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

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Running title

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life, and uncertainty. A trend in time towards personalization was also remarkable. However, more research is needed on parental perspectives on personalizing prenatal counseling.

Tweetable abstract

Parental values, emotions and uncertainty are most important for prenatal counseling for extreme prematurity.

Keywords

Extreme prematurity, limit of viability, prenatal counseling

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 will survive; some without disabilities, others with serious long-term disabilities.[1] 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.[2-4]

A major goal of prenatal counseling for extreme prematurity in the gray zone is to facilitate parental decision-making.[5,6] A decision has to be made between an active care approach and a palliative comfort care approach for the extremely premature infant. When parents receive prenatal counseling for extreme prematurity *beyond* this gray zone, more emphasis lies on informing the parents.[7] Since the goal of prenatal counseling changes beyond the gray zone, this article will focus solely on prenatal counseling for extreme prematurity in the gray zone, at the limit of viability.

Overall, prenatal counseling practices are heterogenous, varying per country, medical center and physician.[8,9] Without disregarding such variability, we aimed to identify the main characteristics of prenatal counseling for extreme prematurity at the limit of viability that can be found in the existing body of literature.

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".[10] 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.[10,11] This scoping review will be conducted in accordance with the scoping methodology proposed by Arksey and O'Malley in 2005.[12]

Identifying the research question

What are the main characteristics of prenatal counseling for extreme prematurity at the limit of viability?

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 for relevant studies.

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. Articles were excluded if

(1) they were official policy statements, clinical reports or guidelines, (2) they were focused on the education or training of physicians, or (3) they were focused only on the parental decision-making process instead of the prenatal counseling consultation.

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. Thus, 70 articles were included, of which 2 were systematic reviews. In the 2 systematic reviews, 23 articles were included. These 23 articles were excluded from this scoping review. Ultimately, 47 articles were included in this review. Disagreements that arose between the reviewers at each stage of the selection process were resolved through discussion until agreement was reached. 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.[13] A flow diagram of the screening process can be found in Figure 1.

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."[11] For this scoping review, it was first searched for characteristics of the included body of literature, and then for the main characteristics of prenatal counseling for extreme prematurity at the limit of viability. Data was charted from the included studies using a data extraction tool developed by the reviewers. The tool included data about the authors, the year of publication, the journal, the study design, the country in which the study was conducted, the objective of the study, and the result or conclusion of the study. Two researchers (LDP, EJTV) discussed the extracted data and categorized the data for further analysis.

Collating, summarizing and reporting the results

Two researchers (LDP, EJTV) then analyzed the included studies for findings that are relevant to the research question of this scoping review: the main characteristics of prenatal counseling for extreme prematurity at the limit of viability. In a first round of full text analysis, characteristics of prenatal counseling were identified and coded. In a second round, the studies were analyzed again and coded in reference to the characteristics that were identified in the first round.

RESULTS

Characteristics of the included body of literature

47 articles are included in this scoping review. The included body of literature has been published between 1998 and February 2021.[14] Only 7 of the included articles were written before 2010. More than half of the included studies were written between 2018 and 2021. Also, more than half of the studies were conducted in the USA (n=30), of which one was conducted in Australia and the USA.[15] The remaining studies were conducted in four countries: Canada (n=10), the Netherlands (n=5), Italy (n=1), and Dubai (n=1). Many different study designs are represented in the included body of literature (see Table 2). There were questionnaire studies (n=14), interview studies (n=9), 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), a conference abstract (n=1) and an editorial (n=1). The included studies and their characteristics can be found in Table 2.

Characteristics of prenatal counseling for extreme prematurity

In this scoping review, the following characteristics of prenatal counseling could be identified: a trend towards personalization, the importance of the parent-physician relationship, shared decision-making (SDM), the pitfall of physician bias, the role of emotions, anxiety and uncertainty, psychosocial factors, the importance of elucidating parental values, preferences and or goals, the role of religion, spirituality, and hope, and quality

of life (QoL). For an overview of the characteristics and the number of included articles than mention these characteristics, see Figure 2.

A trend toward personalization

In the past decade, personalizing or individualizing prenatal counseling seems to have become increasingly important. Only 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.[16,17] After 2010 however, many of the included articles mention some form of personalization as important for prenatal counseling. 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.[6] Two of the included articles offer recommendations to enable personalization in practice.[18,19] In an article written by parents of extremely premature infants, one of the ten recommendations for healthcare providers is to have a personalized approach.[20]

Parental values, preferences and goals

Like personalization, parental values seem to have become increasingly important for prenatal counseling in the last ten years. After 2010, nearly all articles refer to parental values, preferences, and or goals. In the article by Staub et al., it is recommended to make prenatal counseling about values instead of abstract data.[20]Geurtzen et al. similarly recommend that "parents should be asked for their personal perspectives and values regarding outcome information".[5] Although the importance of parental values is recognized in theory, almost half of the physicians participating in the study by Edmonds et al. do not elucidate values in practice.[21]

Shared decision-making (SDM)

Many articles refer to SDM. However, conclusions about SDM in relation to prenatal counseling are 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.[14] Over time, this tendency seems to have changed. In 2005, for example, Bastek et al. show that 77 percent of the neonatologists participating in their study prefer joint decision-making with the parent(s).[22]Moreover, in a study by Geurtzen et al. in 2018, 80 percent of the parents felt they were involved in decision-making.[23]Another article shows, however, that many physicians do not exactly know what SDM means.[6] Zupancic et al. show that physicians find it hard to identify parental decision-making preferences: they do mostly not know whether parents want SDM or decision-making autonomy without any physician interference.[24]

Parent-physician relationship

Often, it is referred to the significance of the parent-physician relationship for good quality prenatal counseling. Ruthford et al. refer to the relationship as a "partnership".[25] In the literature, the importance of trust is often mentioned in this regard.[24-26] The parent-physician relationship is considered to be of more importance than the actual content of the prenatal counseling consultation. The systematic review by Kharrat et al. reaches a similar conclusion: "[The] quality of the antenatal consultation is not purely about information content, but also the manner in which it is provided".[27]

Physician bias

In several articles, physician bias is explored along with the question how this can complicate the provision of information to parents in prenatal counseling. Studies have shown possible effects on prenatal counseling of physician bias towards parental socioeconomic status, sociodemographic characteristics, and the desiredness of the pregnancy.[28-30] Also Harrison warns about physician bias with regard to motives for providing active care.[31] The literature generally discusses physician bias as a possible detraction from the quality of information provision and/or the quality of the prenatal counseling consultation itself.

Quality of life (QoL)

Many articles mention QoL, even if there is no agreement in the included body of literature on whether, and if so how to incorporate it in prenatal counseling. Furthermore, it is not always specified what is meant by QoL: information on what is known regarding future QoL in premature infants and families, or a conversation to search for parental views and values regarding a 'good' QoL. Harrison pleads against discussing QoL studies in prenatal counseling because of the ambiguity of such research.[31] Other authors claim, by contrast, that discussing QoL is important.[18,19] Research in one article shows that physicians do not *only* discuss the QoL of the infant in prenatal counseling, but also that of the mom and or family.[32]

Psychosocial factors

Non-medical, psychosocial factors are also considered in the literature to be of importance for prenatal counseling. 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 this results in more directive counseling.[33] Janvier et al. however, mention in their article that some physicians may be hesitant to speak about non-medical, psychosocial topics in prenatal counseling.[34] Bastek et al. also found much variability in the extent to and way in which physicians discuss social factors in prenatal counseling.[22]

Religion, spirituality, and hope

Religion and spirituality play a role in prenatal counseling. This is one of the main conclusions of both the included systematic reviews.[27,35] In addition to religion and spirituality, hope seems to be of major importance. Although hope is of significant value for the parent(s), physicians prefer to be "objective" and avoid giving "false hope".[36,37]Research by Roscigno et al. shows that physicians and parents have different views of hope. The authors maintain, however, that "it is possible for parents to have both a realistic understanding of the prognosis, even when it seems grim, and simultaneously maintain hope".[38]

Emotions and anxiety

In the literature, emotions, anxiety, and uncertainty are said to influence prenatal counseling. The emotional state of parents is discussed in two ways. On the one hand, emotion is described as a factor blurring rationality in decision-making and information processing. Anxiety, for example, is said to negatively influence the quality of recall of the counseling conversation and to imply limited ability to gather information.[24] On the other hand, the positive side of parental emotions is 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.[18,19]

Uncertainty

Uncertainty and how this influences prenatal counseling is also discussed in two ways. On the one hand, there is uncertainty about the prognosis, possible outcomes, the overall situation and or the treatment decision.[16,34,39] On the other hand, uncertainty itself is a topic of discussion in prenatal counseling.[6,16,32] Yet, a simulation study by Edmonds et al. shows that only 42 percent of physicians discussed uncertainties.[21] Another study by Edmonds et al. finds that many physicians experience communicating uncertainty as challenging.[40] 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.

DISCUSSION

Parental values, uncertainty, SDM, and emotions are most mentioned in the literature. Also, a trend in time seems to be personalization: to adjust the counseling to the parents being counseled, so that it optimally fits the them and the yet unborn infant. Some of the identified characteristics tally with personalization. For example, elucidating parental values might lead to adjustments in the informational content of counseling and eventual recommendations about treatment options to best fit the parents. The same goes for parental views of QoL. Parents can be approached differently according to their personal views of QoL and disabilities, and physicians can adjust treatment recommendations to parental beliefs. Personalizing prenatal counseling

works best if the counseling physician knows who the parents are and what it is that they value most in life. This can only be achieved within a strong parent-physician relationship.

Other identified characteristics however, may be in tension with personalization. In one article, for example, it is suggested that *instead* of SDM, personalized or individualized decision-making may be better suited to reach parental decision-making preferences.[18] These authors 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: as, for example, Stiggelbout et al. describe in the last step of their SDM model, the eventual decision may be made by the parents, the physician, or both, according to parental preferences – incorporated as such in, for example, the Dutch counseling recommendations.[41,42] They emphasize that physicians who are asked to make treatment decisions alone must still take into account parental values.[6] Interpreting SDM this way, it can be compatible with personalization.

Other tensions may exist as well. Physician bias, for example, might endanger personalization and influence the way physicians interpret parental values. How can we ensure that adjustments in prenatal counseling are prompted by family characteristics instead of physician bias about those characteristics? Also, what if anxious parents decide that they do not want to hear any painful information about their unborn infant and her future? Maybe, certain informational content just *has* to be shared, whether it fits the parents or not. Furthermore, the hesitancy of physicians to speak about non-medical topics and values might be detrimental to personalization: if personalization is preferred, physicians have to be prepared to speak about psychosocial factors when parents feel a need to do so.

The wish for personalization is based upon common sense. Personalization includes physicians sharing prognostic information that pertains to the specific child and her surroundings. Current literature provides good theoretical frameworks and grounds for preferring personalization in prenatal counseling for extreme prematurity.[18,42] Yet, it has not yet been extensively and qualitatively explored with parents. Although qualitative research has been conducted on parents' perspectives on prenatal counseling, 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 major research gap. Also, personalizing prenatal counseling can have different meanings: a personalized prognosis, a personalized relationship with the healthcare team, an overall personalized approach to the parent(s) by taking into account their values, preferences and or goals e.g.. More research should be done on what aspects of prenatal counseling should be personalized. Furthermore, personalization as we know it in other fields asks for specification for the field of extreme prematurity: how to resolve potential conflicts between what best fits the parent(s) and what best fits the unborn infant? Similarly, there may be conflict between what best fits the pregnant woman and the eventual other parent. 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.

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, and 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, which does provide some scientific validity. Our decision to exclude the articles that were included in the 2 systematic reviews could be a limitation; we could have missed certain characteristics. However, we are convinced that the systematic reviews are of high quality and that their results represent the most important findings of the articles that are therein included.

CONCLUSION

In this scoping review, we explored the existing body of literature on prenatal counseling for extreme prematurity at the limit of viability. Parental values, emotions, and uncertainty were mostly mentioned. Also, a trend in time towards personalization was found. Although this might seem ideal, more research is needed on parental views of personalizing prenatal counseling, on how to personalize in practice, and on what aspects of prenatal counseling should be personalized.

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Disclosure of Interests

The authors have no conflicts of interest to disclose.

Contribution to Authorship

LDP conceptualized the article, conducted the formal analysis, and wrote the original draft. EJTV conceptualized the article, conducted the formal analysis, supervised, and reviewed and edited the draft. RG, HIM, IR, and ES reviewed and edited the draft.

Details of Ethics Approval

No ethics approval was needed for this scoping review.

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