizing the role of ethics leads to better care for infants [10]. It is the case because of two reasons. Firstly, better care is reached indirectly via resolving the ethical tensions within teams. Resolving ethical tensions leads to better organizational culture that, as suggested by a Canadian survey, in turn has an impact on the quality of care provided [35]. Secondly, ethics education empowers the NICU professionals when facing normatively challenging decisions. As it was suggested in a US survey, ethics education among NICU doctors played a large role in their decision-making, especially in situations when they considered active care mandatory with respect to their understanding of the notions of best interest and beneficence [36, 37].

Facing the explicit moral challenges connected to uncertainty of data and the ambiguous notion of best interest as well as the implicit challenges surrounding the tool of nudging, NICU professionals should recognize the normative aspect of their work. Virtues of the NICU profession are to guide the use of the tool of nudging on a case by case basis.

5 Virtue ethics solution

Recognizing the role of ethics education for clinical practitioners brings the moral sphere of the profession forward. I want to suggest, however, that in order to allow NICU professionals to develop as moral agents, education itself is not enough and a more holistic virtue ethics approach has a particular role to play. Assuming MacIntyre's position that virtues develop in practices [38], I want to scrutinize the practice, or profession in this sense [39], of neonatology to see the room for virtue ethics there. The profession of clinical medicine (and hence also the NICU professionals), are orientated toward an end (*telos*) inherent to the their profession, which is the good of the patient [39]. The clinical professionals commit to act in the best interest of the patient served and through their Hippocratic oath, they enter into a covenantal trust relationship with patients. This is their *act of profession* [39]. As opposed to mere occupations, professions entail a clear act of profession that is committed to the pursuit of its concrete end. On the way of this pursuit, there are specific character traits or virtues that enable one to attain the end of the profession best [39]. These are the virtues internal to the respective profession.

The virtues we are concerned with are both intellectual and moral. I have argued elsewhere that intellectual virtues in the neonatal context concern the virtues of *episteme* and *phronesis* and moral virtues include the virtues of *courage, compassion, fidelity to trust*, and *integrity* [10]. What

distinguishes these moral virtues from mere character traits is their commitment to goodness [40]. Virtues are understood here as lasting character features of a person that persist through challenges and that are weakened or strengthened depending on success or failure [40]. They are reliable in the sense that they make others know what they can expect of us because the virtues are characteristic of us – they are deep features of a person. However, virtues are not merely static dispositions of character that do not change over time, but they are active features of a person that develop via selective response to circumstances [40]. Thus, they can be acquired through habituation.

Following Artistotle's understanding of human psychology, we start with a set of dispositions and we develop them as life progresses [18]. We move from an untutored state to the tutored state via formation and education [40]. The acquisition of virtues is understood to occur via habituation as it is the case in acquisition of practical skills such as playing the piano. The first step is to consciously learn the skill step by step, note by note. Through repetition of scales and simple sonatas, the pianist becomes more skilled to the point that little conscious thinking is needed to play from the notes. Observing a skilled pianist may make one think that the conscious experience present at the beginning of learning the piano has disappeared and that mere habit acquired via repetition is now present [40]. That is, however, wrong. Even though the pianist does not need the conscious input for playing, his playing is now infused with his individual expression and feeling about the piece played [40]. Hence, what makes a good pianist is not solely the mastery of his routine, but rather his capacity to put an expression into the piece played. Important to note is that just as the skill was once acquired, practice is required for the sake of maintaining its level [40].

The same applies to virtues of the NICU profession. It has been repeatedly reported in qualitative literature that what makes the NICU professional different from the fellow obstetrician is the disposition to be *compassionate* [41-43]. Having compassion as a starting point, the NICU professionals face situations that challenge, for instance, their virtue of *courage* that may at times be required from them, for instance, when having to override the parental decision to withhold active care when medically indicated [10]. Furthermore, the virtue of *fidelity to trust* and *integrity* need to be acquired by NICU professional in practice when facing the parents of EP infants and when communicating uneasy messages to them [10].

Virtues require appropriate response to unique situations – especially to unforeseen situations that require prompt action – and those occur frequently in a NICU. A rational moral calculus may be the method of choice when time is plentiful, but under time constraints, it is the dispositions of character acquired through the repetitive work in the neonatal department - just like the practical skill of playing the piano - that make a good NICU professional stand out. The professional's virtuous character is, however, not just the result of the everyday routine in the neonatal department, but it is the acquired skill that the professional developed over time thanks to which he or she can face the challenging reality of the profession and make apt decisions. The above listed virtues require precisely this intellectual

virtue of *phronesis*, practical wisdom, that is an analogue to *clinical judgment* in the moral sphere. Since virtues cannot be learned in isolation, *phronesis* is needed to help one discern what action to pursue in what situation.

It is important to stress out a concluding remark that for the flourishing of NICU professionals, the respective organizational culture needs to recognize the importance of growth of NICU professionals as moral agents [10]. Some of the methods applied already are support from ethics committees, in-house supervision mechanisms, and ethics moderation of team discussion [10]. The organizational culture need to recognize the role of ethics in the NICU profession and support the NICU professionals on the way.

6 Conclusion

I have argued in the essay that there are normative challenges at the *limit of viability* that force NICU professionals to participate in ethics that include the explicit moral challenges connected to uncertainty, best interest, and implicit challenges connected to coercion related to nudging. I suggested that on the one hand, nudging cannot seem to escape its criticism of coercion because even if the choice is just guided by choice alteration, nudging may interfere with the agent's intention and voluntariness as well as understanding of the good. On the other hand, however, I argued that there are situations when nudging is inevitable and hence when the NICU professional should use the tool of nudging, but deal with it as transparently as possible in line with his or her professional virtues and professional commitment. In sum, I have argued that the role of ethics needs to be recognized more and that the virtue ethics approach has a particular role to play in guiding the tool of nudging and in allowing the NICU professionals to grow as moral agents. It may have an impact on improving the practice of neonatology and hence the quality of care delivered.

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Conflict of interests
None

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Further publications related to the doctoral dissertation

Chapter 5

Nudging: Behavioral Sciences Applied to the Big Four Public Health Issues and Health Inequalities

OPEN ACCESS REPORT BY LUDWIG BOLTZMANN INSTITUTE FOR HEALTH TECHNOLOGY ASSESSMENT

Full publication is available at: http://eprints.hta.lbg.ac.at/1078/2/HTA-Projektbericht_Nr.83_Addendum.pdf

Abstract

Background: This report is an addendum to the LBI-HTA report "Material and immaterial incentives – effects of incentives on health behaviour" [1]. Internationally, the application of behavioral economics and psychology – *nudging* – into policy-making in general and health policy in particular, has attracted much attention. Lead predominantly by the Anglo-Saxon world, a 2008 book by Cass R. Sunstein and Richard H. Thaler called *Nudge: Improving Decisions about Health, Wealth, and Happiness* coined the term and stirred the debate such that in 2010, the United Kingdom Coalition Government appointed the first Behavioral Insights Teams (BIT), nicknamed The Nudge Unit. *Nudging* operates on the premises that it is legitimate to influence people's behavior for the sake of making their lives better (paternalism) but that such influence should be unobtrusive and not entail compulsion (libertarian).

Method: The analysis of nudging, definitions, underlying premises and current practices is based on a systematic literature search conducted in Medline via Ovid, Embase and TRIP databases, where a total of 62 articles were unlisted and in addition, 25 more articles were hand searched. The narrative analysis of the researched literature was carried out to clarify the relationship between nudging, the *big four* health issues, and health inequalities.

Results: The BIT has created a framework called EAST proposing that if the government wants to encourage a behavior, it should think about making it *Easy, Attract, Social, Timely*. In the report, this framework is used for suggesting the possible nudges that can be used for addressing the *big four* public health issues (i.e. smoking, alcohol consumption, nutrition and physical activity); for example by serving alcoholic drinks is smaller glasses or by making the public know that majority of smokers want to quit as a way of correcting the social norms.

Compared to incentives, which attempt to motivate and encourage the rational individual to perform an action or inaction, *nudging*, among other subtle strategies, involves subconscious cues, altering of the profile of different choices or changing which options are the default.

The theoretical debate around nudging revolves mainly around the notion of *paternalism* and the problems highlighted in the literature range from the questions of consent and autonomy, manipulation and coercion, to responsibility and moral character. It is naïve to expect nudging not to include any compulsion whatsoever, but because no intervention is neutral, nudging is inevitable. It remains to be a matter of *how* the choice architecture will be designed and here the notion of transparency and public scrutiny is needed in order to prevent manipulation and coercion. Indeed, respecting the limits to ethically acceptable forms of nudging that respect person's autonomy is crucial. The evidence seems to suggest that nudging works best with those already heading the direction of the nudge anyway. Furthermore, the topic of health inequalities is explored and it is suggested that because nudging tends

to focus on more downstream factors, it should be used as a complementary tool for the sake of a more holistic approach in health policies.

Conclusion: This report critically reflects on the notion of nudging and argues that such choice architecture is inevitable and, even though it prima facie does not seem to reduce health inequity directly, it has the potential to do so if targeted well, complemented with incentive structures, and backed-up by robust legislation.

Keywords: choice architecture, nudging, smoking, alcohol, nutrition, physical activity

1 Background

This report is an addendum to the LBI-HTA report "Material and immaterial incentives – effects of incentives on health behavior"[1]. Internationally, the application of behavioral economics and psychology – *nudging* – into policy-making in general and health policy in particular, has attracted much attention. In the effort of "finding intelligent ways to encourage, support and enable people to make better choices for themselves" [2], governments of the Western Europe, United States, Australia and others have mandated behavioral teams to apply this approach of *choice architecture* into policy making.

Lead predominantly by the Anglo-Saxon world, a 2008 book by Cass R. Sunstein and Richard H. Thaler called *Nudge: Improving Decisions about Health, Wealth, and Happiness* [3] coined the term and stirred the debate such that in 2010, the United Kingdom Coalition Government appointed the first Behavioral Insights Teams (BIT), nicknamed The Nudge Unit. Based on the premises of *libertarian paternalism*, the BIT has since proved successful in guiding everyday actions of citizens, which, such approach assumes, are often not conscious and rational. *Nudging* operates on the premises that it is legitimate to influence people's behavior for the sake of making their lives better (paternalism) "but that such influence should be unobtrusive and not entail compulsion (libertarian) [4].

Compared to incentives, which attempt to motivate and encourage the rational individual to perform an action or inaction, *nudging*, among other strategies, involves subconscious cues, altering of the profile of different choices or changing which options are the default. *Nudging* can also include incentives as part of its strategy but the imposition of significant material incentives such as taxes, subsidies, and fines no longer falls under the heading of *nudging* [5]. So far, the overall positive impact of *nudging* is hard to deny, but the impact of *nudging* on specific groups of citizens and the question of health equality is yet unclear.

Against this background, the research project is trying to answer this question: What is the relationship between *nudging* and health inequalities against the backdrop of the *big four* public health issues; smoking, alcohol consumption, nutrition and physical activity?

The report is structured in three parts; the first part includes definitions and underlying premises for nudging, the second part provides an overview of current practices of choice architecture applied to the *big four* health issues; and the third part provides a critical reflection of nudging over against the background of the current academic debate and the question of health inequalities. Furthermore, the report argues that choice architecture – nudging – is inevitable and, even though it prima facie does not seem to reduce health inequity directly, it has the potential to do so if targeted well, complemented with incentive structures, and backed-up by robust legislation.

2 Method

The narrative analysis of nudging, definitions, underlying premises and current practices is based on a systematic literature search conducted from the 28th of October to 13th of November in the following databases:

- Medline via Ovid
- Embase
- TRIP Database

More than 60 articles were unlisted as relevant as a result of searches that used terms as Nudge, Nudging, In/equality, In/equity and Life Style Change (s), Life Style Factor (s), Health Determinant (s). A total of 62 articles were unlisted and in addition, 25 more articles were hand searched.

The narrative analysis of the researched literature was carried out based on the research questions outlined above to clarify the relationship between nudging, the *big four* health issues, and health inequalities.

3 Results

3.1 Definitions and premises

3.1.1 Definitions

A simple nudge, in other words a gentle push in a direction, is the popular nickname for what is also referred to as choice architecture. Building upon insights from behavioral psychology and economics, choice architecture attempts to design impactful ways for presenting different choices to consumers. Up until recently, the field of choice architecture was predominantly lead by marketing companies that have made use of non-deliberative ways to sell their products to the costumers [6]. However, since the early 2000s, governments of the United States and the United Kingdom have tried to apply behavioral insights into the public structures, and other countries like Canada, France, Singapore, New Zealand, and Australia have followed since.

Nudging, as defined by the coiners of the term Thaler and Sunstein, is "... any aspect of the choice architecture that alters people's behavior in a predictable way without forbidding any options or significantly changing their economic incentives. To count as a mere nudge, the intervention must be easy and cheap to avoid. Nudges are not mandates. Putting the fruit at eye level counts as a nudge. Banning junk food does not" [3]. As opposed to the mere giving of 'sticks and carrots', i.e. rewards and

punishments for the sake of inducing behavior, nudging involves the usage of "subconscious cues (such as painting targets in urinals to improve accuracy) or correcting misapprehensions about social norms (like telling us that most people do not drink excessively)" [4]. It can also include altering of "the profile of different choices (such as the prominence of healthy food in canteens)" or changing of the default options "(such as having to opt out of rather than into organ donor schemes). Nudges can also create incentives for some choices or impose minor economic or cognitive costs on other options (such as people who quit smoking banking money they would have spent on their habit but only being able to withdraw it when they test as nicotine free)" [4].

In this report, the terms of health inequality and health inequity will be used in the sense that health inequalities are unavoidable differences in the distribution of health determinants between different population groups whereas health inequity refers to avoidable differences that are unfair and are to be changed.

3.1.2 Premises behind nudging

Nudging operates on the premises that a) people are not *rational economic optimizers* when making decisions, b) that the environment can be reshaped such that people's actions better reflect their underlying real desires through the above mentioned subtle cues and alike, c) and that the government, in some respects, knows better what is good for the individual.

Choice architecture works within the framework of behavioral psychology dating back to the 1970s research of David Kahneman and Amos Tversky, which suggests that people are not conscious and rational when making decisions. Kahneman and Tversky found that when faced with a decision, people not only tend to take mental shortcuts that ease their cognitive load of making a decision [7], but they also tend to be erroneous [6]. The theory of *heuristics*, i.e. mental shortcuts, assumes that an individual cannot really fit the rational Socratic ideal of thorough integrity between thoughts and actions, but rather that the individual tends to decide in more intuitive ways described in plain language by terms such as *educated guess, rule of thumb* or *common sense*. Applying Kahneman and Tversky into economics, the field of behavioral economics assumes that people are not *rational economic optimizers* when faced with a decision but that the architecture of the choice setting greatly influences their decision-making.

Thus, the subtleties of the way the environment is shaped tap into triggering of different mental shortcuts. Subconscious cues – such as placing of red vegetables against the background of green ones and the repetition of such pattern of contrasting blocks of opposing colors – can attract our *attention spotlight* and supermarkets have learned that that which is visible is that which sells [6]. Hence, the goal of choice architecture in the government policy is to "reshape the environment in which people act" for instance by getting people's attention so that their actions "better reflect their underling 'real' desires" [8].

Whereas the private sector uses behavioral economics for the sake of driving profit, the public sector's usage of nudging claims to be for the "good" of the population The notion of choice architecture as such is based on the premises of *libertarian paternalism*, which "believes it is legitimate for governments to design environments and contexts ... in which people make decisions in order to make it easier for them to maximize their well-being" [9] without obtrusion and compulsion [4]. It needs to be noted though that some of the reasons that drive public interest in nudging are current economic austerity, attempts to change behavior in deregulatory ways, and better application of particular policies into practice.

The above outlined premises behind nudging find themselves in opposition to the *rational decision theory*, which argues that if individuals are adequately informed, they are better able to make those choices that maximize their own best interests [10]. Here lies the main difference between nudging and incentives. Whereas nudging counts with an individual who is often unable to make consistent choices for oneself due to various behavioral influences, incentive structures bet on individual's rationality to discern what is right. It assumes the individual's integrity to follow with actions what has been discerned with reason. Hence, an example of a nudge when approaching the issue of smoking would be making non-smoking more visible in the media in order to apply social pressure on smokers and support, or *nudge*, those intending to quit. Whereas an incentive in the same field would be to create a reward structure for those who are successful in quitting such as awarding them with straight cash rewards.

3.2 Current practices

Current trends in choice architecture are predominantly set by the Anglo-Saxon world with its beginnings in Tony Blair's Prime Minister Strategy Unit and Barack Obama's Office of Information and Regulatory Affairs lead by one of the coauthors of *Nudge*, C.R. Sunstein. It was however the 2010 Coalition Government in the UK that has appointed the first Behavioral Insights Team (BIT) dedicated to the application of behavioral sciences in the public sector. Since then, the team has expanded significantly, yet its objectives of "making public services more cost-effective and easier for citizens to use; improving outcomes by introducing a more realistic model of human behavior to policy; and wherever possible, enabling people to make 'better choices for themselves'" remained the same [11]. Recently, the BIT has expanded its activities to Singapore and Australia's New South Wales, which established their own BIT units and in 2015, Barack Obama issued an Executive Order formally establishing the Social and Behavioral Sciences Team. The Nudge Unit, as the BIT is nicknamed, is a social purpose company, which works in various areas of public policy ranging from sustainability and local governance, to tax and health. In the past two years, the BIT has expanded its health programs specifically focusing on the areas of "behavioral drivers of health and the administrative efficiencies of healthcare systems", and it is its health related work that this report focuses on in the context of the *big four* health issues [12].

The BIT has created a framework called EAST, which is a heuristic of heuristics, in other words a mental shortcut introducing the theory of mental shortcuts. EAST suggests that if the government wants to encourage a behavior, it should think about making it [6]:

- Easy
- Attract
- Social
- Timely

In the context of the *big four*, Table 1 introduces a list of interventions that fall under the heading of nudging and focus on the health issues concerned.

Table 1: EAST applied to the big four health issues, Sources: [6, 9, 13]

	EASY	ATTRACT	SOCIAL	TIMELY
Smoking	Reduce cues for smoking by keeping cigarettes, lighters and ashtrays out of sight	Put stickers on pregnancy tests pointing out that the purchaser could easily access help to stop smoking in pregnancy	Make the public know that majority of smokers want to quit smoking	Target the moments of 'transfer' when new habits are being created, such as first-time mothers
Alcohol consumption	Serve alcoholic drinks in smaller glasses	Prevent alcoholic drinks from being put at the end-of-aisle spots in supermarkets as that increases sales	Make the majority of students know that binge drinking at university is not the default behavior	Make General Practitioners recommend their patients not to consume excessive amounts of alcohol right after the check-up as that is when patients are most responsive
	EASY	**ATTRACT**	**SOCIAL**	**TIMELY**
Nutrition	Nudge supermarkets to introduce smart shopping baskets that counts calories and keep separate compartments for fruit and vegetables	Put nutrition labels on pre-packaged food in university halls at the level of eye-sight for healthier food to sell better	Use eyes and faces in health nutrition campaigns as that tends to make people behave more virtuously	Make food choice in canteen available ahead of time as that boosts people to be more consistent with choosing the healthy option
Physical activity	Make public transport and city bikes easy to access and easy to use	Create an entertaining show aimed at young children to make a healthy lifestyle fun and automatic	Make physical activity the social norm, such a walking up the stairs in public	Support the making of commitments towards being fit or losing weight

3.2.1 Easy

"If you want to encourage something, make it easy", a statement by the coauthor of the *Nudge* R.H. Thaler summarizes the first principle of applying behavioral sciences to policy [6].

One of the ways of simplifying is through the work with *friction costs*. Friction costs represent obstacles that a person finds on the way towards performing an action and "it explains why otherwise perfect models might sometimes throw out predictions at odds with messy real-world observations" [6]. Friction can be either reduced or applied, depending on the outcome observed. The reduction of cues for smoking by keeping cigarettes, lighters and ashtrays out of sight is an example of applied friction. When kept out of sight and out of reach, applying the extra cost of getting a cigarette has a plausible effect towards putting people off from smoking. To the contrary, removing friction from travelling by the public transport, such as making the transport scheme more user friendly, barrier-free, and easy to understand, or establishing city cycle schemes encourages people to choose the healthier option [6].

The other key concept in simplifying is the work with defaults. Bryan Wansink's research on eating behavior suggests that people are generally inattentive as to the amount of food they consume and use external cues to decide how much to eat [6]. "Plate shapes and package sizes, lighting and layout, color and convenience" contribute to how much a person eats and so setting up the default option of placing smaller plates in school canteens may help tackle obesogenic behavior as well as serving alcoholic drinks in smaller glasses may help to limit the amount drank [14]. As it was the case in the UK and the US where the default of pension schemes changed from opt-in to opt-out, in the UK alone, the "proportion of employees of large firms saving for pensions rose from just over 60% ... to over 80%" [6]. Due to people's natural tendency towards inaction, 90% of all eligible workers chose not to opt-out while at the same time 9 out of 10 workers supported the opt-out system – showing that having automatic enrollment as the default is the better option [6]. By setting the healthier option as the default and by removing the friction costs involved, such as in the case of smart easy-to-use shopping baskets in supermarkets that add up calories, salt or added sugar and have compartments for vegetables and fruit, the simple nudge can contribute markedly towards health in general [6].

3.2.2 Attract

Getting person's attention is one of the key strategies in nudging. Tapping into the limited *attention spotlight* is crucial for the sake of the message to be registered.

One of the means of attracting is by making the key point in the message salient or distinctive. For instance, in order to get pregnant women realize as soon as possible that their habit of smoking can cause harm to the newborn and get help to quit, one of the options is to put a salient sticker "on pregnancy tests pointing out that the purchaser could easily access help to stop smoking" [12]. A research conducted at Cornell University, Ithaca, NY also concluded that putting salient "nutrition labels on pre-packaged foods in a large university dining hall produce[d] a small but significant reduction of labeled high calorie and high fat foods purchased and an increase in low calorie, low fat foods" [13]. The BIT has also tested for the use of different easy-to-understand labelling and concluded that "a four-light traffic-light system leads to significantly lower calorific choices than a three-light system" (with red marking the least healthy

and green the most healthy foods) and that "adding a human figure also improves impact" [6]. Furthermore, working with salient messages can also involve guiding providers of services to make healthier choices more distinctive. For instance, preventing alcoholic drinks from being put at the end-of-aisle spots in supermarkets has a major impact on their sales. Because our eyes naturally scan as we turn corners, items placed at the end of aisles sell better [15]. A non-alcoholic drink at the end of aisle increases sales by 52-114% and an alcoholic one by 23-46% [15].

Moreover, what helps to attract person's attention is addressing the person by name. The BIT has tested the impact of personalization with the UK's tax office of HMRC and found that just by sending the tax letter in a white and not brown envelope with a personalized message on top, such as 'Michal, you really need to open this', the "envelope raised the response and completion rate in previous non-respondent from 21.8 to 26%" [6]. Such personalized messages could be made use of also in the health setting for instance in sending text messages to avoid missed doctor appointments reminding people the date and time of their appointment signed by the doctor or nurse (as the messenger acknowledgment seems to also boost response [6]).

In order to boost physical activity, Islandic televisions show *Lazy Town* with its main protagonist Spotacus attempts to nudge children towards understanding the importance of health and fitness. Sportacus, a portmanteau of the ancient figure *Spartacus* and the word sport, attracts the attention spotlight of children and gives them cues for a healthier lifestyle. *Lazy Town* is an attempt to make incentives more attractive and, combined with salience and personalization of messages, may positively contribute towards public health.

3.2.3 Social

People are strongly influenced by what others do. Watching a comedy with someone else makes a person laugh twice as much and the more fellow diners one has around the table, the more one eats [6].

Social nudges in the context of the *big four* health issues for the most part revolve around correcting of misapprehensions about social norms. In a 2011 US study, researches put signs next to elevators stating that stair use is a good way of getting some exercise but such nudging did not work. Instead, telling student that "most people use the stairs" lead to an increased stair use by 46% [16]. Based upon the same principle, social nudges could be introduced to clarify to smokers that majority of smokers actually want to quit as well as to explain to university students that binge drinking is not the norm [6]. In terms of alcohol consumption, the BIT has found that pubs that require customers to order behind the counter tend to contribute to the culture of 'rounds', which puts unduly pressure on those members of the group who would have otherwise not ordered another alcoholic drink [6]. A restaurant style ordering behind the table seems to be the type of a nudge that creates less social pressure and hence leads to less drinking [6].

Another element of social nudging is the use of network suggestions and reminders of others. BIT conducted a randomized controlled trial in an investment bank concerning raising money for charities and concluded that if sent a personal email followed by a tub of sweets, 17% more employees of the bank were ready to give their day's salary to the charity [6]. In terms of reminders of others, several studies have indicated that "eyes and faces looking at us tend to make us behave more virtuously" [6]. Such could be used in nutrition campaigns as a personal remainder to eat healthier foods. Social norms, network suggestions and reminders of others represent a group of subtle social nudges that can, via the use of subconscious cues and corrected misapprehensions about social norms, contribute towards targeting some of the *big four* health issues.

In the context of social nudging, policymakers tend to miss the power of social norms and inadvertently use them in counterproductive ways. They commit what Robert Cialdini, author of the book *Influence*, calls *the big mistake* [17]. By emphasizing the negative behavior on the social scale, policymakers tend to discourage the behavior they want to reinforce. For instance, in the health care contexts, "signs in doctor's surgeries about the number of people who missed their appointments in the last month" creates the norm that missing an appointment is socially acceptable, even though its intention is to put people off from missing their appointments [6]. Conscious architecting of social norms is one of the means to avoid making of the *big mistake*.

3.2.4 Timely

Timing is another important part of choice architecture. Interventions tend to be more effective when timed well; before habits kick in, when behavior is disrupted, and when rightly framed against the backdrop of 'time inconsistency' [6].

In order to get people acting in ways that are more consistent with people's underlying preferences, governments need to design their interventions in a timely manner. It has been reported that critical periods matter in adulthood as well as they do in childhood [6]. The David Olds Nurse Family Partnership of supporting young at-risk mothers, developed in the US but applied also in the UK, showed particularly good results with mothers having their first child [18]. "It was not clear if it had any effect at all on mothers having second or later child" and it was concluded that the reason lies in the question of habits. "Learn it first, learn it right" is a mantra that captures well how critical timely interventions are [6]. It is therefore particularly critical to pin-point those 'transfer' moments in people's lives where new habits are being created such as pregnancy, moving of houses, change of work, and others. For pregnant women, the time of pregnancy with the first child seems to set the habits for the following and hence if asking when to target mothers to adopt a heathy lifestyle and stop smoking, it is during the time of first pregnancy [6].

Not only is it crucial to impact upon unhealthy behavior in the process of habit creation, but it is also important to time the advice appropriately. After being examined at the general practitioner's office, i.e.

after metaphorically receiving the 'gift of advice', it seems to be the crucial time when patients are most receptive to the doctor's advice on healthy lifestyle, moderate alcohol consumption and physical activity [6].

Because of people's 'time inconsistency' of discounting the future and focusing on the present, it is crucial to follow through the health choices made in the past. In a study on 'time inconsistent preferences' three-quarters of Danish workers "chose fruit over chocolate when the prize was due to be delivered the following week", yet majority chose chocolate when offered the choice at the point of delivery [19]. Hence, choices in school canteens could be made in advance with the aim of nudging the heathier behavior. Another possible timely intervention in the context of the *big four* is to create the structures so as to avoid time inconsistency. A stickk.com, an internet platform, focuses precisely on helping people follow through their decisions and so far has helped "people complete 300,000 workouts, and has prevented more than 2,500,000 cigarettes being smoked" [6]. If timed well, such help can have a major impact on the *big four* health issues.

Applied to the *big four* health issues, the EAST framework has the potential to architect healthier choices in a deregulatory way.

3.3 To nudge or not to nudge

The third part of the report is concerned first with objections to nudging and its critical reflection, mainly from the side of paternalism, and second with the question of health inequalities and nudging in particular.

3.3.1 Criticism of paternalism in nudging

The theoretical debate around nudging revolves mainly around the notion of *paternalism*. As mentioned above, the notion of choice architecture as such is based on the premises of *libertarian paternalism*, which "believes it is legitimate for governments to design environments and contexts ... in which people make decisions in order to make it easier for them to maximize their well-being" (paternalism) [9] without obtrusion and compulsion (libertarian) [4]. It is however unclear where the boundaries of compulsion are when it comes to subtle deregulatory moves of choice architecture. Problems highlighted in the literature range from the questions of consent and autonomy, manipulation and coercion, to responsibility and moral character.

One of the core criticisms is the question of consent and autonomy. As mentioned above, a core premise behind nudging is the assumption that governments act in the name of *public good* and hence implicitly claim to know better what is good for the individual. Understandably then, in the context of the current economic austerity, this premise stirs disagreement for it seems to intrude on person's autonomy for the sake of a 'dubious' public good. As it is the case with the private sector that uses nudges for budget-

driven reasons in marketing and sales, the government's usage of nudges can also be perceived against the backdrop of budget implications and cost-effectiveness, and hence not necessarily viewed by the public as a public good.

What if it is the case that people do act "against their own best interests – by using drugs, eating junk, failing to save or taking loans they can't repay ... because of individual behavioral flaws, [20] not because of poverty, inequality or lack of hope" [21]? Nudging seems to disregard the question of individual's autonomous decision of consent, but in the context of the *big four*, it pursues a particular understanding of what is good for an individual. Nudges may be oriented towards trying to make a person quit smoking, because smoking as such causes negative health implications that the health care system needs to bear, without attempting to get the person's agreement. By some, this can be perceived as manipulation or coercion because "libertarian paternalism often fails in its promise to track target agents' own normative standards" and so it manipulates the person into what it perceives as 'good'" [22]. "The use of public authority to change citizens' behaviours, even if the altered behaviours are better for the citizens themselves, violates spheres of privacy, integrity and autonomy ... The state ought not to patronise people, by singling out a subset of the population and treating them as if they lacked the full use of reason" [20].

Moreover, such singling out may have a negative impact on the person's sense of responsibility and moral character. Because "[n]udges, by aiming at behavioural change through strategic manipulation of cognitive patterns, achieve their objective neither through education nor personal will", there is a risk that such choice architecture will only weaken person's "capacity for self-control" [23]. There is a possibility that nudging, having brought for the most part financial benefits in short-term, will long-term contribute to weakening of moral character and *infantilisation* by "decreasing responsibility in matters regarding one's own welfare" [23]. Because nudging in the public sector is a relatively recent development, there is little data on its long-term sustainability, which will eventually prove or disprove its impact on responsibility and moral character. "[T]o date, few nudging interventions have been evaluated for their effectiveness in changing behavior in general populations and none ... has been evaluated for its ability to achieve sustained change of the kind needed to improve health in the long term" [4].

The above mentioned criticism attempts to qualify the notion of choice architecture as compulsive, and hence not really libertarian but only paternalistic. Such perspective implies that nudging rather falls under communitarianism and not libertarianism by its priorities set on what contributes to the communal good rather than what is good for the autonomous individual.

3.3.2 Critical reflection

It is naïve to expect nudging not to include any compulsion whatsoever. "[I]n many cases, we face informational constraints on what a person's good really is" and the government's drive for cost-

effectiveness by definition will compel people to act a certain way [22]. a) However, because no intervention is neutral, nudging is inevitable. It remains to be a matter of *how* the choice architecture will be designed and b) here the notion of transparency and public scrutiny is needed in order to prevent manipulation and coercion. c) Indeed, respecting the limits to ethically acceptable forms of nudging that respect person's autonomy is crucial and, d) in order to avoid unethical nudges, governments should consult with a specimen of the target group of individuals in advance of the nudge. e) The evidence seems to suggest that nudging works best with those already heading the direction of the nudge anyway.

No policy intervention is neutral and every policy intervention is based on a set of assumptions that serve as its theoretical underpinnings. Choices are presented to individuals and hence "[c]hoice architecture happens anyway, it is just a matter of how we do it, not if" [24]. Indeed, "once you know that every design element has the potential to influence choice, then you either close your eyes and hope for the best, or you take what you know and design programmes that are helpful" [25]. Hence, choice architecture cannot be avoided. Applied to the health care context, "[c]linicians will usually have an opinion about what course of action represents the patient's best interests and thus may "frame" information in a way which "nudges" patients into making choices which are considered likely to maximise their welfare" [26]. This kind of nudging can be viewed as "interfering with patient autonomy and constitute medical paternalism", however clinicians cannot avoid giving advice but rather "have a responsibility to try and correct "reasoning failure" in patients" in order to maximize their wellbeing [26]. Therefore, nudging as a policy measure is inevitable.

Despite the fact that nudging is inevitable, the question of '*How* to nudge?' remains to be answered. Nudging ought to be transparent with clear limits and open to public scrutiny, so as to define what the public good is.

Bovens suggests that there is a need to distinguish between two sorts of transparency, one that tells people directly about an intervention and second that ensures that a "perceptive person could discern for [himself] that an intervention had been implemented" [27]. In the case of nudges however, "this fuller sort of transparency might limit the effectiveness of the intervention" and so the latter, weaker form, should be adopted [27]. Bovens suggests that the latter is ethically acceptable "provided those who were nudged had the ability to discern its implementation" [27]. Such condition is necessary as it is arguably ethically unacceptable to nudge with the use of subliminal message such as priming. It is "wrong to influence people in a way that they are incapable of identifying" and it is under these circumstances that nudging respects person's autonomy and thus avoids the criticism of manipulation and possible coercion [27]. Because "coercion entails an element of control over the behavior of agents" and because it is "not plausibly displayed by the kinds of serious examples of nudges posited in the literature", such nudging is to be considered ethically sound [28]. Nudging needs to be detectable by perceptive individuals and so left open to public scrutiny.

In order however, to get better understanding of what people themselves consider *good*, it is important not only to leave it on the public scrutiny, but also to consult a specimen of the target group of the intervention (in order not to ruin the nudge, it is enough to consult just a specimen of the target group for the sake of bettering understanding). Because one type of nudge does not fit all, it is important to have nudges tailored to the target groups at stake [29]. It is a reoccurring conclusion in the literature that nudging works best with that subset of population, which inclines to the change suggested by the nudge regardless [6]. One of the explanations of why banning smoking in public places in the UK has been so successful as well as why the use of e-cigarettes has helped to "save around 100,000 years of life per annum in the UK alone" is because majority of smokers intend to quit smoking anyways [6]. Sunstein suggests that nudges are more like a GPS in the sense that they have a goal to increase navigability "of making it easier for people to get to their referred destination. Such nudges stem from an understanding that life can be simple or hard to navigate, and a goal of helpful choice architecture is desirable as a way of promoting simple navigation" [30]. Thus, the goal of nudging is to help people avoid procrastination and help them through the process of "their own value clarification" [31].

Hence, even though it is to be expected that nudging will involve some level of compulsion, it is necessary to highlight that nudging as such is inevitable. In order however, for it to be ethical, it needs to be done a transparent way (in the weaker sense of the word transparent), involve public scrutiny and respect person's autonomy through not using subliminal messages. And for the sake of maximizing of the effectiveness of choice architecture, it is crucial to consult a specimen of the target group of the intervention and see to the direction the group is heading anyways.

3.3.3 Health inequalities and nudges

The 2010 review by Michael Marmot provided a robust evidence for the link between social justice and health equity [32]. According to Marmot, "[t]here is a social gradient in health – the lower a person's social position, the worse his or her health", which suggests that health matters to justice in a fundamental way as well as that creating a fair society is important for the sake of health [32]. Marmot further suggests that "[a]ction on health inequalities requires action across all the social determinants of health", which range from income and social status, education, physical environment, social support networks to health services and gender [32]. According to Marmot, reducing health inequalities will require action on these policy objectives:

- Give every child the best start in life
- Enable all children young people and adults to maximize their capabilities and have control over their lives
- Create fair employment and good work for all
- Ensure healthy standard of living for all

- Create and develop healthy and sustainable places and communities
- Strengthen the role and impact of ill health prevention [32]

To answer the question of what is the relationship between nudges and health equity, it is suggested that if targeted well, nudging is a useful tool for reducing health inequalities and can contribute both directly as well as indirectly towards a fairer society. However, it needs to be backed up by robust legislation and alternatively also by coherent structure of incentives.

The UK's Coalition Government strategy of using choice architecture as a way "to encourage, support and enable people to make better choices for themselves" [2] has been criticized for not targeting the upstream factors that lead to inequity suggested by Marmot "such as poverty, neighborhood deprivation, and over-reliance on fossil fuels" but for focusing of "downstream factors such as how individuals absorb information and perceive choices" [4]. A systematic review "as to which type of interventions are more likely to produce 'intervention-generated inequalities'(IGI)" tentatively concluded that "downstream interventions are more likely to produce IGIs" [33].

Because nudging seems to largely ignore the socioeconomic determinants of behavior, it ought not to be used as a substitute for legislation in targeting the issue. Marmot makes "a strong evidence-based case for governmental action to promote public health, including thorough legislation, regulation, taxation, and welfare" in order to tackle the socioeconomic determinants of health [4], where choice architecture can be used as a contributing tool. That is because nudging does not focus on the "merits of privatizing social security, but the best way of doing it. It considers why Americans aren't saving more for their retirement, without mentioning that, for the majority, real wages haven't risen in a decade" [21]. It terms of health inequalities, it is to say that nudges do not focus on eradication of poverty, but for instance on making the health care system more accessible to the poor. A long term solution to health inequalities is needed and mere nudges, and also incentives for that matter, are insufficient [34]. Nudges are rather to be seen as "behavioral insights [that] are more incremental rather than revolutionary in their impact, just as the engineer's use of a wind tunnel does not fundamentally change the design of a car, but it subtly reshapes it to be more efficient, and better suited for the task it is made for" [6]. Table2 is an example of a robust strategy that includes legislative steps as well as choice architecture.

Table 2:Robust regulation to back-up nudging interventions [9].

	Nudging	**Regulating**
Smoking	Make non-smoking more visible through mass media campaigns communicating that the majority do not smoke and the majority of smokers want to stop Reduce cues for smoking by keeping cigarettes, lighters and ashtrays out of sight	Ban smoking in public places Increase the price of cigarettes
Alcohol	Serve drinks in smaller glasses Make lower alcohol consumption more visible through highlighting in mass media campaigns that the majority does not drink to excess	Regulate pricing through duty or minimum pricing per unit Raise the minimum age for the purchase of alcohol

Diet	Designate sections of supermarket trolleys for fruit and vegetables Make salad rather than chips the default side order	Restrict food advertising in the media directed at children Ban industrially produced trans fatty acids
Physical Activity	Make stairs, not lifts, more prominent and attractive in public buildings Make cycling more visible as a means of transport, e.g. through city bike hire schemes	Increase duty on petrol year on year (fuel price escalator) Enforce car drop-off exclusion zones around schools

Undoubtedly, in the context of *health in all policies*, nudging have indirectly contributed towards health and social justice through interventions such as changing the default system from opt-in to opt-out for university application for students from deprived neighborhoods in a project done in New York city [6]. By tapping into the behavioral tendencies that people have, nudging has made an important impact that contributes towards the public good (for the most part in deregulatory ways), especially in its interventions focused on health as well as in its successful interventions in other areas. Choice architecture could however, bring more impact to targeting health inequalities by applying its behavioral knowledge of specific groups of the society alongside the gradient of health, from lower social positions to higher. An example of this could be an already existing method of applying 'smart defaults' tailored to the target group [6]. In practice that could mean that against the backdrop of the behavioral psychology of poverty, nudges would be applied for instance to the group of citizens that lives below the poverty line. Such a prioritarian approach would in practice mean that decisions would be planned that "improve access to sports facilities or shops/markets that sell fresh fruit and vegetables, or the distribution of food vouchers to people of lower socio-economic status" [35]. It needs to be noted that careful considerations would need to be made to avoid stigmatization for instance by universalizing the intervention scaled alongside the Marmot's social gradient.

4 Conclusion

Choice architecture – nudging – as part of the effort of "finding intelligent ways to encourage, support and enable people to make better choices for themselves" [2], was argued to be an inevitable tool that governments should use for the sake of better provision of public health. Indeed, the deregulatory potential of nudging ought not to replace either incentive structures or robust legislation, but the EAST framework developed by BIT should be used as a complementary tool in health policy. Nudging is to "refine and improve the cost-effectiveness of policies [and] to make services easier for citizens to use" [6].

Nudging tends to be criticized for being paternalistic, assuming to know better what is good for an individual and hence involving a level of compulsion. This report suggests that nudging needs to be nonetheless applied because architecting of choices cannot be avoided. In order however, for nudging

to be ethical, it needs to be done in a transparent way (in the weaker sense of the work transparent), involve public scrutiny and respect person's autonomy through not using subliminal messages.

Because these approaches have not been used for very long, at least not in the government policy, there is little data on its long-term effectiveness. Also, there is little data on its effectiveness after having been repeated, so as to know if the effect of behavioral insights fades out with time. Undoubtedly however, the evidence suggests that nudging in short term is very cost effective [6]. Against the backdrop of health inequalities, also there, there is more research needed into the relationship between nudging and health inequalities, but nudging is seen as a potentially useful tool for its reduction. It is further suggested that nudging should focus on more upstream factors behind health inequity for instance by focusing on architecting choices for specific groups alongside the social gradient of health.

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Conflict of interests
None

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Chapter 6

Nudging in Screening: Literature Review and Ethical Guidance

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Abstract

Objectives: Nudging is the purposeful alteration of choices presented to people that aims to make them choose in predicted ways. While nudging has been used to assure high uptake and good outcome of screening programs, it has been criticized for being paternalistic, undermining free choice, and shared decision making. Accordingly, the objective of this study is to explore a) nudging strategies identified in screening, b) arguments for and against nudging; and on basis of this, to c) suggest a tentative conclusion on how to handle in screening.

Methods: Literature searches in Ovid MEDLINE and PsycINFO for combinations of screening and nudging. Screening based on content analysis of titles, abstracts, and articles.

Results: 239 references were identified and 109 were included. Several forms of nudging were identified: framed information, default bias, or authority bias. Uptake and public health outcome were the most important goals. Arguments for nudging were bounded rationality, unavoidability, and beneficence, while lack of transparency, crowding out of intrinsic values, and paternalism were arguments against it. The analysis indicates that nudging can be acceptable for screenings with (high quality) evidence for high benefit-harm ratio (beneficence), where nudging does not infringe other ethical principles, such as justice and non-maleficence. In particular, nudging should not only focus on attendance rates, but also on making people "better choosers."

Practice implications: Four specific recommendations follow from the review and the analysis: 1) Nudging should be addressed in an explicit and transparent manner. 2) The means of nudging have to be in proportion to the benefit-harm ratio. 3) Disagreement on the evidence for either benefits or harms warrants special care. 4) Assessing and assuring the intended outcome of nudging appears to be crucial, as it can be context dependent.

Keywords:

Nudging, ethics, information, choice, paternalism

1 Introduction

The purpose of screening is to improve individual as well as population health. Screening aims to detect and treat diseases in their early stages in order to reduce morbidity and increase survival. Screening is thus introduced in most health care systems for a wide range of conditions. One example of a screening program which is considered to be of great benefit is newborn screening, as the detection of Phenylketonuria (PKU) and subsequent treatment make a tremendous difference to the affected child's life.

With this goal in mind, screening providers have aimed to increase the uptake of screening programs to assure good outcomes. Building upon the knowledge from behavioral sciences that the way choices are presented has an impact on the outcome of choice, providers have become intentional about how they design the choices to the potential screening subjects [1-10]. Screening providers have thus nudged people to participate [11, 12]. Deciding on content and wording in information leaflets and invitation letters as well as making choices on providing screening as opt in or opt out may be examples of such intentional work.

Nudging is a tool of public policy decision-makers that has recently gained a lot of popularity in governments across many high-income countries like Denmark, Australia, or the UK, to name a few [13]. It presents an alternative to restrictions and incentives as it aims to influence the choice subtly, without the use of regulation. It aims to guide people in making decisions and encourage them to choose in their broad self-interest. For that reason, such intentional alteration of choices presented to people that aims to make them choose in the predicted way stirred a debate about paternalism and manipulation.

The theory of nudging operates on two assumptions. Firstly, people exhibit bounded rationality. When making decisions, rather than being rational economic optimizers, they follow their mental shortcuts and cognitive biases [13, 14]. They do not always make what rational decision theory would call the "optimal" decision, rationally weighing the options at hand and deciding for the best one, but follow other principles such as common sense, rule of thumb, or educated guess. Furthermore, their attitude to risk-taking, their current emotional states, or the time available to make a decision also influence their decisions. Secondly, institutions inevitably act in ways that influence peoples' choices and so the choice design in place pushes people one way or the other regardless of whether the institutions are intentional about it or not [15]. Becoming intentional about it, however, means that institutions need to take a stance on what is good for a given individual and nudge him or her in that direction. That however, constitutes paternalism. In daily life, default setting on a computer are a nudge, so is a text message reminding a patient of a scheduled doctor's appointment, or the graphic warnings on cigarette packages [13].

Despite great benefits of many screening programs, some screening programs have attracted vast debates and vivid controversies. There are many reasons for this. First, screening programs are directed at

healthy persons, and to improve the health of healthy persons may be more difficult than to improve the health of persons with manifested disease. Second, there has been increased attention on the negative consequences of screening programs as detecting diseases too early can lead to overdiagnosis and overtreatment. Thirdly, there have been controversies about the outcomes of screening programs, i.e., how many persons are saved from disease and death. These debates have been particularly heated for thyroid [16], prostate [17], and breast cancer screenings [18].

Such controversies raise the question of how screening programs should handle nudging. High uptake is important for good public health outcomes. At the same time, people's right to make autonomous and free choices has gained increased attention.

After having received criticism for being biased, not supporting shared decision-making, and not being clear about information on outcomes passed onto the participants [1-10, 19], many screening programs have adjusted the way they present the choice to their invitees. Nonetheless, there is still a debate on whether people are unduly nudged to ensure attendance.

Accordingly, the objective of this article is to explore a) nudging strategies identified in screening, b) arguments for nudging; and on basis of this, to c) suggest a tentative conclusion on how to handle nudging in screening. Nudging influences educational, counseling, and communication models in health care, and the awareness and handling of nudging is of great importance for patient education and counselling.

2 Methods

2.1 Material

Literature searches have been performed in Ovid MEDLINE (1946 – October 2017) and PsycINFO (1908 – October 2017) for screening and nudging (exact Search strategies are provided in appendix). The search terms were as follows:

Database: Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to Present> Search Strategy:

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1 exp Mass Screening/ (120594)

2 screening.tw,kf. (462083)

3 1 or 2 (505078)

4 (nudg* or libertarian paternalism).tw,kf. (759)

5 persuasive communication/ or (persuasion or persuasive).tw,kf. (6536)

6 (decision making/ or choice behavior/) and informed consent/ and ethics.fs. (1152)

7 4 or 5 or 6 (8345)

8 3 and 7 (228)

Database: PsycINFO <1806 to October Week 2 2017> Search Strategy:

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1 (screening and nudg*).mp. (5)

2 (screening and paternalism).mp. (13)

3 1 or 2 (16)

4 limit 3 to "0100 journal" (11)

2.2 Method

Identified references were screened for title and abstracts. References were included to full text analysis based on content relevance. Articles that addressed the following questions (in one way or the other) were included:

1. What nudging strategies are identified in which type of screening?
2. What arguments are used with respect to nudging and what are their backgrounds?

As important aspects and good arguments can appear in poor quality publications and vice versa, no quality limitations were set for publications beyond being peer reviewed indexed publications. Moreover, as the point is to identify important aspects of nudging in screening (content) and not extension (i.e., counting how many times certain aspects are mentioned or discussed), the review does not aim at being exhaustive. Unless references add new aspects or nuances, they are not included. Hence, the review does not pretend to be exhaustive.

Articles were analyzed according to standard content analysis [20] to address the above questions. Primary screening was conducted by BH and checked by MS.

3 Results

239 references were identified. 75 references were included after removing duplicates and after irrelevant articles were assessed by title. Of the 75 references, 56 were included based on assessing abstracts. 43 of these were included based on the content of the articles. Additionally, 76 references were added by a snowballing technique.

The topics identified in the literature that concern the empirical practice of nudging in screening are structured under: forms of screening, types of nudging, and aims of nudging. The topics that concern the theoretical discussion about nudging in screening are presented as arguments for or against nudging,

as well as who does the nudging. An overview of the search results are given in Figure 1 and an overview of the other results is presented in Table 1.

Table 1:Overview of results of empirical practice and theoretical issues and arguments

Empirical Practice of Nudging in Screening					
Types of screening	Prenatal screening [21-27],	Newborn screening [28, 29],	Adult screening		
Examples of Conditions	Obesity [30-33]	diabetes [34, 35]	abdominal aorta aneurisms [14]	HIV [21, 37-39]	chronic beryllium disease [36]
Examples of Conditions	Various types of cancer screening [40-58], predominantly breast cancer screening [2, 59-75]				
Aim of nudging	Ensure high uptake and attendance [76]	Promote screening among decision-makers (second order nudging) [14]			
Forms of nudging	Framing information [2, 62, 65, 69, 70, 75, 77-85]	Default bias, e.g., predetermined appointments [49, 86, 87]	Screening kits sent by mail [49]	Personalized letters, educational phone calls and videos [42]	Telephone reminders [49]
	Minor monetary incentives [89]	Appeals to fear [90]	The offered service appears as a recommendation [45, 65]	Appealing to people's sense of responsibility, solidarity, and duty [45, 65]	
Theoretical Issues on Nudging (arguments on nudging and their basis)					
Premises	Unavoidability		Bounded rationality [92]		
	Any screening recruitment strategy has an inevitable impact on the choices		People are not able to make rational decisions [93]		
Arguments	Beneficence with screening [This is the main argument for nudging mentioned in most publications]		Authority, Paternalism [12, 21, 23, 30, 48, 65, 66, 77, 87, 92, 94-110]		
	Increased outcome, efficiency, deregulatory [13, 113]		Less transparent, difficult to monitor [99, 108]		
	Making better choosers [114]		Undermining accountability [100]		
Who is nudging	Health authorities / providers		Experts		
Who is nudged	The population		Decision makers		

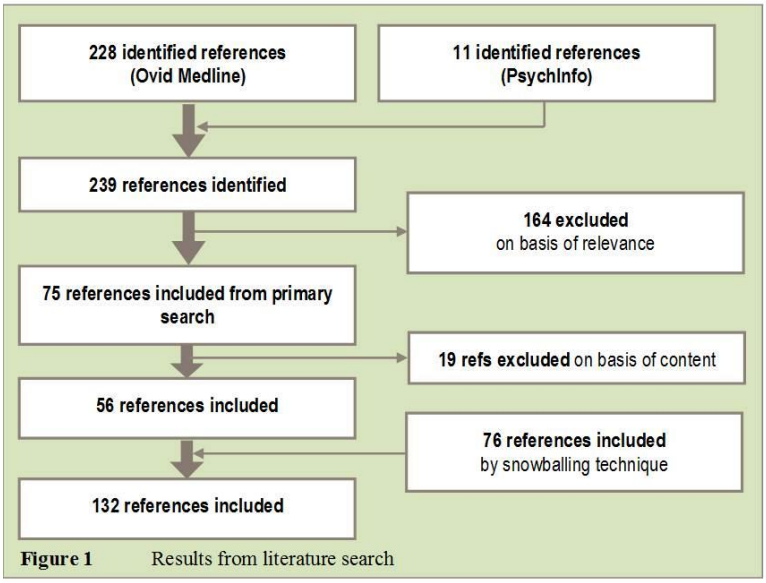

Figure 1 Results from literature search

3.1 What nudging strategies are identified in the literature?

3.1.1 Types of screening where nudging is discussed

Nudging is discussed in a wide range of areas, such as prenatal screening [21-27], newborn screening [28, 29], and adult screening. Nudging is also debated in areas such as screening for abdominal aorta aneurisms [14], obesity [30-33], diabetes [34, 35], chronic beryllium disease [36], and HIV [21, 37-39]. However, the majority of references are to various types of cancer screening [40-58], predominantly breast cancer screening [2, 59-75].

3.1.2 Aim of nudging

The aim of nudging is mainly to ensure high uptake and attendance [76], but nudging has also been discussed in the context of scientists framing research results for health decision-makers in order to promote screening (second order nudging) [14].

3.1.3 Forms of nudging in screening

Several forms of nudging are identified in the literature. Framing information is the most predominant form discussed as nudging [2, 62, 65, 69, 70, 75, 77-85]. Another form of nudging is working with the default bias, e.g., predetermined appointments [49, 86, 87], as well as screening kits sent by mail (reduction of the "hassle factor/friction cost") [49]. Personalized letters, educational phone calls and videos [42], as well as telephone reminders (availability heuristics) [49], persuasion [88], and GP's signature (authority bias) [49] are also discussed. Minor monetary incentives [89], appeals to fear, and the use of threats have also been discussed [90]. Moreover, the mere offering of a screening program is interpreted as a recommendation by the public and may also be viewed as nudging [45, 65]. In this

context, appealing to people's sense of responsibility, solidarity, and duty have been pointed out to be mechanisms by which to increase attendance.

3.2 What are the general arguments for nudging based on?

Nudging has been endorsed by a range of arguments identified in the literature.

3.2.1 Premises upon which nudging operates

Nudging has been defended on grounds of a) unavoidability and b) bounded rationality. With respect to the former, it is argued that any screening recruitment strategy has an inevitable impact on the choices that people make. It expresses some type of influence. With respect to the latter, it is argued that people are not able to make rational decisions [91]. While some argue that the evidence for our bounded rationality is wanting [92], the point has been backed by influential research in behavioural sciences [93]. Hence, as we cannot avoid choice design, or be neutral about it, we may as well be intentional about it and thus nudge.

3.2.2 Paternalism

Nudging has also been associated with authority and paternalism. Intentionality about nudging leads to paternalism and to the questions of what kind of paternalism and hence what kind of consent is required [12, 21, 23, 30, 48, 65, 66, 77, 87, 92, 94-110]. While paternalism has been previously the *modus operandi* in health care, it has gained less favor with the increased respect for autonomy [83, 111, 112].

3.2.3 Beneficence

The main pragmatic argument for nudging in screening is related to the beneficence of screening, i.e., the net benefits over risks and harms. For example, there is a broad agreement on the benefit of newborn screening for PKU, and nudging has been used to increase uptake. Increasing the uptake thus increases the overall benefit.

3.2.4 Deregulatory nature of nudging

Nudging is also argued to be deregulatory and efficient [13, 113], and hence, more covert, less transparent, and more difficult to monitor than traditional regulatory tools [99, 108]. If this is the case, it could also be an argument against nudging as one empirical study shows that nudges appear to undermine accountability [100].

3.2.5 Help "bad choosers"

Another interesting issue debated in the literature is whether people should be nudged to make informed choices [114] because, at times, people are "bad choosers" as they may choose without being informed

or be under strong influence from others. Nudging can be used to improve their understanding and thus strive to make them "better choosers" – more in line with intrinsic values. For instance, it can be focused on improving the understanding of reasons for undergoing screening programs and thus be less paternalistic.

3.2.6 Who is nudging who?

While most of the screening literature on nudging is about health authorities or nudging the population in the interest of public health or screening providers nudging individuals, some attention is also given to patient groups or experts influencing decisions on various types of screening, e.g., through the economic models they use in health technology assessments [14]. In such second order nudging (see above), scientists may try to influence decision makers [14]. This indicates that stakeholder interests are important in assessing nudging in screening.

4 Discussion and Conclusion

In this article, we have reviewed the screening literature for references, discussions, and reflections on nudging. We have identified several forms of nudging (framed information, default bias, authority bias), which fit well with the general nudging literature [61, 106, 108, 115].

We have also found that nudging is discussed for a wide range of screening programs and for diverse screening target groups. This is not surprising as uptake and public health concerns are crucial to most screening programs. We did also identify several arguments for nudging in the literature, such as bounded rationality, unavoidability, and beneficence, while lack of transparency and paternalism are arguments against nudging.

4.1 Discussion

4.1.1 The pro and cons of nudging in screening

The main pragmatic argument for nudging in screening is its beneficence. While there is a wide agreement on this for PKU screening, there is less agreement with respect to both benefits and harms for other types of screening. Hence, one crucial criteria deciding on nudging in screening appears to be whether there is a large benefit-harm ratio and whether there is consensus on this. Nudging appears to be easier to justify if the benefit is great and there is little risks of harm, which, in fact, should be the basis for justification of any screening program as such. However, no screening program is 100% sensitive and 100% specific. Hence, a specific assessment of risks of possible harms related to false positives, false negatives, overdiagnosis and overtreatment, as well as adverse effects of diagnostics and treatments has to be balanced against benefits. Some would argue that one should never offer a screening

program unless the benefit-harm ratio justifies nudging. However, this would exclude a range of screening programs offered today, as their benefit-harm ratios are contested. Ideally these programs should be discarded, but it is difficult to disinvest or abolish screening programs [116]. This poses the difficult question of whether nudging is warranted in these cases. Such non-ideal situations could warrant non-ideal nudging strategies, i.e., moderating nudging ambitions when benefit-harm ratios are not favourable or contested.

Correspondingly, the ethical principle of non-maleficence and justice are relevant as well. Screening programs may harm individuals who do not benefit from participation (opportunity cost). Hence, it can be argued that screening healthy persons violates the principle of justice as long as there are suffering persons that will not receive relevant treatment. While these arguments may be used against screening of healthy persons altogether, they may not be relevant against nudging in (existing) screening programs.

Another criterion appears to be to what extent people experience that nudging affects their self-determination. If people do not feel pushed in certain directions, but feel nudged to become better choosers and choose more in accordance with their explicit or implicit values, nudging may be less objectionable and more appropriate. However, this depends on how subtle the nudging is. For instance, nudging families to donate their deceased relative's organs may amount to unwarranted manipulation in an emotional situation [117]. This can be categorized as a "shove" and not a nudge, which is more paternalistic and thus harder to justify.

The use of nudging strategies has been criticized for "crowding out" the intrinsic motivation – forcing out the natural reasons due to which people tend to participate in screenings – driven by understanding of the benefit of screening [118]. On the one hand, in Germany and England, nudging strategies were used to boost the attendance of their breast cancer screening program. In both countries, the strategies worked in the sense that they increased the turn up to screenings to 50% in Germany and 70% in England. However, only 2–4% of both German and British women understood the benefit of screening and the rest overestimated the benefit 10-fold, 100-fold, or 200-fold or did not know [43]. On the other hand, Russian women that were not nudged to participate in breast cancer screening had a lower turn up, but 18% of them understood the reasons for undergoing such screening [43]. This data suggests that nudging for the purposes of increased participation worked, but possibly crowded out the intrinsic motivation for participation in screening (knowledge of its benefits).

Another issue is related to uncertainties and continuous advances in knowledge and technology. As no preventive methods are perfect, there are uncertainties with offering screening. However, advances in knowledge or technology may continuously alter the various types of uncertainty. For example, overdiagnosis was not an issue for breast cancer screening for many years (although being present) and digital mammography has changed the accuracy of screening. Hence, public health decision-makers must update their knowledge continuously and adjust their screening programs accordingly, including their nudging strategy.

The argument that nudging is justified and even needed as we are not rational agents [108] is difficult to defend, as it justifies other types of (hard and/or strong) paternalism, e.g., shoving or compulsory screening (and not just nudging). At the same time, the arguments that we cannot avoid influencing peoples' choices by the way we inform about and offer a screening, are in line with the general literature on nudging [97,115] and are compelling. People have different interpretations of what it means that the way choices are presented (i.e., the choice design) has an inevitable impact on decision-making. Some will argue that it means that we should be intentional and hence paternalistic. Others will argue that we should not be intentional (and hence not nudge) and leave choice design to have its impact of people's decision-making in a random way.

As it may be very difficult to provide screening in an objective or neutral way that does not influence people's choice, the crucial question is much less whether to nudge or not to nudge, but more how to inform and apply a recruitment strategy that is ethically sound.

4.1.2 Lessons learned

The first lesson learned from the review is, therefore, that choice design may not be avoided, and that addressing it in an explicit and transparent manner is of the outmost importance. Being intentional about choice design of screening provision is better than closing our eyes [119]. Being transparent about nudging is also crucial for the sake of avoiding manipulation. A sufficient level of transparency is necessary for patients to be able to recognize that they are being nudged. Moreover, this is of great import for education, counselling and communication in health care.

The second lesson is that means of nudging have to be proportional to the benefit-harm ratio. If the benefit is documented to be great while the harm is low, nudging can be warranted. If the benefit-harm ratio is very low, we should of course not offer screening, while if the ratio is exceptionally high, compulsory participation may be considered (i.e., paternalism, as is the practice for PKU and extended new-born screening in some places).

The third lesson is that when there is disagreement on the evidence for either benefits or harms, we should be very cautious and careful. For example, a recent study shows that the published outcomes of mammography screening are highly polarized [120]. When nudging is used in cases where research data is polarized, the tool of nudging may be misused for the pursuit of one or the other goals of the contradicting "poles". In such cases one should be specifically careful and refer to results from independent sources (not identified as being polarized).

The fourth lesson learned is that appropriate use of nudging is context dependent [74,121–123]. In certain cultural contexts, nudging may be counterproductive, e.g., opt-out approaches may decrease attendance rates [21]. Moreover, there may be social or cultural diversity in the target group, e.g., where persons in various social groups may experience and act on nudging quite differently [98]. Hence,

context sensitivity and “tailored nudges” [124] may be important to make sure that nudging outcomes are in accordance with its intentions.

4.1.3 Weaknesses of the study

As with all empirical studies, there are some weaknesses with this study. First, there may be other relevant search words or other databases that might have increased the number of included articles and the identified issues. However, as reference comprehensiveness is not within the scope of this study, the number of references is not as important as comprehensiveness in issues, reasons, and arguments on nudging in screening. With respect to the latter, the 10 lastly added references did not add any new issues. The aim of this study was neither qualitative comprehensiveness (to identify all relevant issues, e.g., nudging by phone call reminders in screening for prostate cancer), nor quantitative comprehensiveness (to identify all articles discussing such specific issues).

Second, other researchers may interpret the findings differently, and third, even if interpreted in the same manner, the findings may lead to other conclusions than what we have made. We fully accept this, but this is why we have made this review as transparent as possible in order for others to scrutinize and discuss our work. We welcome other researchers to apply or comment on our findings.

4.2 Conclusion

This review has identified several forms of nudging in the screening literature, such as framed information, default bias, and authority bias.

We have also found that nudging is discussed for wide range of screening programs and for diverse screening target groups. Uptake and public health outcome are the most important goals. The review has also identified a wide range of arguments for intentional nudging in the screening literature, such as unavoidability, bounded rationality, and beneficence, while lack of transparency, crowding out of intrinsic values, and paternalism are arguments against nudging. This fits well with the general nudging literature.

Four specific lessons have been learned and result in recommendations:

1. As choice design may not be avoided, we need to address nudging in an explicit and transparent manner.
2. The means of nudging have to be assessed in light of the benefit-harm ratio.
3. We should pay special attention when there is disagreement on the evidence for either benefits or harms.
4. The outcome of nudging can be context dependent, and what nudges one group towards a specific goal may have the opposite effect on others. Assessing and assuring the outcome of nudging appears important.

These recommendations are relevant for health policy makers, health care providers, councilors, and patient educators.

4.3 Practice implications

Nudging can be acceptable for screenings when following specific recommendations. However, this presupposes (high quality) evidence for high benefit-harm ratio (beneficence) and that nudging does not infringe other ethical principles, such as justice and non-maleficence. In particular, nudging should not only focus on attendance rates, but also on making people "better choosers."

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Conflict of interests:

We have no conflict of interests to declare.

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Concluding Discussion

Summary of conclusions

Operating at the intersection between health policy, behavioural sciences, and moral philosophy, this dissertation project provides answers to all five research questions outlined in the Preamble and it comes to the following conclusions. It claims that tragic moral dilemmas occur in the neonatal profession – particularly around the situations concerning the *limit of viability*. The more explicit reasons behind it concern the uncertainty of data and ambiguity of best interest. There is, however, also a more subtle reason that concerns paternalism and coercion that comes to the surface through the notion of nudging – particularly in communication with parents of EP infants. There is, hence, a need to recognize the role of ethics in the neonatal profession and support neonatal intensive care unit (NICU) professionals in order to allow them to grow as moral agents and to develop a practically wise judgment for morally challenging situations (judgment that is on a par with clinical judgment, but applied to the moral sphere). It is also necessary for the sake of, for instance, avoiding moral distress and thus improving the quality of care provided.

It is important to note that in many cases, what is defined as nudging (according to the Nuffield Ladder of Intervention as outlined in Chapter three [1]) is in practice described by a different vocabulary. In neonatology, the discussion about nudging uses terms such as communication strategies of choice options, which, as it is argued here, may have an impact on parental decision-making and hence also on the survival and (NDI) outcomes of extremely preterm (EP) infants. Professional biases, parental understanding, and the process of information giving were identified as aspects possibly influencing outcomes. Moreover, the way the notion of nudging plays out in the context of neonatology is further analysed and it is suggested that NICU professionals are, so-to-speak, stuck between the rock and a hard place. On the one hand, nudging cannot seem to escape its criticism of coercion because even if the choice is *just* guided by choice alteration, nudging may interfere with the agent's intention and voluntariness as well as understanding of the good. The reason why nudging is understood to be coercive in a substantive sense in because it bypasses the agent's capacity for deliberation as it aims at changing the behaviour without changing the mind. On the other hand, however, it is argued that there are situations when nudging is inevitable and hence when the NICU professionals should use the tool of nudging. It is argued that they should deal with it as transparently as possible in line with the framework of accountability for reasonableness (A4R) and their professional virtues - particularly the virtue of practical wisdom. There are even situations when "nudges to reason" are justified to improve decision-making such as when communicating data via decision aids to parents of EP infants. Based on the reasons above, it is concluded that nudging ought not to be ignored, but rather accounted for in the guidelines and trainings for NICU professionals.

Please see my Academic Curriculum Vitae in the appendix that outlines the list of oral and poster presentations I have held where the conclusions above were discussed with the relevant scientific communities.

Methods used

Details concerning the core dataset used are primarily outlined in Chapter one [2]. This dataset derived from a mixed methods approach where in the first step, a systematic literature search was conducted in six databases (Medline via Ovid, Embase, The Cochrane Library, CRD (DARE, NHS-EED, HTA), PsychInfo, CINAHL) in order to identify the most relevant sources applying the MIP (Methodology, Issue, Participants) question and inclusion criteria. The search focused both on decision-making strategies as well as on ethics in neonatology and ethical dilemmas. The MIP table together with further details concerning the systematic search and the steps of selecting studies for the analysis (such as the PRISMA Flow Diagram) can be found also in Chapter one [2]. On top of the 428 search hits from Chapter one [2], additional 127 hits were hand searched for the analysis presented in chapters two, three, and four [1, 3, 4]. Hence, on top of the 80 publications selected for the analysis and presented in Chapter one [2], 14 additional publications (of the 124 additional hits) were selected for the analysis presented in chapters two, three, and four [1, 3, 4]. Regarding the systematic search, specific search strategies can be found in the Appendix.

In the second step, interviews with the heads of departments of neonatology of five perinatal care centres and a clinical ethicist working at a NICU were conducted to gather data specific to the Austrian neonatal context. 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 a short sentence to identify themes. The main codes and themes were organised in a code-tree. Details concerning the interviews as well as an example of the code-tree can be also found in Chapter one [2]. The Interview guide sent out as well as Interview questions can be found in the Appendix. Data from the systematic search as well as the interviews were then integrated into the literature review on decision-making at the *limit of viability* that focused particularly on the Austrian neonatal choice context [2].

For the sake of quality assurance, the HTA of which Chapter one [2] is an excerpt was reviewed by an internal as well as an external reviewer (see [5]). They 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)?

Furthermore, Chapters two, three, and four are built on the dataset outlined above [1, 3, 4]. All three chapters provide an analysis of the empirical data outlined in Chapter one [2] with the aim of answering the five research questions set forth. The order in which they answer the research question is explained in the Preamble.

Chapters five and six include their own methods sections explained in the respective chapters [6, 7].

Limitations

Concerning limitations of the literature review, using only the search languages of German and English is seen as a limitation as presumably, some literature was left out. Another limitation is that the systematic literature search lead merely to a literature review and not to a systematic review. Hence, risk of bias or quality of the included studies was not assessed. The reason for unsystematic reporting was the challenge of finding a common denominator that would allow for comparison between the variety of publication types.

Further set of limitations concerns the qualitative part of interviews with the heads of neonatology departments and the clinical ethicist. More participants could be included for the sake of higher saturation and other groups of stakeholders (such as NICU nurses, obstetricians, or parents of EP infants) could be included for the sake of a more holistic picture. Both gaps provide a room for further research. Room for further research is also to be found in the need of providing a normative framework to nudging in other clinical as well as public health contexts – perhaps via developing the role respective professional virtues in combination with the A4R framework.

Contribution to the academic debate

The research project at hand aims to contribute to the academic debate in the following ways:

Firstly, it attempts to elucidate the nuances behind nudging and analyze the challenging notions that dwell at the heart of nudging: agency and responsibility. It further develops the question that is echoed in the literature with respect to the notion of avoidability. It tries to draw the line between what is avoidable and what is not in the specific context of conversations with parents at the *limit of viability*.

Secondly, while the notion of nudging is relatively widely discussed in the public health context (see Chapters five and six), there is little discussion about nudging in the clinical context. This project thus tries to bring the topic of nudging into the forefront also in the micro world of the doctor-patient

relationship. It further also attempts to show that the particular challenges in Austrian neonatology are in line with the general challenges discussed in the medical literature.

Thirdly, this project puts a finger on uncertainty as a potential source of tragic moral dilemmas. Compared to the challenge of discerning the best interest that is widely discussed as an ethically relevant issue, there is less discussion on the impact of the challenge of uncertainty on neonatal bedside decision-making.

Fourthly, this project argues that the role of ethics needs to be recognized more in order to improve the quality of care delivered in neonatology by facilitating the experience of moral dilemmas encountered by the neonatal professional. That is because ethical challenges have an impact on individual agents and thus also on the atmosphere of NICU teams. That may indirectly have an impact of quality of care provided and thus on outcomes of EP infants. It is stressed though that structural support is needed as a pre-requisite for any open discussion on ethics within NICU teams.

Lastly and most importantly, there is very little debate on the right use of nudging and on discerning the boundaries and terms of its right use. This project attempts to contribute to this discussion by offering a particular virtue ethics approach that is combined with the framework of A4R. In the neonatal ethics debate, there is next to no mention of the virtue ethics approach and hence this is another uniqueness of the present research project. This project also takes Norman Daniels' A4R framework from its macro context where is it applied it takes it to a meso context of neonatal guidelines. Moreover, it also tries to show that the A4R is equally subject to biases in the communication of rationales.

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Appendix

Dissertation abstract (English)

Neonatology and Nudging: The Case of Professional Ethics

Much of the nudging debate in Austria focuses on public health interventions and it generally takes a negative standpoint on nudging – condemning it for being too coercive. This project looks at nudging in the clinical context and argues that some forms of nudging are inevitable, while others could be used to "nudge people to reason". Alongside incentives and restrictions, nudges are understood as an additional tool of decision-makers. However, particularly due to their subtle de-regulative nature, it is argued that nudges need to be nested in a normative framework. The framework of accountability for reasonableness together with virtues of the respective professions are suggested as the solution.

This project is set in the context of neonatology, particularly in the situations surrounding the *limit of viability* (weeks 22–25 of gestation). The dataset used comes from a systematic review of literature (in six databases) as well as from in-depth interviews with five heads of neonatal departments and one clinical ethicist. Analyzed through a combination of open coding and structured thematic analysis, the aim of the interviews is to identify decision practice models specific to the Austrian neonatal decision-making context as well as moral challenges therein.

The explicit challenges identified are concerned with notions of uncertainty and best interest, while the implicit ones concern the notion of nudging. At times, these challenges make the moral dilemmas in neonatology tragic and they require a particular set of virtues. Intellectual virtues of episteme and phronesis, together with moral virtues of courage, compassion, keeping fidelity to trust, and integrity are highlighted as key for the neonatal profession. It is further argued that recognizing the tragic moral dilemmas should lead to actions taken toward establishing ethics frameworks to support neonatal decision-making, avoid moral distress, improve the team cohesion, and thus the quality of care provided.

Dissertation abstract (German)

Neonatologie und Nudging: Der Fall der Berufsethik

Ein Großteil der Nudging-Debatte in Österreich konzentriert sich auf Interventionen im Bereich der öffentlichen Gesundheit, und im Allgemeinen wird das Nudging negativ bewertet - es wird als zu zwingend verurteilt. Dieses Projekt befasst sich mit Nudging im klinischen Kontext und argumentiert, dass einige Formen von Nudging unvermeidlich sind, während andere verwendet werden könnten, um „Menschen zur Vernuft zu nudgen“. Nudges werden neben Anreizen und Restriktionen als zusätzliches Instrument von Entscheidungsträgern verstanden. Insbesondere aufgrund ihres subtilen de-regulativen Charakters wird jedoch argumentiert, dass Nudges in einem normativen Rahmen verschachtelt sein müssen. Als Lösung wird das (moralische) Konzept “Verantwortlichkeit für Angemessenheit” (Accountability for Reasonableness) zusammen mit den Tugenden der jeweiligen Berufe vorgeschlagen.

Dieses Projekt ist im Kontext der Neonatologie angesiedelt, insbesondere in Situationen, in denen die Grenze der Lebensfähigkeit überschritten ist (22. bis 25. Schwangerschaftswoche). Der verwendete Datensatz stammt aus einer systematischen Literaturrecherche (in sechs Datenbanken) sowie aus eingehenden Interviews mit fünf Leitern von Neonatologie-Abteilungen und einem klinischen Ethiker. Ziel der Interviews ist, durch eine Kombination der offenen Kodierung und strukturierten thematischen Analyse Entscheidungsmodelle zu identifizieren, die spezifisch für den Entscheidungskontext “Neonatologie in Österreich“ und die darin enthaltenen moralischen Herausforderungen sind.

Die expliziten Herausforderungen befassen sich mit Fragen der Unsicherheit und des besten Interesses, während sich die impliziten mit Fragen des Nudging befassen. Manchmal machen diese Herausforderungen die moralischen Dilemmata in der Neonatologie tragisch und diese erfordern eine Reihe bestimmter Tugenden. Die intellektuellen Tugenden der Episteme und Phronesis sowie die moralischen Tugenden des Mutes, des Mitgefühls, der Vertrauensbasis und der Integrität werden als Schlüssel für den Beruf der Neonatologie hervorgehoben. Es wird weiter argumentiert, dass das Erkennen von tragischen moralischen Dilemmata zu Maßnahmen führen sollte, die zur Schaffung von ethischen Rahmenbedingungen ergriffen werden, um die Entscheidungsfindung bei Neugeborenen zu unterstützen, moralische Belastungen zu vermeiden, den Zusammenhalt der Teams und damit die Qualität der Versorgung zu verbessern.

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 and anonymous. The following questions will be the main topics that will guide the interview.

1. How do the guideline criteria for deciding between active and palliative treatment translate into reality?
    a. 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?

2. How do social factors like educational or socio-economic background of parents influence the decision-making process?

3. 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?

Questions NICU interviews

Engagement questions

1. Could you tell about how did you come in contact with NICU?
2. (possibly, as discussed, ask questions about resources of NICUs)

Exploration questions

3. Could you tell us about the decision-making processes at a NICU?
    a. Who makes the decisions for active or palliative treatment? Based upon what criteria?
4. What is the role of parents in the process?
    a. Out of your experience, do the social factors play any role in the decision-making of parents?
5. What do you think is the role of ethical analysis in the decision-making process?
    a. What are the key ethical struggles from your perspective?
    b. What do you think are the key character traits (excellences or virtues) of the people who make the decision that are necessary for arriving at a "right" decision?

Exit question

6. Is there anything else that you would like to say about your experience with NICUs?

Main goals questions

1. What are the decision-making processes at NICU's in Austria?

2. What is the role agents, decision-makers, in the ethical analysis (what are the virtues of the profession of NICU decision-making)?

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 ((prematur* 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	periviable 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 ((prematur* 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 (prematur* 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 (prematur* 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 'periviable*':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 (prematur* 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 'periviable*':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 (prematur* 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 'periviable*':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 ((prematur* 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 ((prematur* 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 ((prematur* 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	periviable
#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