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Review Article

Prenatal counseling for extreme prematurity at the limit of viability: A scoping review

Lien De Proost[a,b,c,*], Rosa Geurtzen[d], Hafez Ismaili M'hamdi[a], I.K.M. (Irwin) Reiss[b], E.A.P. (Eric) Steegers[c], E.J. (Joanne) Verweij[c,e]

[a] Department of Medical Ethics, Philosophy and History of Medicine, Erasmus MC, Rotterdam, The Netherlands
[b] Department of Neonatology, Erasmus MC, Rotterdam, The Netherlands
[c] Department of Obstetrics & Gynecology, Erasmus MC, Rotterdam The Netherlands
[d] Department of Neonatology, Radboud University Medical Center, Amalia Children's Hospital, Nijmegen, The Netherlands
[e] Department of Obstetrics, Leiden University Medical Center, Leiden, The Netherlands

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ABSTRACT

Objectives: To explore, based on the existing body of literature, main characteristics of prenatal counseling for parents at risk for extreme preterm birth.
Methods: A scoping review was conducted searching Embase, Medline, Web of Science, Cochrane, CINAHL, and Google Scholar.
Results: 46 articles were included. 27 of them were published between 2017 and 2021. More than half of them were conducted in the United States of America. Many different study designs were represented. The following characteristics were identified: personalization, parent-physician relationships, shared decision-making, physician bias, emotions, anxiety, psychosocial factors, parental values, religion, spirituality, hope, quality of life, and uncertainty.
Conclusions: Parental values are mentioned in 37 of the included articles. Besides this, uncertainty, shared decision-making, and emotions are most frequently mentioned in the literature. However, reflecting on the interrelation between all characteristics leads us to conclude that personalization is the most notable trend in prenatal counseling practices. More and more, it is valued to adjust the counseling to the parent(s).
Practice implications: This scoping review emphasizes again the complexity of prenatal counseling at the limit of viability. It offers an exploration of how it is currently approached, and reflects on how future research can contribute to optimizing it.

Contents

* Correspondence to: Dr. Molewaterplein 40, 3000 CA Rotterdam, The Netherlands.
E-mail address: l.deproost@erasmusmc.nl (L. De Proost).

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1. Introduction

Parents at risk for delivering an extremely premature infant receive prenatal counseling. Prenatal counseling is of major importance for the parent(s), especially when the infant is born in the so-called 'gray zone', that is, at the limit of viability. When infants are born at the limit of viability, only a proportion of them survives; some without disabilities, others with serious long-term disabilities [1–3]. The gray zone is primarily characterized by prognostic uncertainty: no treatment option prevails based on what is known about the prognosis of the infant. The delineation of the gray zone, however, differs between countries going from – for example –22 and 23 weeks of gestational age (GA) in Sweden to 24 and 25 weeks of GA in the Netherlands [4–6].

A major goal of prenatal counseling for extreme prematurity in the gray zone is to facilitate decision-making [7,8]. A decision has to be made between an active care approach and a palliative comfort care approach. When parents receive counseling for extreme prematurity *beyond* this gray zone, the goal of the counseling is no longer decision-making [8]. Since the main goal of prenatal counseling changes beyond the gray zone, this article will focus solely on counseling for extreme prematurity *in* the gray zone, that is, at the limit of viability.

Overall, prenatal counseling practices are heterogenous, varying per country, medical center and physician. For example, heterogeneity has been found among trainees in regards to their use of guidelines and documentation, their education, and their provision of written material to families [9]. System-based hospital variation in prenatal counseling practices has also been found [10]. Without disregarding such variability, we aimed to identify main characteristics of prenatal counseling for extreme prematurity at the limit of viability that can be found in the existing body of literature on this topic.

2. Method

To achieve our goal, we opted for the scoping review method. Scoping reviews are considered "an ideal tool to determine the scope or coverage of a body of literature on a given topic and give clear indication of the volume of literature and studies available as well as an overview **…** of its focus" [11]. Moreover, this relatively new method is the preferred option when the research aim is to identify main characteristics of a certain topic based on an existing body of literature [11,12]. This scoping review was conducted in accordance with the scoping methodology proposed by Arksey and O'Malley in 2005 [13].

2.1. Identifying the research question

We were interested in identifying characteristics of prenatal counseling for parents at risk for preterm birth at the limit of viability. We aimed to find characteristics related to the *process* as well as the *content* of prenatal counseling. Also, we wanted to study two perspectives that are of importance in this counseling consultation: that of the parents and that of the physicians. This scoping review answers the following research question: 'What are – based upon the existing body of literature – main characteristics of prenatal counseling for extreme prematurity at the limit of viability?'

2.2. Identifying relevant studies

We systematically searched Embase, Medline, Web of Science, Cochrane, CINAHL, and Google Scholar to find relevant studies (updated until February 2021). No filter was used on date range. Only English articles were searched. Since the search string was built for a scoping review, it was construed as broadly as possible so as not to miss any relevant literature. The electronic search strategies can be found in Table 1. Additionally, we searched the reference lists of the sources that were included after full-text screening.

2.3. Study selection

Articles were included if (1) the topic was the prenatal counseling *consultation* for extreme prematurity at the limit of viability and (2) the *perspective* was either that of parents or physicians, or the *study participants* were either parents or physicians. Articles were excluded if they were (1) official policy statements, clinical reports or guidelines, (2) about the development of official policy statements, clinical reports or guidelines, (3) focused solely on the education or training of physicians to provide prenatal counseling.

Titles and abstracts of 1876 articles were screened by two reviewers (LDP, EJTV) that selected the articles independently for assessment against the inclusion criteria. The two researchers screened 143 articles full text and excluded 79 of them for further analysis. A screening of the reference lists of the 64 included articles yielded 6 more relevant articles. 70 articles were eventually included, of which 2 were systematic reviews. In the 2 systematic reviews, 24 articles were in total included. These 24 articles were screened full text but decided to be excluded from this scoping review. This decision was made because (1) no new substantive results

Table 1
Electronic search strategies (last updated 4 March 2021).

Database	Search strategy	Years of coverage	References	After de-duplication
Embase	('prematurity'/de OR 'extreme prematurity'/de OR 'premature labor'/de OR 'very low birth weight'/exp OR (prematurit* OR prematures OR preterms OR ELBW OR VLBW OR ((prematur* OR pre-matur* OR preterm* OR pre-term* OR extremely-low OR very-low) NEAR/3 (child* OR infant* OR neonat* OR birth* OR baby OR babies OR newborn* OR adolescent* OR born* OR labor* OR labour* OR deliver* OR gestat*))):ab,ti,kw) AND ('parent counseling'/de OR 'family counseling'/de OR 'counseling'/mj/exp OR (((parent* OR prenat* OR famil* OR preterm* OR pre-term* OR pre-natal* OR prematur* OR pre-matur* OR antenatal*) NEAR/3 (counsel*))):ab,ti,kw OR (counsel*):ti) AND [ENGLISH]/lim	1971 - Present	1200	1190
Medline ALL	(exp Infant, Premature/ OR exp Obstetric Labor, Premature/ OR exp Infant, Very Low Birth Weight/ OR (prematurit* OR prematures OR preterms OR ELBW OR VLBW OR ((prematur* OR pre-matur* OR preterm* OR pre-term* OR extremely-low OR very-low) ADJ3 (child* OR infant* OR neonat* OR birth* OR baby OR babies OR newborn* OR adolescent* OR born* OR labor* OR labour* OR deliver* OR gestat*))).ab,ti,kf.) AND (Counseling/ OR (((parent* OR prenat* OR famil* OR preterm* OR pre-term* OR pre-natal* OR prematur* OR pre-matur* OR antenatal*) ADJ3 (counsel*))).ab,ti,kf. OR (counsel*).ti.) AND english.la.	1946 - Present	716	205
Web of Science Core Collection	TS=(((prematurit* OR prematures OR preterms OR ELBW OR VLBW OR ((prematur* OR pre-matur* OR preterm* OR pre-term* OR extremely-low OR very-low) NEAR/2 (child* OR infant* OR neonat* OR birth* OR baby OR babies OR newborn* OR adolescent* OR born* OR labor* OR labour* OR deliver* OR gestat*)))) AND ((((parent* OR prenat* OR famil* OR preterm* OR pre-term* OR pre-natal* OR prematur* OR pre-matur* OR antenatal*) NEAR/2 (counsel*))) OR (counsel*):ti)) AND LA=(English)	1975 - Present	445	57
Cochrane Central Register of Controlled Trials	((prematurit* OR prematures OR preterms OR ELBW OR VLBW OR ((prematur* OR pre-matur* OR preterm* OR pre-term* OR extremely-low OR very-low) NEAR/3 (child* OR infant* OR neonat* OR birth* OR baby OR babies OR newborn* OR adolescent* OR born* OR labor* OR labour* OR deliver* OR gestat*))):ab,ti) AND ((((parent* OR prenat* OR famil* OR preterm* OR pre-term* OR pre-natal* OR prematur* OR pre-matur* OR antenatal*) NEAR/3 (counsel*))):ab,ti OR (counsel*):ti)	1992 - Present	202	161
Google Scholar	prematurity|premature|preterms|ELBW|VLBW|"premature|pre-mature|preterm|pre-term child|children|infant|infants|neonate|birth|baby|babies|newborn|adolescent|born|labor|labour|delivery|gestatation" counseling|counselling	100 top ranked	100	53
Cinahl	(MH Infant, Premature OR MH Labor, Premature OR MH Childbirth, Premature OR MH Infant, Very Low Birth Weight OR TI(prematurit* OR prematures OR preterms OR ELBW OR VLBW OR ((prematur* OR pre-matur* OR preterm* OR pre-term* OR extremely-low OR very-low) N2 (child* OR infant* OR neonat* OR birth* OR baby OR babies OR newborn* OR adolescent* OR born* OR labor* OR labour* OR deliver* OR gestat*))) OR AB(prematurit* OR prematures OR preterms OR ELBW OR VLBW OR ((prematur* OR pre-matur* OR preterm* OR pre-term* OR extremely-low OR very-low) N2 (child* OR infant* OR neonat* OR birth* OR baby OR babies OR newborn* OR adolescent* OR born* OR labor* OR labour* OR deliver* OR gestat*)))) AND (MH Counseling OR AB(((parent* OR prenat* OR famil* OR preterm* OR pre-term* OR pre-natal* OR prematur* OR pre-matur* OR antenatal*) N2 (counsel*))) OR TI(counsel*))	1982 - Present	524	210
Total			**3187**	**1876**

Table 2
Characteristics of the studies included in this scoping review [1].

First author et al (year)	Journal	Design	Country	Objective	Result/conclusion
Martinez et al [23] [2]	*Obstet Gynecol*	Questionnaire	USA	To determine physician opinions, parental counseling, and medical practices for extremely low birth weight infants	Obstetric opinions about delivery room resuscitation are influenced by birth weight and GA thresholds, infant, and parental factors. There is a limited willingness by physicians to allow a parental role in decision-making in the delivery room
Munro et al (2001) [3]	*Aust N Z J Obstet Gynaecol*	Questionnaire	Australia, USA	To ascertain antenatal counseling, resuscitation practices, and attitudes towards life support in the extremely preterm infant of Australian neonatologists	The establishment of national guidelines would be helpful to aid Australian obstetricians and neonatologists in their clinical practice
Janvier et al (2005) [4]	*J Pediatr*	Retrospective review	Canada	To determine the adequacy of records of parental counseling, whether interventions at birth were consistent with recorded antenatal decisions, and whether extent of resuscitation affected occurrence of serious short-term morbidity	Records of antenatal consultations were often lacking important information. Variations in physician documentation practices are substantial and affect the care offered to infants at the threshold of viability
Bastek et al [20] [5]	*Pediatrics*	Questionnaire	USA	To determine attitudes and practices regarding prenatal counseling of neonatologists in New England	Neonatologists are consistent in discussing clinical issues but varied in discussing social and ethical issues
Yee et al (2007) [6]	*Paediatr Child Health*	Questionnaire	Canada	To explore whether the information content, process and social interaction of prenatal counseling satisfies the informational needs of women admitted to hospital in preterm and threatened preterm labor	Respondents were generally satisfied with the information provided but remained highly anxious. Recall of the discussion about disability was inconsistent. They reported needing an opportunity to express their feelings, and to talk about their baby and their anticipated interaction with their baby
Harrison [31] [7]	*Sem Fet Neo Med*	Literature	USA	To reflect on parental decision-making and information provision in prenatal counseling	The use of directives and other techniques for transparency in obstetric and neonatal care could improve the process of informed parental choice
Griswold et al (2009) [8]	*Pediatrics*	Literature	USA	To provide an evidence-based overview of prenatal counseling	Suggestions for the incorporation of morbidity and mortality data as well as the structure and approach to discussion with parents were made
Tomlinson et al [39] [9]	*Am J Obstet Gynecol*	Clinical opinion	USA	To detail problems with prenatal counseling and describe the development of a program designed to improve the process	They developed a set of guidelines to guide prenatal counseling. It resulted in a substantial improvement in the care of pregnant women
Boss et al [37] [10]	*Sim Healthcare*	Simulation	USA	To examine how simulation might be used to engage neonatologists in reflecting on their usual prenatal counseling behaviors	Simulation can reproduce the decisional context of prenatal counseling
Janvier et al [35] [11]	*Acta Paediatr*	Viewpoint	Canada	To analyze the complexities of parental informed consent for treatment	Personalization is preferred: doctors should try to discern what parents want and need and to adapt counseling to those needs
Edmonds et al [41] [12]	*AJOG*	Interview	USA	To examine factors that influence obstetric decision-making and counseling and to describe counseling challenges	Decision-making and counseling were influenced primarily by patient preferences. Communicating uncertainty, managing expectations, assessing understanding, and relaying consistent messages across specialties were identified as challenges
Srinivas [21] [13]	*Sem Perinat*	Literature	USA	To provide a systematic approach to communicating and counseling for extreme prematurity	There is a need for a multidisciplinary approach and multiple sessions of counseling. Parents are the principle focus regarding decision-making. Information shared should be consistent and understandable. Variability between providers should be minimized
Mehrotra et al [10] [14]	*J Perinatol*	Questionnaire	USA	To study counselor-independent elements of prenatal counseling	Substantial system-based variability in execution was found
Staub et al [17] [15]	*Acta Paediatr*	Letter	Canada	To help clinicians understand what parents want and need from them	Ten concrete recommendations for healthcare providers
Kim et al (2014) [16]	*Clin Perinat*	Literature	USA	To elaborate on communicating risks and outcomes of prematurity in prenatal counseling	Efforts in prenatal counseling must focus on improving communication and not on decreasing information provided to parents
Janvier et al [19] [17]	*Sem in Perinat*	Literature	Canada	To suggest ways to personalize prenatal discussions with parents	The mnemonic "SOBPIE" may help providers have fruitful discussions
Boss et al [34] [18]	*J Amer Med Assoc Pediatr*	Commentary	USA	To answer the question whether social context should matter when responding to parents' requests for resuscitation	

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Table 2 (*continued*)

First author et al (year)	Journal	Design	Country	Objective	Result/conclusion
					The contextual realities of family circumstances should influence counseling, in an active way, towards directive counseling
Edmonds et al [33] [19]	*J Perinatol*	Simulation	USA	To compare the management options, risks and the content that obstetricians and neonatologists discuss in prenatal counseling	Both specialties organized decision-making around medical information, survival, quality of life, time and support. Neonatologists also introduced themes of values, comfort or suffering, and uncertainty
Geurtzen et al [9] [20]	*J Mat Fet Neo Med*	Questionnaire	Netherlands (study participants: Europe)	To evaluate current practices in prenatal counseling amongst European trainees	Wide variation in content and organization was observed
Geurtzen et al [7] [21]	*Eur J Pediatr*	Interview	Netherlands	To gain insight into professionals' preferences on three domains of counseling: content, organization and decision-making	There is limited familiarity with SDM although it is the preferred model
Haward et al [18] [22]	*Clin Perinat*	Literature	Canada	To present practical recommendations for antenatal counseling	Personalized decision-making empowers parents and should replace SDM
Haward et al [18] [23]	*AJOB Empirical Bioethics*	Interview	USA	To explore neonatologists' views on decision-making processes and their own roles in counseling	Neonatologists are concerned that parents understand the decision facing them. They differ on what information they offer and how they balance parents' need for cognitive and affective support
Kharrat et al (2017) [24]	*J Pediatr*	Systematic review	Canada	To synthesize and describe parental expectations on how healthcare professionals should interact with them during prenatal counseling	Six themes emerged: perception of support, degree of understanding, hope, spirituality, and decision-making influences
Kunkel et al [30] [25]	*J Perinat*	Questionnaire	USA	To determine the relative influence of maternal factors in counseling	Parity and intendedness had the highest importance scores, followed by race, education, and age
Pedrini et al [36] [26]	*BioMed Res Inter*	Systematic review	Italy	To describe the outcomes of prenatal counseling for preterm delivery	Parents' choices about treatment seemed to be influenced by spiritual-related aspects and or pre-existing preferences rather than by the level of detail or by the order with which information was provided
Ruthford et al [26] [27]	*Pediatrics*	Commentary	USA	To reflect on a couple's experience of prenatal counseling and premature birth	Physicians should try to understand the values and motivations that influence parental decision-making
Moore et al (2017) [28]	*J Perinatol*	Field testing, questionnaire	Canada	To assess and modify an existing decision aid and field-test decision coaching with the modified aid during prenatal counseling	Consultations using the aid with decision coaching were feasible, reduced decisional conflict and may facilitate SDM
Geurtzen et al [24] [29]	*BMC Pregnancy Childbirth*	Questionnaire	Netherlands	To explore preferred prenatal counseling by Dutch professionals and compare this to current care	Dutch professionals would prefer more protocolized counseling, joint counseling, supportive material and local outcome statistics
Geurtzen et al [24] [30]	*Pat Educ Counsel*	Questionnaire	Netherlands	To investigate experienced and preferred prenatal counseling among parents	Parents want to be involved in the decision-making process but differed on the preferred extent of involvement
Lantos (2018) [31]	*J Pediatr*	Editorial	USA	To reflect on the purpose of prenatal counseling	Doctors should strive to understand what parents want: less talking, more listening. Discussions should be individualized and respond to the family's needs
Myers et al [27] [32]	*Sem Fet Neo Med*	Literature	USA	To address opportunities and difficulties for prenatal counseling	Multi-timepoint counseling provides the opportunity to address important goals and continue communication as the trajectories of infants, families, and the counseling team change
Drago et al (2018) [33]	*Mat Child Health J*	Interview, simulation	USA	To characterize Latino parental perceptions of antenatal counseling in order to construct and validate a Spanish decision-aid	A decision-aid for Latino parents may improve comprehension of antenatal counseling
Shapiro et al [29] [34]	*J Pediatr*	Questionnaire	USA	To assess whether neonatologists show implicit racial and/or socioeconomic biases and whether these are predictive of recommendations at extreme periviability	Unconscious socioeconomic bias influences recommendations when counseling at the limits of viability. Physicians who display a negative socioeconomic bias are less likely to recommend resuscitation when counseling women of high socioeconomic status

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Table 2 (*continued*)

First author et al (year)	Journal	Design	Country	Objective	Result/conclusion
Barker et al (2018) [35]	*Paediatr Child Health*	Interview	Canada	To explore health care providers' perceptions of using SDM and to identify facilitators of and barriers to its use in prenatal counseling	Nine facilitators and sixteen barriers were identified that can be used to inform development of tailored strategies to facilitate future implementation of SDM in prenatal counseling
Geurtzen et al [32] [36]	*Pat Educ Counsel*	Interview	Netherlands	To analyze parental preferences in prenatal counseling	Various preferences were found related to the content, the organization, and decision-making
Edmonds et al [22] [37]	*J Mat Fet Neo Med*	Interview	USA	To examine prospective parents' perceptions of management options and outcomes and the values they apply in decision-making	Over half desired a shared decision-making role. The potential for disability influenced decision-making to variable degrees
Guillén et al (2019) [38]	*J Pediatr*	Randomized controlled trial	USA	To assess decisional conflict and knowledge about prematurity when the counseling clinicians were randomized to counsel using a validated decision aid compared with usual counseling	Use of a decision aid did not impact maternal decisional conflict, but it significantly improved knowledge of complex information.
Tysdahl et al (2019) [39]	*Pediatrics*	Commentary	USA	To share delivery stories and let parents offer advice to clinicians developing care approaches for families like theirs	Careful decision-making should be shared by physicians and parents. Parents and physicians must engage in discourse to make treatment decisions aligned with parental values and appropriate expectations
Feltman et al (2020) [40]	*Am J Perinatol*	Retrospective review	USA	To describe periviability counseling practices and decision-making	Areas requiring improvement include delivery/content of neonatology consultations, social work support, consideration of centers' patient populations, and opportunities for shared decisions
Rau et al (2020) [41]	*BMC Medical Informatics and Decision-making*	Questionnaire, interview	USA	To look into parental understanding of medical jargon commonly used during prematurity counseling	Cognitive interviews provided empirical testing of parental understanding of crucial medical jargon and highlighted that language commonly used during prenatal prematurity counseling is not understood by many parents. For parents to participate in shared decision-making, plain language should be used to maximize their understanding of medical information.
Mardian et al (2020) [42]	*The Journal of Maternal-Fetal & Neonatal Medicine*	Interview	Canada	To explore parental perceptions of written handbooks provided to them during ante-natal counseling for anticipated extremely preterm birth	Overall, parents positively evaluated the handbooks, supporting their utility for parents anticipating extremely preterm birth. Concrete suggestions for improvement were made; the handbooks will be modified accordingly. Parents at other perinatal centers may bene-fit from receiving such handbooks
Reed et al (2020) [43]	*J Perinatol*	Questionnaire	USA	To investigate the frequency with which neonatal and maternal–fetal medicine (MFM) providers perform joint periviability counseling (JPC), compare content of counseling, and identify perceived barriers to JPC	JPC is recommended but infrequently performed, with both specialties interested in further collaboration to strengthen the counseling provided
Abusalah (2020) [44]	*Archives of Disease in Childhood*	Conference abstract	Dubai	To highlight the importance of effective communication with parents and to suggest a structured approach for counseling	The paper will advocate the adoption of the SPIKES protocol (with permission) that was originally described to disclose unfavourable clinical information to patients with cancer. The six steps of Modified SPIKES: S— Setting up the interview P—assessing the parents' Perception I—obtaining the parents' Invitation K —giving Knowledge and information E —addressing the parents' Emotions with empathic responses S—Strategy and Summary
Fish et al (2021) [45]	*J Perinatol*	Randomized controlled trial	USA	To determine if antenatal counseling delivered in the outpatient setting improves parental knowledge and satisfaction without contributing to anxiety	Antenatal counseling in the high-risk outpatient setting improved parental knowledge and satisfaction without leading to increased anxiety

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Table 2 (*continued*)

First author et al (year)	Journal	Design	Country	Objective	Result/conclusion
Arnolds et al (2021) [46]	*The Journal of Pediatrics*	Commentary	USA	To support clinicians seeking consistent strategies for counseling and shared decision-making in the gray zone by exploring the moral and practical dimensions at the margin of gestational viability, with emphasis on contemporary normative and empirical work	Compassionate and up-to-date counseling of expectant parents at the margin of gestational viability requires the clinician to take into account contemporary outcome data, current ethical frameworks, and modern approaches to value based SDM. A structured approach to prenatal consultation at the margin of gestational viability is essential as it does not simply improve communication and clinician and parent satisfaction, but also serves to reduce the encroachment of unconscious biases and structural inequities for already vulnerable babies and families
Georgescu et al (2021) [47]	*J Pediatr Intensive Care*	Questionnaire	USA	To describe the characteristics and content of intrapartum counseling provided to women hospitalized for premature birth between 23 and 34 weeks of GA	The authors found that the duration of most sessions is 30 minutes; the father of the baby is not present during counseling for most premature births, and the topics discussed are fairly similar and extensive irrespective of the GA. These findings highlight the existing contrast between the recommended counseling practices and the actual practice reported by counselors

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were found in the included articles, (2) several of the articles were duplicates – they were included in both systematic reviews, (3) both systematic reviews had closely related results, and (4) the systematic reviews were judged to be of sufficient quality. Therefore, it was opted to *only* include the 2 systematic reviews and not the 24 individual articles. For the sake of completeness, however, the study characteristics of the included studies in both systematic reviews can be found in Table 3. This Table can be found in the online supplemental material.

Ultimately, 46 articles were included in this scoping review. Disagreements that arose between the reviewers at each stage of the selection process were resolved through discussion until agreement was reached. If necessary, disagreements were also mediated by a third reviewer (RG). The results of the search and the study inclusion process were reported in full and presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for Scoping Review (PRISMA-ScR) diagram [14]. A flow diagram of the screening process can be found in Fig. 1.

2.4. Charting the data

According to the methodological framework of Arksey and O'Malley, charting the data and collating the results are iterative and narrative processes: “A 'narrative review' or 'descriptive analytical' method is used to extract contextual or process oriented information from each study” [13]. A scoping review protocol was designed prior to data extraction. An initial coding strategy and coding scheme were also developed. Throughout the scoping review process, the initial coding scheme was repeatedly discussed and adjusted by the reviewers. Data were charted from the included studies using a data extraction tool developed by the reviewers. The data extraction tool was made in Excel. The tool included data about the authors, the year of publication, the journal, the study design, the country in which the study was conducted or the country in which the authors of the article are based, the objective of the study, and the result or conclusion of the study.

2.5. Collating, summarizing and reporting the results

Two researchers (LDP, EJTV) then analyzed the included studies for findings relevant to the research question of this scoping review. In a first round of full text analysis, characteristics of prenatal counseling were identified and coded. In a second round, the studies were analyzed and coded again in reference to the characteristics that were identified in the first round. The characteristics that were mentioned most frequently in the included body of literature are discussed in the result section of this scoping review.

3. Results

3.1. Characteristics of the included body of literature

The included studies and their characteristics can be found in Table 2**.** 46 articles were included in this scoping review. The included body of literature has been published between 1998 and February 2021. Only 7 of the included articles were published before 2010, 27 articles were published between 2017 and 2021. More than half of the studies was conducted in the United States of America (n=29), of which one was conducted in Australia and the USA. The remaining studies were conducted in 4 countries: Canada (n=10), the Netherlands (n=5), Italy (n=1), and Dubai (n=1). The included studies are questionnaire studies (n=14), interview studies (n=8), literature studies or reviews (n=7), systematic reviews (n=2), retrospective reviews (n=2), commentaries, viewpoints or letters (n=7), randomized controlled trials (n=2), simulation studies (n=2), conference abstracts (n=1) and editorials (n=1).

Table 3
Characteristics of the studies included in the identified systematic reviews (Kharrat et al. (2017) and [36]) [1].

First author et al (year)	Journal	Design	Country	Objective	Result/conclusion
Young et al (2012) [2]	*Paediatr Child Heal*	Interview	Canada	To ascertain from parents of neonates born before 27 weeks' gestational age how to improve predelivery counseling for delivery room resuscitation	Information about prematurity should be offered when the pregnancy is deemed high risk, with repeat counseling opportunities for both parents to discuss options. Once the decision is made to resuscitate, parents want the neonatal team to convey a message of hope and compassion
Payot et al (2007) [3]	*Soc Sci Med*	Interview	Canada	To explore how parents and neonatologists engage in decision-making in a context of imminent and unplanned delivery at the threshold of viability	Results highlight how neonatologists and parents engage in decision making from different standpoints: while neonatologists focus on the management of the unborn baby, parents have yet to fully conceptualize their infant as a distinct entity since they are in a process of grieving their pregnancy and their parenthood project. Parents express the need to receive more than just factual information from neonatologists. They also require support and engagement from caregivers to manage the uncertainty
Grobman et al (2010) [4]	*Obstet Gynecol*	Interview	USA	To better understand preferred approaches that health care professionals could use when caring for parents who are at risk of giving birth to an extremely premature infant	Both patients and providers agree about the centrality of information provision and emotional support for women at risk of periviable delivery. This study not only elucidates preferred approaches and methods by which this information and support could be optimized, but also shows pitfalls that, if not avoided, may impair the relationship between provider and patient
Kavanaugh et al (2009) [5]	*J Perinatol Neonatal Nurs*	Case study	USA	The authors describe a case from a larger collective case study that examines the decision making and the decision support needs of parents regarding life support decisions made over time (prenatally and postnatally) for extremely premature infants from the perceptions of parents, physicians, and nurses	The findings in this case study demonstrate the importance of the nurse being present when information is given to parents, of informing with compassion, and helping parents to understand treatment options and decisions
Daboval et al (2016) [6]	*PloS One*	Interview	Canada	To document interactions during the antenatal consultation between parents and neonatologist that parents linked to their satisfaction with their participation in shared decision making for their infant at risk of being born at the limit of viability	Parent descriptions indicate that the opportunity to participate to their satisfaction in the clinical antenatal consultation depends on how the physician interacts with them
Roscigno et al (2012) [7]	*Qual Health Res*	Interview	USA	To evaluate parents' and health care providers' descriptions of hope following prenatal counseling	Divergent views of hope were found between parents and providers
Moro et al (2011) [8]	*J Perinat Neonatal Nurs*	Interview	USA	To describe how parents make life support decisions for extremely premature infants from the prenatal period through death from the perspectives of parents, nurses, and physicians	Mothers were found to exhibit these characteristics: desire for and actual involvement in life support decisions, weighing pain, suffering and hope in decision making, and wanting everything done for their infants. All mothers received decision making help and support from partners and family, but relationships with providers were also important. Finally, external resources impacted parental decision making in several of the cases
Bohnhorst et al (2015) [9]	*Am J Perinatol*	Questionnaire	Germany	This article aims to investigate the impact of prenatal counseling on subsequent parents' experiences during in-patient care of their infant(s) and whether feelings of parents with deceased infants are different in principle	This study stresses the impact of prenatal counseling and shows that, regardless of outcome, the course of a trusting relationship between parents and health care team is already set before birth

(*continued on next page*)

Table 3 (*continued*)

First author et al (year)	Journal	Design	Country	Objective	Result/conclusion
Boss et al (2008) [10]	*Pediatrics*	Interview	USA	The aim of this study was to characterize parental decision-making regarding delivery room resuscitation for infants born extremely prematurely or with potentially lethal congenital anomalies	The values that parents find most important during decision-making regarding delivery room resuscitation may not be addressed routinely in prenatal counseling. Parents and physicians may have different interpretations of what is discussed and what decisions are made. Future work should investigate whether physicians can be trained to address effectively parents' values during the decision-making process and whether addressing these values may improve physician-parent communication and lead to better post-decision outcomes for parents
Partridge et al (2005) [11]	*Pediatrics*	Interview	USA, Australia, Hong Kong, Japan, Malaysia, Taiwan, Singapore	To characterize parent perceptions and satisfaction with physician counseling and delivery-room resuscitation of very low birth weight infants in countries with neonatal intensive care capacity	Counseling differs by center among these centers in Australasia and California. Given that parents desire to play an active role in decision-making for their premature infant, physicians should strive to provide parents the medical information critical for informed decision-making. Given that parents do not seek sole decision-making capacity, physicians should foster parental involvement in life-support decisions to the extent appropriate for local cultural norms
Zupancic et al (2002) [12]	*Arch Dis Child Fetal Neonatal Ed*	Nonrandomized controlled trial	Canada	To assess outcome of counseling in a routine setting of care	The agreement score correlated negatively with the level of anxiety. The agreement for obstetric variables was good, while concordance on potential neonatal problems was generally poor
Kavanaugh et al (2005) [13]	*J Pediatr Nurs*	Interview	USA	To describe decision making and the decision support needs of parents, physicians, and nurses regarding life support decisions made over time prenatally and postnatally for extremely premature infants	Most parents wanted a model of shared decision making and perceived that they were informed and involved in making decisions. Parents felt that to be involved in decision making they needed information and recommendations from physicians. Parents also stressed the importance of encouragement and hope. In contrast, physicians informed parents but most physicians felt that parents were the decision makers. Physicians used parameters to offer options or involve parents in decisions and became very directive at certain gestational ages. Nurses reported that they believed that parents needed information from the physician first, then they would reinforce information
Keenan et al (2005) [14]	*Pediatrics*	Interview	USA	To understand mothers' and counselors' perceptions of their roles in decision-making about resuscitation of extremely premature infants at delivery and to assess mothers' and counselors' satisfaction with the counseling and decision-making process	The decision-making process in this study conforms most closely to a model of informed assent. Mothers may have been satisfied with this type of counseling because they felt informed and included in the decision-making process. Physicians and nurses need to elicit mothers' preferences to incorporate them into the treatment plan, as counseling about the resuscitation of extremely premature infants at delivery is considered directive by mothers even when it is not intended to be directive
Guillén et al (2012) [15]	*J Pediatr Nurs*	Nonrandomized controlled trial	USA	To assess outcome of a decision-aid to counsel parents facing premature delivery	Participants found the cards useful and easy to understand. The level of knowledge improved after counseling both for "experienced" parents and "naïve" parents

(*continued on next page*)

Table 3 (*continued*)

First author et al (year)	Journal	Design	Country	Objective	Result/conclusion
Kavanaugh et al (2015) [16]	*Palliat Support Care*	Interview	USA	When infants are at risk of being born at a very premature gestation (22-25 weeks), parents face important life-support decisions because of the high mortality for such infants. Concurrently, providers are challenged with providing parents a supportive environment within which to make these decisions. Practice guidelines for medical care of these infants and the principles of perinatal palliative care for families can be resources for providers, but there is limited research to bridge these medical and humanistic approaches to infant and family care. The purpose of this article is to describe how parents at risk of delivering their infant prior to 26 weeks gestation interpreted the quality of their interpersonal interactions with healthcare providers	Parents' expectations for caring included: (a) respecting parents and believing in their capacity to make the best decisions for their family (maintaining belief); (b) understanding parents' experiences and their continued need to protect their infant (knowing); (c) physically and emotionally engaging with the parents (being with); (d) providing unbiased information describing all possibilities (enabling); and (e) helping parents navigate the system and creating a therapeutic environment for them in which to make decisions (doing for)
Guillén et al (2016) [17]	J Perinatol	Mixed methods	USA	The objective of the study is to develop and validate a video-based parental decision aid about the outcomes of extremely premature infants	A short video showing the range of outcomes of extreme prematurity has been produced. It is well accepted and does not increase levels of anxiety as measured by the STAI. This video may be a useful and non-stress-inducing aid at the time of counseling parents facing extreme prematurity
Kett et al (2016) [18]	J Clin Neonatol	Randomized controlled trial	USA	To assess whether a written information provided after the prenatal consultation could improve recall and satisfaction	The two groups did not differ in factual recall (within 72h) of satisfaction with the prenatal consultation
Kaempf et al (2009) [19]	Pediatrics	Nonrandomized controlled trial	USA	To assess the outcome of consensus medical staff guidelines for counseling woman at risk of premature birth	The woman felt comfortable asking questions. About 60% of the mothers mentioned the written guidelines as the most useful information given to them
Kavanaugh et al (2014) [20]	Neonatal Netw	Interview	USA	To outline parents' descriptions of extended family involvement and support surrounding decision making for their extremely preterm infant	Most parents did not seek advice from family members for life-support decisions made prenatally. Instead, parents made the decision as a couple with their physician without seeking family input. Family members provided certain types of support: emotional support, advice and information, prayer, and instrumental help such as child care. Most parents described at least one way their family supported them. For postnatal and end-of-life decisions, parents were more likely to seek advice from extended family in addition to the other forms of support
Kakkilaya et al (2011) [21]	Pediatrics	Randomized controlled trial	USA	To assess outcome of a visual aid to counsel parents facing premature delivery	Women counseled with visual aid recalled more short-term problems, more long-term disability, and longer NICU stay than controls. Attitudes toward resuscitation did not change after counseling in either group
Muthusamy et al (2012) [22]	Pediatrics	Randomized controlled trial	USA	To assess the effect of providing written information during counseling	Written information improved knowledge of long-term problems and numerical outcome data, and it also decreased anxiety
Haward et al (2012) [23]	Pediatrics	Randomized controlled trial	USA	To examine whether choices between comfort care and intensive care are affected by the details and the order of presentation	Order had no effect on final choice. Participants were significantly less likely to choose comfort care if they were highly religious or values preservation of life over quality of life
Edmonds et al (2014) [24]	Simul Healthc	Randomized controlled trial	USA	To assess the feasibility of simulation to test the effect of maternal race and insurance status on shared decision-making in periviable counseling	Information regarding diagnosis and prognosis was heavily emphasized, while attempts to elicit goals and values were often lacking. Shared decision-making occurs differentially based on patients' race and insurer
Geurtzen et al (2014) [25]	Simul Healthc	Nonrandomized controlled trial	USA, The Netherlands	To compare the contents and styles of counseling as delivered by subjects from two cultural backgrounds in a highly standardized scenario	American and Dutch neonatologists diverged in the discussed and emphasized options for immediate care in the delivery room

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[15] Kavanaugh K, Roscigno CI, Swanson KM, Savage TA, Kimura RE, Kilpatrick SJ. Perinatal palliative care: parent perceptions of caring in interactions surrounding counseling for risk of delivering an extremely premature infant. *Palliat Support Care* 2015;13:145-55.
[16] Guillén U, Suh S, Wang E, Stickelman V, Kirpalani H. Development of a video decision aid to inform parents on potential outcomes of extreme prematurity. *J Perinatol* 2016;36:939-43.
[17] Kett J, Mohamed M, Bathgate S, Larsen J, Aly H. Written information may not improve factual recall after verbal counseling of mothers in premature labor – a randomized controlled trial. *J Clin Neonatol* 2016;5:39-45.
[18] Kaempf JW, Tomlinson MW, Campbell B, Perguson L, Stewart VT. Counseling pregnant women who may deliver extremely premature infants: medical care guidelines, family choices, and neonatal outcomes. *Pediatrics* 2009;123:1509-15.
[19] Kavanaugh K, Nantais-Smith LM, Savage T, Schim SM, Natarajan G. Extended family support for parents faced with life-support decision for extremely premature infants. *Neonatal Netw* 2014;33:255-62.
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3.2. Characteristics of prenatal counseling for extreme prematurity

The following characteristics of prenatal counseling for extreme prematurity at the limit of viability were identified: personalization, parent-physician relationships, shared decision-making (SDM), physician bias, emotions, anxiety, psychosocial factors, parental values, religion, spirituality, hope, quality of life (QoL), and uncertainty. It seems that most of the characteristics cannot be said to mainly relate to the content *or* the process of prenatal counseling; most of them are related to both. Uncertainty, for example, seems to be a topic in prenatal counseling but at the same time influences the process of the counseling. Furthermore, most of the identified characteristics are interrelated. For example, adjusting the counseling information to parental values and discussing ideas about quality of life are aspects of personalized prenatal counseling, and taking into account the parents' religion and/or spirituality might in fact be part of taking into account their values.

It becomes clear from the result section that there is thematic overlap between the characteristics. Since our aim is to gain a thorough understanding of prenatal counseling practices, we first discuss the characteristics individually – by also providing concrete examples or quotes from the included studies. In the discussion section then, we focus on the bigger picture; the interrelation between the characteristics. For an overview of the number of included articles than mention the identified characteristics, see Fig. 2. For a schematic representation of the interrelation between the identified characteristics, see Fig. 3.

3.2.1. Personalization

In the past decade, personalizing prenatal counseling seems to have become increasingly important. Two articles written before 2010 refer to personalizing certain aspects of prenatal counseling, namely, the prognosis and treatment options, and the general principles of prenatal counseling [15,16]. After 2010, 22 of the included articles mention personalization or individualization. The literature shows that personalization can pertain to different aspects of prenatal counseling, such as medical, parental, and informational aspects as well as aspects related to decision-making [7]. Geurtzen et al. discuss personalization in relation to the preferred input of parents in decision making, the preferred amount of information shared in prenatal counseling, and the preferred use of statistics and/or outcome data [7]. In an article written by parents of extremely premature infants, one of the ten recommendations for physicians is the following: "Some parents want statistics, others want the general picture. Some parents want to make important decisions on their own, while others want recommendations. Please listen to us individually" [17]. In this article, it is also advised to "have a personalized approach" [17].

Two of the included articles offer recommendations to enable personalization in practice [18,19]. Haward et al., for example, advise to personalize by, among others, considering factors beyond GA, acknowledging emotions as integral in deliberations and adjust the 'agenda' of prenatal counseling. According to the authors, the goal of personalization is "for parents to feel like parents and to feel like they are good parents, before birth, at birth and after, either in the NICU or until the death of their child."[18]

3.2.2. Parental values

The next characteristic is closely related to personalization, however, can be seen as a specific *aspect* of personalization; prenatal counseling can be personalized by elaborating on parental values and incorporate these into the counseling and decision-making. Of all the characteristics that we identified in this scoping review, parental values (n=37) were mentioned most frequently in the literature. Before 2010, parental values were mentioned in 3 articles. In 2005 already, Bastek et al. discuss that "it is concerning

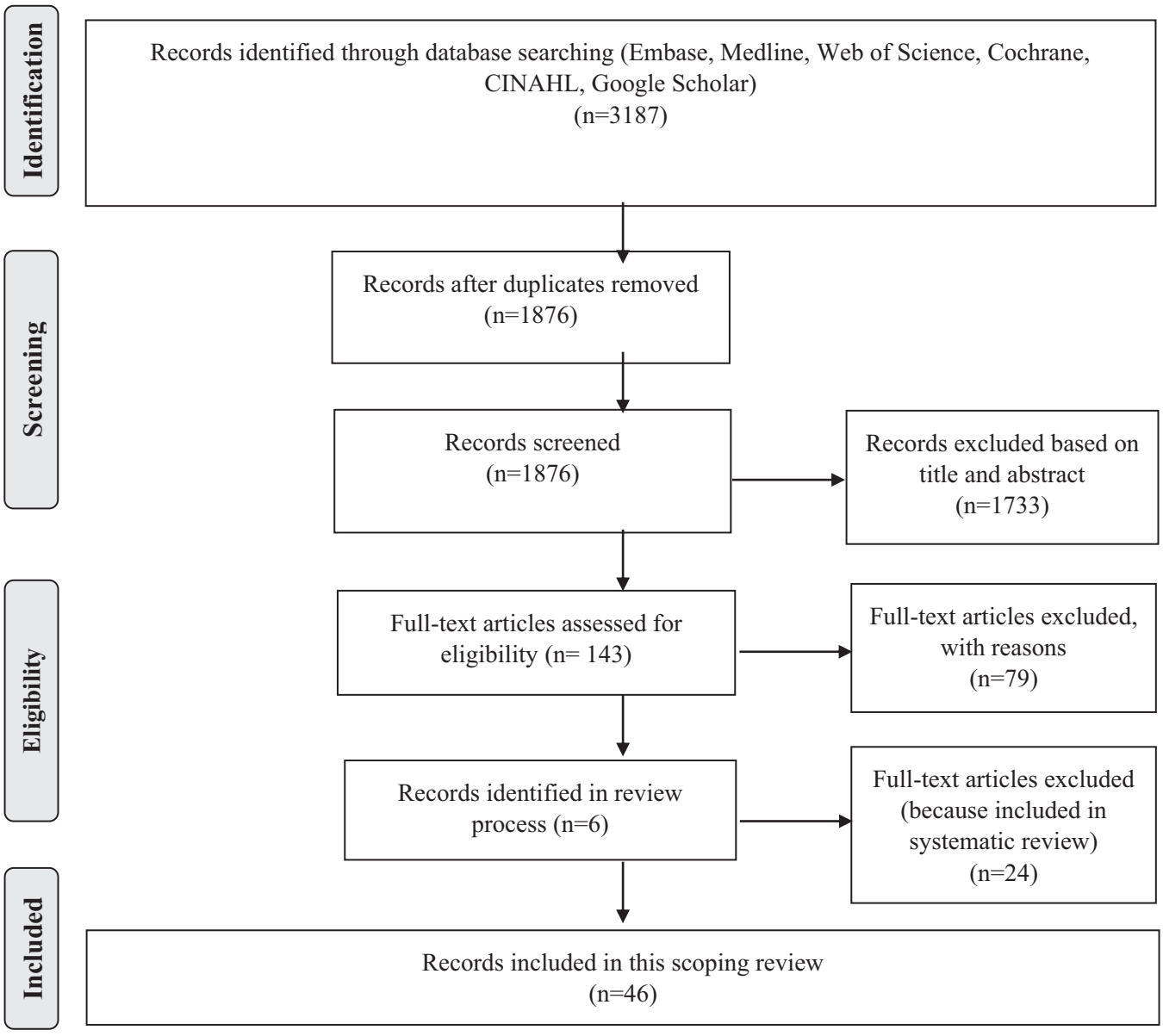

Fig. 1. Flow diagram of search and reduction of results.

that … families may not be receiving much assistance in identifying and discussing the nonmedical values important in making difficult decisions regarding resuscitation of their children." [20] In the article by Staub et al., it is recommended to make prenatal counseling about values instead of abstract data.Staub et al. [17], In this regard, Srinivas states the following: "Recognition of the different values and perceptions patients and providers bring to the discussion is important to consider when counseling patients and their families. At the onset of discussion, it is critical to assess patient preferences and beliefs." [21] Although the importance of parental values is recognized in theory, almost half of the physicians participating in the study by Edmonds et al. did not elucidate values in practice [22].

3.2.3. SDM

28 articles referred to SDM. Conclusions about SDM seem to be divergent and changing over time. In 1998, Martinez et al. show that physicians do mostly not prefer parents to have any role in decision-making [23]. Over time, this tendency seems to have changed. In 2005, for example, Bastek et al. show that 77% of the neonatologists participating in their study prefer joint decision-making with the parent(s) [20]. Moreover, in a study by Geurtzen et al. in 2018, 80% of the parents felt they were involved in decision-making [24].

In most of the included papers that mention or elaborate on this characteristic, no formal definition of SDM is provided. In one study, it even shows that not all physicians know what SDM means [7]. Barker et al. state however, that: "Both correct knowledge of SDM and belief in its benefit are required for this approach to perform as intended" [25]. In this same article, several barriers to the use of SDM in prenatal counseling were identified, of which one was the workload: "Health care professionals described an increased workload with SDM because of the need to coordinate efforts between obstetricians, neonatologists and nurses, as well as the need for multiple encounters with some parents to clarify information and address their concerns."[25]

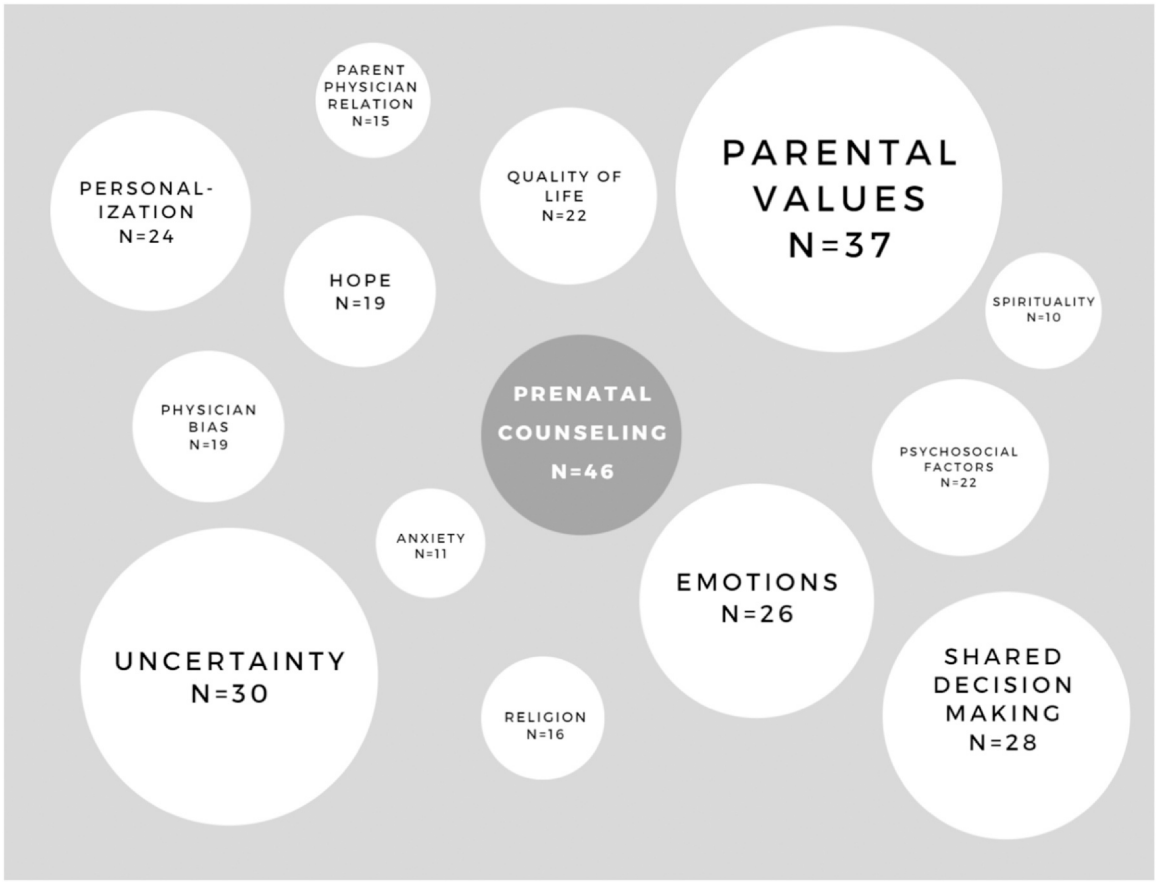

Fig. 2. Characteristics of prenatal counseling for extreme prematurity. Fig. shows the number of included articles that mention the identified characteristics in this scoping review. N is the number of articles in which the characteristic is mentioned. The size of the circle is based upon the number of articles in which the characteristic is mentioned.

3.2.4. Parent-physician relationships

15 articles referred to the significance of the parent-physician relationship for good quality prenatal counseling. Ruthford et al. refer to the relationship as a "partnership" [26]. In the literature, the importance of trust is often mentioned in this regard [18,26]. For example, Haward et al. refer to the following: "Relationships begun in the antenatal consultation have been shown to be important determinants for future adaptation, by decreasing decisional regret and enhancing trust between physicians and parents. … Building relationships and focusing on trust increases the credibility of the informant and the validity of the decision" [18]. Another important aspect of the parent-physician relationship is respect, as mentioned by Myers et al.: "The relationship between the counseling team and the family is healthiest in an atmosphere of respect, continued communication and a spirit of nonabandonment."[27]

3.2.5. Physician bias

In 19 articles, physician bias was mentioned. Two different kinds of physician bias were discussed. On the one hand, there were studies that show physician bias about parents and/or parental characteristics. Studies have, for example, shown possible effects on prenatal counseling of physician bias towards parental socioeconomic status, sociodemographic characteristics, and the desiredness of the pregnancy [28,30]. Harrison then, warns for a different kind of physician bias [31]. She warns for bias with regard to motives for providing active care: "… the scope of neonatal life support has rapidly expanded, professional and financial motives for its use have become more compelling, and the philosophies of aggressive interventionists have prevailed. … Perinatal and neonatal specialists should closely examine their motives for resuscitating and treating at ever-shorter gestations." [31]

3.2.6. QoL

22 articles mentioned QoL, even if there was no agreement in the included body of literature on whether, and if so how**,** to incorporate it in prenatal counseling. Harrison pleads against discussing QoL studies in prenatal counseling because of the ambiguity of such research [31]. In another article however, parents are clear about their wish to discuss QoL in prenatal counseling [47]. Also, one of the recommendations of the article written by parents of extremely premature infants is the following: "Tell us about what our children may, or may not, be able to do. Also tell us about the quality of life of other preterm infants have when they get older" [17]. In one article then, research shows that physicians do not *only* discuss the QoL of the infant in prenatal counseling, but also that of the mom and/or family [33]**.**

3.2.7. Psychosocial factors

The prenatal counseling consultation can include 'medical' as well as 'nonmedical' information. In 22 articles, nonmedical factors were mentioned. We will call these psychosocial factors, because they seem to be mostly related to the psychological, social or socioeconomic sphere. One of the included articles explicitly explores whether the social context of parents should matter for decision-making in prenatal counseling; the authors conclude that it should, even when it results in more directive counseling [34]. They state that: "For some families, socioeconomic disadvantages, compounded by physical or mental health challenges, and chaotic living conditions exceed the parents' abilities and community resources necessary to safely bring the newborn home." [34] Janvier et al. also discuss the importance of

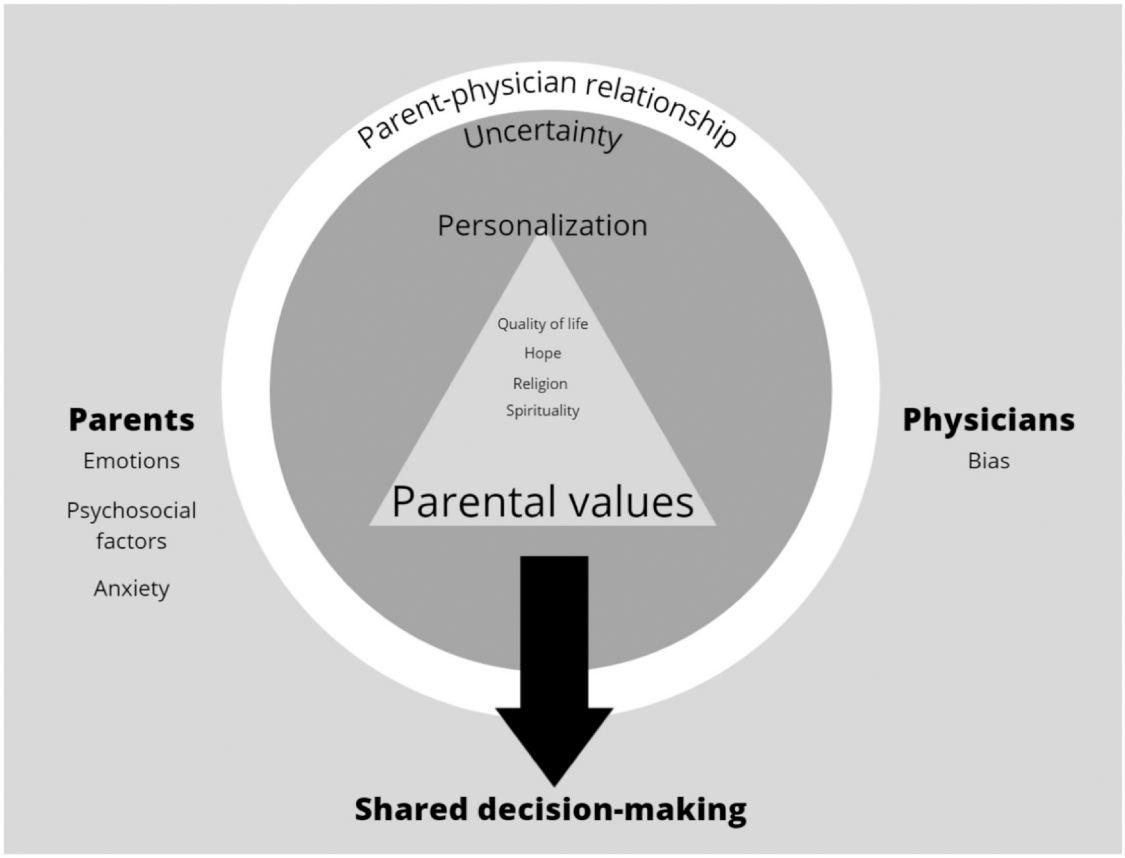

Fig. 3. Schematic representation of the interrelation between the identified characteristics. Fig shows the interrelation between the identified characteristics. The outer circle is the parent-physician relationship; the connection between the parent(s) and the physician. For parents, anxiety, psychosocial factors, and emotions possibly influence prenatal counseling. For physicians, bias possibly influences prenatal counseling. The inner circle is uncertainty, which is typical of situations of preterm birth and will inevitably influence the consultation. The triangle then, is the prenatal counseling consultation. The top of the triangle is personalization. Personalization is based upon parental values – the basis of the triangle. Parental values may among others include perspectives on quality of life, religion, spirituality, and hope. Taking into account all these elements, the parent(s) and the physician will eventually come to a shared decision.

nonmedical factors; they mention that some physicians may be hesitant to speak about such topics in prenatal counseling [35]. Bastek et al. found much variability in the extent to and way in which physicians discuss nonmedical factors in prenatal counseling [20].

3.2.8. Religion, spirituality, hope

Religion (n=16) and spirituality (n=10) play a role in prenatal counseling. This was one of the main conclusions of both the included systematic reviews [28,36]. Pedrini et al. conclude that "parents' choices about treatment seemed to be influenced by spiritual-related aspects and/or preexisting preferences, rather than by the level of detail or by the order with which information was provided." [36] In addition to religion and spirituality, hope (n=19) seems to be of major importance for parents. Hope can be a coping mechanism [28]. In one article, parents advise the following: "Do not take away the hope we have. There is always hope that we will deliver tomorrow. There is hope that we will be able to spend some time with our child. There is hope that we can survive the death of our child with positive memories."[17]

3.2.9. Emotions, anxiety

In the literature, emotions (n=26) or anxiety (n=11) were mentioned to be important for/in prenatal counseling. Srinivas, for example, writes about the emotionally charged nature of situations of threatening preterm birth [21]. In a study by Boss et al., one physician states the following: ""I wish [the parents] could have been less emotional and more focused on what they needed to know to make a decision." [37] The same study reports however, that "aside from delivering biomedical information, physicians spent the next largest proportion of each encounter talking about and responding to emotion." [37] The positive side of parental emotions is also stressed in the literature; emotions can be the driving force for parents to make decisions, help to elucidate values, or serve as a basis for building a strong parent-physician relationship [18].

3.2.10. Uncertainty

Uncertainty (n=30) was discussed in two ways in the included body of literature. Uncertainty about the prognosis, possible outcomes, the overall situation and/or the treatment decision was mentioned in the literature [35,38,39]. Besides that, uncertainty was mentioned as a specific topic of discussion in prenatal counseling [7,33]. Yet, a simulation study by Edmonds et al. shows that only 42% of physicians discussed uncertainties [40]. Another study by Edmonds et al. finds that many physicians experience communicating uncertainty as challenging [41]. In general, there seems to be agreement in the literature about the importance of addressing uncertainty in prenatal counseling: it is inevitable, so it should better be acknowledged. In their systematic review, Kharrat et al. refer to one of their included studies to state that "honesty about uncertainties and being informed that there are no guarantees regarding outcomes was valued."[28]

4. Discussion and conclusion

4.1. Discussion

4.1.1. Towards personalized counseling

Parental values, uncertainty, SDM, and emotions are most frequently mentioned in the literature. However, reflecting on the interrelation between the identified characteristics may lead us to conclude that personalization is the most notable trend in prenatal counseling practices. More and more, it is valued to adjust the counseling to the parent(s) so that it optimally suits them and the unborn infant. The elucidation of parental values, the discussion of ideas about quality of life, and shared decision-making, can all be seen as aspects of personalized prenatal counseling. For example, elucidating parental values might lead to adjustments in the informational content of counseling and eventual recommendations about treatment options that best suit the parents. This, in turn, will result in more personalized prenatal counseling. Another example relates to parental views of QoL; parents can be approached differently according to their personal valuation of QoL and disabilities, and physicians can adjust treatment recommendations to parental beliefs.

An increase in personalization is a trend in time. Recommendations for personalizing prenatal counseling can also be found in more recent policy documents and guidelines for extreme prematurity care and/or counseling [42,45]. The American Academy of Pediatrics, for example, advocates personalization based on fetal and maternal characteristics and on parental beliefs regarding their child's best interest [42]. Canadian and UK guidelines also leave room for personalization [43,44]. In the UK guideline, the following advice is provided: "Perinatal care at extremely preterm gestations will always need to be individualised (…). Decisions should be made together with parents, based on the best available evidence about the prognosis for the individual baby, and mindful of the need to act in the baby's best interests."(British Association of Perinatal Medicine. Perinatal Management of Extreme Preterm Birth before 27, 2019) Also, The National Institute of Child Health recommends that "counseling should be personalized and in the best interest of the family and their child, considering aspects beyond the gestational age" [45]. Besides that, it is advised to "individualize the information to be provided, based on family preferences, wants and needs."[45]

Although there is significant thematic overlap and interrelation between the identified characteristics in this scoping review, there can also be some tensions between them. Understanding these tensions can be useful for future research in this field.

4.1.2. Tensions between characteristics

For example, one included article suggests a tension between SDM and personalization [18]**.** It is suggested that *instead* of SDM, personalized decision-making may be better suited to reach parental decision-making preferences. Haward et al. explain that "for many, shared decision making implies that parents want to collaborate in decisions with physicians. In theory, clinicians should learn to discern between parents' informational needs for deliberation and their desires to be involved in making the decision" [18]. The authors also state that: "Instead of aspiring to achieve mutual consent in shared decision making, physicians should seek to practice personalized decision making [that] would take into consideration a parent's preferences for decisional responsibility and deliberation and thereby informational and supportive needs."[18]

Haward et al. plead against SDM since parents should be allowed to defer the final decision to the doctor. However, this apparent tension seems to depend upon how SDM is interpreted. When SDM is interpreted as if the eventual decision must always be *shared* by the parents and the physician, there can indeed be tension with personalization. Nonetheless, this depends upon interpretation. Stiggelbout et al. describe in the last step of their SDM model, that the eventual decision may be made by the parents, the physician, or both, according to parental preferences [46]. This is incorporated as such in, for example, the Dutch counseling recommendations [47]. Geurtzen et al. emphasize that physicians who are asked to make treatment decisions alone must *still* take into account parental values [7]. Interpreting SDM this way, it is compatible with personalization.

Other tensions exist as well. First, physician bias might endanger personalization and/or influence the way physicians interpret parental values. Adjustments in prenatal counseling better be prompted by family characteristics instead of physician bias about those characteristics. Second, the hesitancy of physicians to speak about nonmedical factors might be detrimental to personalization: physicians may have to speak about or take into account these factors when parents prefer so. Third, imagine highly anxious parents who decide that they do not want and/or need to hear any painful information about the long-term future of their infant. In this case, does personalized prenatal counseling mean that this information should not be told? Maybe, certain informational content just *has* to be shared, whether it suits the parents or not. Do we need a personalization limit?

4.1.3. Do we need a personalization limit for prenatal counseling?

Personalization is based upon common sense; it includes physicians sharing prognostic information that pertains to the specific child and her surroundings. Current literature provides good theoretical frameworks and grounds for personalized prenatal counseling [18,19]. However, prenatal counseling should not be personalized for the sake of personalization; it needs to serve the goal of providing the best possible counseling for parents and enable ethical decision-making. Also, personalizing prenatal counseling per se has not yet been extensively and qualitatively explored with parents. Although qualitative research has been conducted on parents' perspectives on prenatal counseling [32,48], none has been done specifically on personalization and on how to personalize in practice. Given the theoretical preference for personalization, this seems to be a research gap. As becomes clear from the literature, personalizing prenatal counseling can pertain to different aspects: a personalized prognosis, a personalized relationship with the healthcare team or personalized decision-making (processes), or an overall personalized approach to the parent(s) by taking into account their values or adjusting the (amount of) information provision.

More research should be done on what aspects of prenatal counseling should be personalized according to parents and physicians. It should also be explored what are the effects of personalization at the limit of viability on parental satisfaction, decisional conflict and regret in prenatal counseling [49]. Lastly, research should be done on effects of personalization at the limit of viability on neonatal mortality. It could be that a uniformly active approach such as in certain medical centers in Sweden comes with greater survival rates [50]. Nonetheless, the possible differences in value prioritization between quality of life and sanctity of life may imply that this greater survival rate is not necessarily preferable.

Furthermore, the context of extreme prematurity comes with specific challenges in regards to personalization: how to resolve potential conflicts between what best suits the parent(s) and what best suits the unborn infant? Similarly, there may be conflict between personalizing the counseling for the pregnant woman, and personalizing for their partner. Concerning this last issue, it is worth mentioning that no current studies pay extensive attention for the role of the partner of the pregnant woman in prenatal counseling.

4.1.4. Limitations

This study is subject to certain limitations. First, it is possible that we missed gray literature or important literature that was written in other languages than English. Second, since the majority of included studies has been conducted in the USA or has been written by American researchers, there might be cultural bias in this article.

Although Canadian and Dutch perspectives are also well-represented, we know little of how prenatal counseling is practiced in the rest of the world. Third, it could be that the same characteristics appear in many of the articles because of cross-referencing in the included body of literature. Moreover, many included articles and studies were written or conducted by the same researchers. Nevertheless, similar topics have arisen in several independent qualitative interview studies with parents, and simulation studies have shown similar tendencies among physicians. Our decision to exclude the articles that were included in the systematic reviews could be a limitation. We are, however, convinced that the systematic reviews are of sufficient quality and that their results represent the most important findings of the articles that are therein included. We are confident that this methodological decision has not influenced the content of this article (the identified characteristics, Fig. 3). Yet, it has surely influenced the number of articles in which the characteristics were mentioned (Fig. 2).

4.2. Conclusion

In this scoping review, we explored the existing body of literature on prenatal counseling for extreme prematurity at the limit of viability. Several main characteristics were identified. Parental values, uncertainty, SDM, and emotions were most frequently mentioned. A trend in time towards an increase in personalization was found. Although personalization might seem ideal, it comes with certain challenges and an eventual limit. Especially, more research is needed on parental views of personalizing prenatal counseling, on how to personalize in practice, and on exactly what aspects of prenatal counseling should be personalized.

4.3. Practice Implications

This scoping review emphasizes again the complexity of prenatal counseling at the limit of viability. The identified characteristics are all interrelated, and at the same time relate to the trend in time that is an increase in personalization. However, this scoping review makes clear that there are some tensions that require attention in future research. Especially an eventual limit of personalization, the challenge of physician bias, and the importance and discussion of psychosocial factors requires attention. One of the conclusions of Kharrat et al. may be a great reminder for future research on prenatal counseling: "[The] quality of the antenatal consultation is not purely about information content, but also the manner in which it is provided" [28].

Details of Ethics Approval

No ethics approval was needed for this scoping review.

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Lien De Proost: Conceptualization, Methodology, Formal analysis, Investigation, Writing – original draft, **Joanne Verweij:** Conceptualization, Methodology, Formal analysis, Supervision, Writing – review & editing, **Rosa Geurtzen:** Writing – review & editing, **Hafez Ismaili M'hamdi:** Writing – review & editing, **Irwin Reiss:** Writing – review & editing, **Eric Steegers:** Writing – review & editing.

Declarations of interest

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