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Published in:
 Seminars in perinatology

DOI:
[10.1016/j.semperi.2021.151532](https://doi.org/10.1016/j.semperi.2021.151532)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
 Publisher's PDF, also known as Version of record

Publication date:
 2022

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Verweij, E. J., De Proost, L., Hogeveen, M., Reiss, I. K. M., Verhagen, A. A. E., & Geurtzen, R. (2022). Dutch guidelines on care for extremely premature infants: Navigating between personalisation and standardization. *Seminars in perinatology*, 46(2), [151532]. <https://doi.org/10.1016/j.semperi.2021.151532>

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Dutch guidelines on care for extremely premature infants: Navigating between personalisation and standardization

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A B S T R A C T

Objective: There is no international consensus on what type of guideline is preferred for care at the limit of viability. We aimed to conceptualize what type of guideline is preferred by Dutch healthcare professionals: 1) none; 2) gestational-age-based; 3) gestational-age-based-plus; or 4) prognosis-based via a survey instrument. Additional questions were asked to explore the grey zone and attitudes towards treatment variation.

Finding: 769 surveys were received. Most of the respondents (72.8%) preferred a gestational-age-based-plus guideline. Around 50% preferred 24^{+0/7} weeks gestational age as the lower limit of the grey zone, whereas 26^{+0/7} weeks was the most preferred upper limit. Professionals considered treatment variation acceptable when it is based upon parental values, but unacceptable when it is based upon the hospital's policy or the physician's opinion.

Conclusion: In contrast to the current Dutch guideline, our results suggest that there is a preference to take into account individual factors besides gestational age.

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Introduction

In most countries there are guidelines for perinatal care at the limit of viability. Worldwide however, much heterogeneity exists regarding these guidelines; there is no consensus on both the type and the content of these guidelines.^{1,2} Different types of guidelines are used in different countries and clinical settings. Mainly, three types of guidelines can be

distinguished: (1) gestational-age-based guidelines, (2) gestational-age-based-plus guidelines, and (3) prognosis-based guidelines. Besides this, it can be preferred to have (4) no guideline at all.

The different types of guidelines all have their advantages and disadvantages. First, a clear gestational age (GA) cut-off may be preferred by some because of its clarity and unambiguity in practice.³ However, GA-based guidelines are called self-fulfilling prophecies. Furthermore, they ignore other

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prognostic factors besides GA⁴ and the gradualness of prognostic changes. Also, determining the exact GA is always prone to error; a GA of 24 weeks and 2 days may in fact be a GA of 23 weeks and 5 days or a GA of 24 weeks and 4 days. For this reason, the term estimated gestational-age (e-GA) was introduced.⁵

A second type of guideline that integrates more prognostic factors than just GA, could be called a GA-based-plus guideline. An example of such a guideline is the recent UK guideline from 2019.^{6,7} It is recommended in the guideline to make a risk assessment and take into account the GA, but also other important prognostic factors such as birth weight, the administration of corticosteroids, the sex of the infant, and whether or not it is a single or multiple birth.

A third type of guideline is prognosis-based.^{3,8} The cut-off points are then based on the expected prognosis – the chance of a “good” or “poor” outcome. This might be the most unbiased approach. No consensus is reached however, about the value-laden definition of what a “poor outcome” entails.⁹ Besides, some but not all could find consensus about prognostic cut-off points.^{8,10,11} It is difficult to determine correct prognostic figures and there is currently no internationally validated model.¹² Furthermore, the prognostic figures vary greatly between centres, countries and cultures.^{13,14}

The importance of parental values, preferences and goals, and the process of shared – or personalised – decision-making is highly emphasized in the literature.^{15–19} These parental preferences should be incorporated in ‘grey zone’ decision-making, or the so-called zone of parental discretion, in either GA-based, GA-based-plus or prognosis-based guidelines.^{20,21} However, some authors are convinced that no guideline is in fact needed for care at the limit of viability.^{4,22} According to them, the existence of such a guideline contributes to treating extremely premature infants at the limit of viability morally different than other patient groups: for no other patient group with comparable survival and morbidity rates guidelines decide whether or not intensive care can be offered. This, they say, is unjust to the infants and their parents.^{3,4,23,24}

In the Netherlands, nine level III perinatal care centres provide care for extreme prematurity. The Dutch guideline on care for extremely premature infants born earlier than 26 weeks GA is a national and interdisciplinary consensus guideline. It is strictly GA-based with a lower treatment limit of 24^{+0/7} weeks GA, and only refers to spontaneous preterm deliveries.²⁵ The 24-to-26-week GA period is considered to be the grey zone in which shared decision making by parents and healthcare professionals (HCPs) is advised.¹⁸

The current Dutch guideline dates from 2010 and is now being revised.²⁵ Therefore, we want to explore Dutch perinatal HCPs’ attitudes on different possible types of guidelines. The views of HCPs on guidelines for perinatal care at the limit of viability have been studied before but these studies mostly focused on the GA-related content of these.²⁶ In this study, we aimed to conceptualize what type of guideline is preferred by most Dutch HCPs. Throughout the online survey, we provided background information on the different types of guidelines because we aimed to explore the *informed* opinion of Dutch HCPs.

Methods

Study design

Cross-sectional, multi-center study using an online survey.

Setting and population

The online survey was sent to a broad scope of HCPs involved: all obstetricians, neonatologists, obstetric nurses, neonatology nurses, clinical midwives (obstetrics) and physician assistants or nurse practitioners (neonatology) from the nine level III centers in the Netherlands. The Dutch framework recommends joint counselling by an obstetrician and neonatologist together. Shared decision making between HCPs and parents is advocated to reach a decision. The survey was sent to (one or two) gynecologists and pediatricians for each level II hospital, involved in either referring pregnant women to the tertiary care center, or in receiving premature neonates after their period of neonatal intensive care.

Survey design

The anonymous online survey was designed to obtain information on HCPs opinions on actual issues relating to the guideline for extreme prematurity. Since not all HCPs may be familiar with the latest literature on the topic of extreme prematurity guidelines and decision-making, we provided background information and references for the various questions. We purposely choose to ask for their ‘informed’ opinion. Topics of interest were: (a) the current Dutch guideline, potential guideline types and guideline development (Table 1 is an example of information given before answering a question, a total overview can be found in supplement (1) (b) the grey zone: limits and acceptance for treatment variation and

Table 1. – Gestational-age-based guideline (based on duration of pregnancy).

<p>The lower limit above which active care is possible and the upper limit above which comfort care is no longer offered are defined based solely on the duration of pregnancy, as is the case in the current Dutch guideline.</p> <p>Arguments / benefits described:</p> <p>This offers clarity to all healthcare providers and patients involved - the literature also describes this need for clarity</p> <p>Ensures consistency in practice</p> <p>Duration of pregnancy is one of the most important prognostic factors for mortality and morbidity</p> <p>Counter arguments / disadvantages described:</p> <p>Inaccuracy in the exact duration of pregnancy</p> <p>Self-fulfilling prophecy (due to the policy decision (always comfort care) made by physicians, the prognosis of children just below the cut-off point is underestimated – for example, 100% mortality at 23 weeks in countries with a strict 24-week lower limit)</p> <p>Other prognostic factors are overshadowed (gender, antenatal corticosteroids, weight, etc.)</p> <p>Less individualized</p> <p>Discriminatory treatment with an equal chance of a good outcome (a fetus at 23 weeks and 5 days may have the same good prognosis as a foetus at 24 weeks and 1 day, for example because the 1st fetus has a higher weight and received corticosteroids and the 2nd foetus had a low weight and there was no time to administer antenatal corticosteroids)</p>

(c) counselling and decision-making. Next to multiple choice questions, open textboxes for comments were provided in each section. In this manuscript, results of section (a) and (b) will be described.

The first version of the survey was created by the authors, based on published literature. In a second round, comment from an expert in survey-development was used for further improvement. In a third round, a pilot-test was done by HCPs, one or two from each professional group, who would not receive the final survey since they were either just retired or switched jobs. The final version was approved by all authors. The original Dutch survey was translated to English by a professional translational service for publication purposes and can be found in the online supplemental material.

Not all survey results will be discussed in this manuscript because of the extensive nature of the survey. For this manuscript, we chose to focus on the survey results for topics (a) and (b). The survey results for topic (c) will be discussed in a separate paper.

Data collection

All neonatology and obstetrics department heads of the level III perinatal centres were approached by the authors and supported this survey, which was then spread to the target population in both their own centre and the regional level II centres by the administrative office, using a web-link. One reminder was sent. The survey was anonymized, e.g., no names or e-mail addresses were collected. Institutional Review Board consent was waived.

Data analysis

Descriptive statistics were given as proportions of the respondents for each completed question. Statistical analyses were conducted using IBM SPSS Statistics (Version 25, Armonk, NY: IBM Corp.).

Results

A total of 297 complete and 472 incomplete surveys were received. Each level III perinatal centre and its region level II centre was represented. The exact response rate could not be calculated since feedback from a few centres feedback was incomplete. However, an estimated total of 2000 to 2200 surveys was sent, meaning a response rate of 35% to 40%. Demographic questions were asked at the very end of the survey, so these were mostly missing for the incomplete surveys. Demographic characteristics of the respondents can be found in [Table 2](#).

Upper and lower limits of the grey zone

Exploration of the preferred upper and lower limits of the grey zone (if the guideline were to be based on GA of a well-grown, singleton pregnancy in a level III centre) revealed that 196 (48.6%) of the participants preferred 24^{+0/7} weeks gestation as the lower limit and 26^{+0/7} weeks gestation was the most preferred upper limit (197, 49.4%). [Fig. 1](#) shows the opinions on the upper and lower limit of the grey zone.

Many additional comments were made about the lower limit. The few participants who choose 22^{+0/7} weeks as a lower limit added that they found it important to provide similar care as in neighbouring countries. Comments of participants with a preference for a lower limit at 23^{+0/7} weeks added consequently that active management only should be offered without additional risk factors like a well-grown baby. An argument given to lower the threshold to 23^{+0/7} weeks was the presumed improvement of the quality of care for all neonates, mainly the slightly older preemies. The most important comments of participants preferring to keep the 24^{+0/7} weeks lower limit were their “lack of good outcomes” and the “lack of improvement in outcomes over the years”. Another problem frequently reported was the capacity problem for the Dutch neonatal intensive care units (NICUs) if more neonates are admitted. For the preferred upper limit, some participants noted that it would be logical to lower the upper limit too, if the lower limit is lowered. On the other hand, some participants noted that personalised care should also include the willingness to withhold neonatal intensive care beyond the upper limits in cases of severe growth restriction. Interestingly 11 participants, mostly obstetrical nurses, felt the lower limit should be 26 weeks’ GA. One comment is noted, summarized ‘we shouldn’t give care too early, but I am not an expert on this topic’.

Opinions on the current Dutch guideline

Most of the participants (82.7%, $n = 593$) were familiar with the Dutch guideline, however only 10.3% ($n = 74$) were familiar with foreign guidelines. The majority 87.7% ($n = 427$) agreed with the recommendations in the current guideline and most participants (94.8%, $n = 435$) found the guideline feasible in practice. A summary of the most mentioned comments in open text boxes were: there is more need for personalization; decision-making in the grey zone is challenging; the current guideline is too strict; the 24-week threshold is too low; the influence of parental wishes is too high; and finally, there were comments regarding worries about the capacity of NICU beds and about the ongoing variety between different hospitals. Only 32.5% ($n = 105$) of the participants said to follow the guideline strictly while 65.3% ($n = 205$) of the participants did deviate from the guideline in some cases. Though the Dutch guideline strictly describes what to do in cases of spontaneous preterm birth, 77.8% ($n = 397$) indicated that they also use it for iatrogenous preterm birth.

Possible guidelines types

Participants were asked to give their opinion on different types of guidelines. The questions were prefaced by information on national and international discussions on the exact boundaries of the grey zone and the discussion on the type of guideline. Four types of guidelines were presented including the benefits and disadvantages; (1) no guideline; (2) a GA-based guideline (the limits of the grey zone are based on duration of pregnancy); (3) a GA-based-plus guideline (based on duration of pregnancy plus other factors); and (4) a prognosis-based guideline (the limits of the grey zone based on the expected prognosis). Participants ranked each type of

Table 2. – Background characteristics of the participants.

Background characteristics		N (%)
Years of experience (*)	Mean 13.2y (SD 8.9) Median 12y (IQR 5 – 19)	
Age (years)	20-30	28 (9)
	30-40	83 (28)
	40-50	93 (31)
	50-60	75 (25)
	60-70	18 (6)
Profession	Neonatal nurse	92 (30)
	Obstetric nurse	53 (17)
	Nurse (not otherwise specified)	5 (2)
	Clinical midwife	13 (4)
	Physician assistant or nurse practitioner neonatology	15 (5)
	Gynaecologist	39 (13)
	Counselling parents	32 (82)
	Paediatrician	82 (27)
	Counselling parents	69 (84)
	Other	6 (2)
Gender	Female	241 (82)
	Male	49 (17)
	Other	0
	Prefer not to answer	3 (1)
Working in level III hospital (with NICU facility)?	Yes	266 (90)
	No	30 (10)
Exposure extreme prematurity (GA 23 ^{+0/7} - 25 ^{+6/7}), (**) frequency in past year	None	9 (4)
	<5	0
	5-10	70 (34)
	10-20	69 (33)
	20-30	32 (15)
	>30	28 (14)
Counselling conversations for imminent extreme premature birth <26 ^{+0/7} weeks GA, (***) frequency in past year	None	0
	1-10	117 (68)
	10-20	41 (24)
	20-30	12 (7)
	>30	3 (2)
Children	Yes	219 (75)
	No	69 (24)
	Prefer not to answer	5 (2)
Religion	Yes	75 (26)
	No	203 (72)
	Prefer not to answer	6 (2)
Type of religion (only in those answering YES to religion)	Christianity	72 (96)
	Islam	2 (3)
	Judaism	0
	Buddhism	1 (1)
	Hinduism	0
	Prefer not to answer	0
	Other	0

(*) for physicians including fellowship, for physician assistants and nurse practitioners including education part in neonatology, for clinical midwives including education part in Level III hospital, for neonatal & obstetric nurses including education part in Level III hospital; (**) depending on profession: trajectory of hospitalization neonate, mother, deliveries or referrals to and from Level II hospital; (***) depending on profession: presence at counselling conversation as counsellor or as observer / supportive person

guideline (Table 3). After scoring each guideline type, participants were asked for their personal favorite. Most respondents preferred a GA-based-plus guideline (72.8%, $n = 295$). The most important comments on the GA-based-plus guideline were: a GA-based-plus guideline is a good balance between personalisation and evidence-based medicine, the 'plus' should be used especially for borderline cases, clear thresholds give less discussion with the parents, and there is often no time for individualised care. Several other comments were on the lack of validated models for a prognosis-based

guideline and on the preference to add criteria for withdrawal of intensive care treatment after birth.

Scenarios: acceptance for treatment variation

The participants were asked to indicate their opinion on similar scenarios of extreme prematurity with only a different motivation for varying treatment (see Table 4 and Fig. 2, a total overview can be found in the only supplementary material). In the open text boxes, many participants commented on the cases. Many emphasized the importance of parental

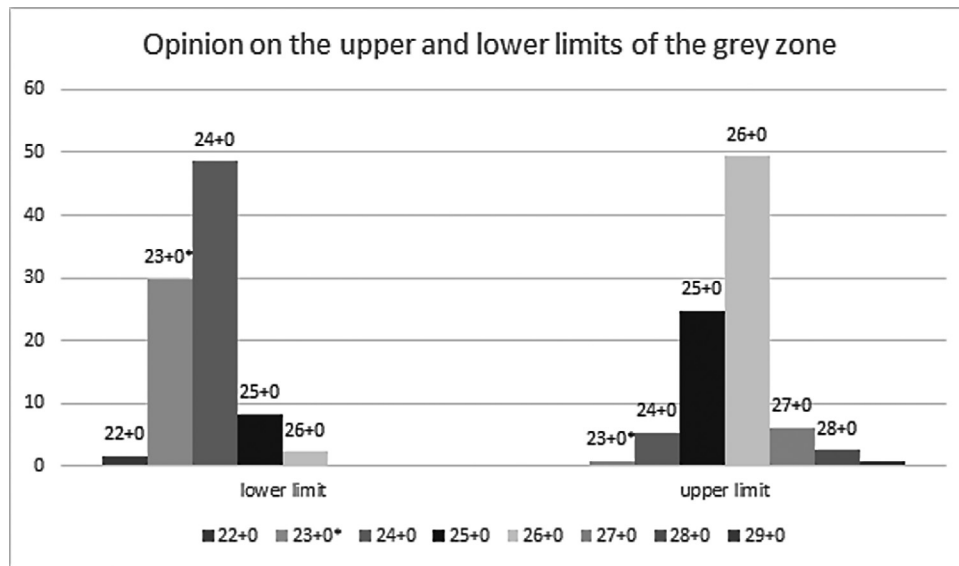


Fig. 1. – Opinions on the upper and lower limits of the grey zone. *Week 23 is the total sum of all opinions (also in open box comments) with a GA mentioned between 23+0 and 23+6. For the lower limit the total sum is not 100% as some participants didn't know (7.7%), or couldn't define a limit in whole weeks (1.2%) or for other reasons (0.2%).

Table 3. – Opinions per type of guideline, *highest percentage.

Type of guideline	Fully agree	Agree	Neutral	Disagree	Fully disagree
	n (%)	n (%)	n (%)	n (%)	n (%)
No guideline	8 (1.7)	55 (11.7)	50 (10.6)	226 (48.1)*	131 (27.9)
GA-based guideline	7 (1.6)	130 (29.2)	112 (25.2)	178 (40.0)*	18 (4.0)
GA-based-plus guideline	78 (18.4)	280 (65.9)*	51 (12.0)	16 (3.8)	0 (0.0)
Prognosis based guideline	19 (4.7)	143 (35.3)*	118 (29.1)	111 (27.4)	14 (3.5)

values. Participants recommended that counselling should be done well and honestly. Some respondents believed that parents often do not realise the possible complications of extreme prematurity. Others noted that counselling is often too positive. It was also noted that it is very understandable

that parents want this chance and that 'we should not judge them for that'.

For different treatment decisions based on medical judgement of the social background, the comments are mostly supporting the opinion that it is highly unacceptable for a physician to judge someone's social situation. Participants frequently labelled this explanation as 'discrimination' or 'paternalism'. A few participants commented that the difference is acceptable since, for example, a young teenage mother and her extreme premature child will both face a difficult future.

For different treatment decisions based on variation in hospital policies most comments were about the wish to have a comparable policy in all hospitals, which is also important in the context of possible transfers between hospitals due to space limitations. An equal chance on starting active care for similar cases is considered important. A few comments underline the importance of transparency on the differences in policy between hospitals.

Finally, different treatment decisions based on varying personal opinions of individual physicians is found highly unacceptable. Most commented that there should be a unanimous policy for the entire health care team. Moreover, it was often mentioned that the counselling should be neutral, uninfluenced by the physicians' personal values, and based on facts. Some participants underlined the importance of a strict guideline, as this will reduce treatment variation based on physicians' opinions.

Table 4. – Scenarios of similar cases of extremely premature birth but variation in treatment.

We would like to know to what extent you are willing/able to accept certain differences in strategy. Please forget the current guideline for a moment and imagine the following hypothetical case: it is November 2020, a pregnant woman (G1P0) has been admitted to a specialised center with cervical shortening and contractions. She is carrying a single female fetus and at 23^{+5/7} weeks gestational age. Corticosteroids have not been administered yet.

In situation A the choice is made to implement palliative comfort care if the labor progresses today.

In situation B the choice is made to implement active neonatal care if the labor progresses today, and corticosteroids are administered. We have provided a number of (hypothetical!) explanations for the difference between situation A and situation B. Please indicate whether you find this acceptable or not.

Motivations of varying treatments:

Scenario 1: based on values/wishes of the patient

Scenario 2: based on social background

Scenario 3: based on differences between hospitals

Scenario 4: based on differences between caregivers

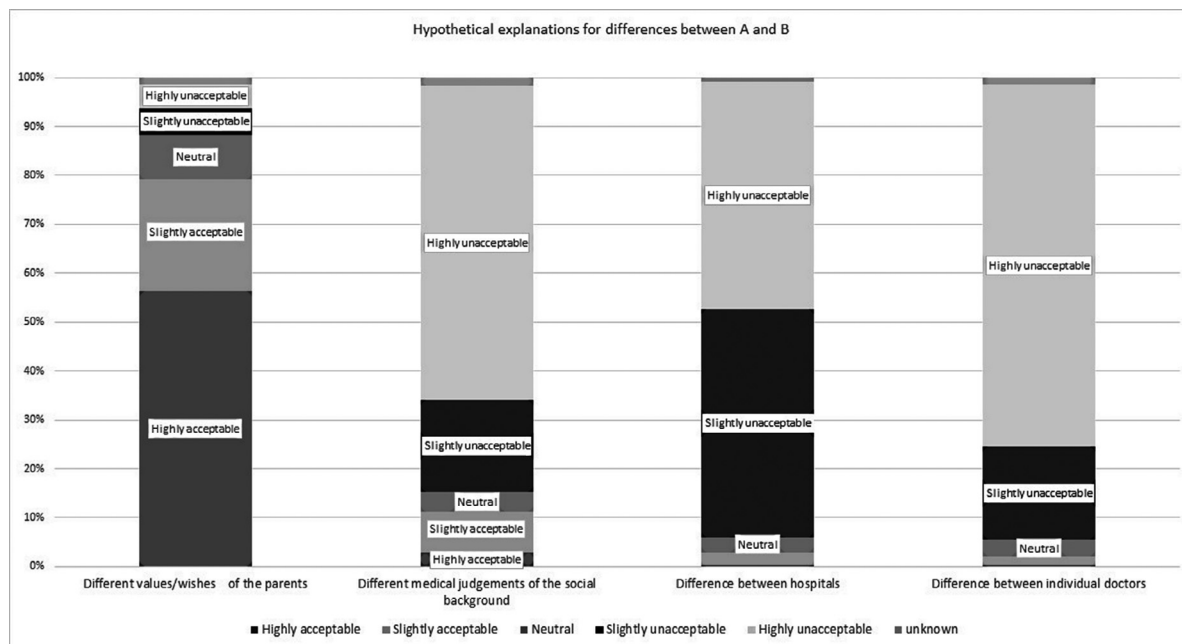


Fig. 2. – Hypothetical explanations for different treatment decisions for similar cases

Discussion

The results of our survey yield three important findings: (1) the majority of Dutch HCPs still find the current Dutch guideline – which recommends the provision of early intensive care for premature babies from 24^{+0/7} weeks GA and above – acceptable; (2) many professionals however, prefer a different type of guideline; the GA-based-plus guideline which advises to take into account other prognostic factors than just GA is mostly preferred. In addition, we found that (3) most study participants find variation in treatment between similar infants acceptable *only* in situations where the variation is based upon individual parental values or wishes, and unacceptable when it is based upon differences in the hospital policy or the physician's preferences.

Revising the Dutch guideline

As mentioned earlier, compared to most other international guidelines on this matter the Dutch guideline may be thought to stand out. The Netherlands can be considered an outlier for “its relatively high age threshold of initiating active care, its grey zone spanning weeks 24 and 25 in which active management is determined by parental discretion, and a slight reluctance to provide active care in case of extreme prematurity.”²⁷ Although the current Dutch guideline was already published in 2010, our survey shows that the majority of HCPs still agree with the recommendations made in this guideline. Only a minority of around 30% find that the threshold should be lowered to 23^{+0/7} weeks of gestational age.

In the light of the current revision of the Dutch guideline, these are important findings. More importantly, we noted that the results of our survey demonstrate an interesting shift in Dutch HCP attitudes. The wish for personalization or individualization of care at the limit of viability is increasing.

Personalization and related terms are often mentioned in the comment sections of several survey questions. The importance of integrating more prognostic factors in the guideline and focusing on parental wishes and values were often mentioned. At the same time however, the participating HCPs underline the importance of a clear guideline while including more prognostic factors.

Personalisation and guidelines

From the survey results it became clear that personalisation or individualization of care at the limit of viability can have different meanings for HCPs. It can mean ‘to take into account other prognostic factors than GA’, but also ‘to take into account parental wishes and values’ or ‘to adjust the information shared in counselling to the parents being counselled’, and so on. A number of HCPs believe that optimal individualization is accomplished if no guideline is present, while others seem to believe that personalisation is independent of a guideline. It may therefore be that the importance of parental values is transcendent of the guideline type; no matter the type of guideline, parental values are significant. Then, there should also be room for parental values when there is, for example, a strictly GA-based guideline.

Furthermore, the wish to individualize care seems to have limits for Dutch HCPs. As said, according to the responses, treatment variation that is based upon parental values is acceptable whereas variation due to differences between (values of) a hospital or physician is not. Also, almost all HCPs wish to have a guideline, a lower treatment limit, and an upper treatment limit. The wish for national uniformity of treatment and standardization of care may be influenced by the fact that in the Netherlands, typically, all national guidelines to date are consensus-based.

A potential way to have more ‘uniformity in personalisation’ could be the organization of training in counselling,

or an up-to-date decision aid to help parents understand outcome data (when preferred) and to help parents discern their own values and preferences. Already, nationwide consensus on important counselling aspects has been reached.¹⁸ Furthermore, since some comments showed several factually-unnudged assumptions, efforts to increase knowledge on treatments and outcomes of extreme prematurity among healthcare providers should be made. Examples of these assumptions are: 'barely good outcome for children born at 24+ weeks GA' and 'only start with active management if the child shows a good start'. Especially the last comment, mentioned several times, is not recommended, as literature shows that 'clinical assessment in the delivery room is a poor predictor of survival'.^{28,29} Also, a national training on prenatally counselling parents is lacking in the Netherlands. First steps are made however, to organize such a training for fellows in neonatology and maternal-fetal medicine.

Strengths and limitations

This is the first study to conceptualize what type of guideline is preferred by HCPs. We asked for their informed opinion by providing background information on different possible types of guidelines. All HCPs involved in the daily care practice around the limit of viability were represented in our survey respondents; this is a strength of this study. The results or our survey may of course be influenced by the Dutch context and the strictly GA-based, national consensus guideline in the Netherlands. The responses might therefore be biased and may not fully apply internationally. Yet, we notice a general trend towards personalisation at the limit of viability also in the international literature.^{6,19,28}

Future research

It is clear that more research is needed to define the preferred personalisation for the specific field of extreme prematurity at the limit of viability. It is also unknown what patients and their families think about this matter. Studies showed that there is variation in parental preferences regarding how they want to be counselled.²⁹⁻³³ Parental views on treatment guidelines however, are largely unknown. Although one article shows that – at least some – parents find it hard to cope with variety between institution, we need more studies to confirm this.³⁴

Conclusion

Further reflection is needed on the relationship between personalisation and the wish for uniformity in guidelines on care at the limit of viability. Also, facilitators and barriers to personalising care and counselling in practice must be explored. An important knowledge gap is the patient and family perspective on this matter. Qualitative research with patients, parents and healthcare providers on preferred guidelines and personalisation is therefore urgently needed.

Disclosure

The authors report no proprietary or commercial interest in any product mentioned or concept discussed in this article.

Supplementary materials

Supplementary material associated with this article can be found in the online version at [doi:10.1016/j.semperi.2021.151532](https://doi.org/10.1016/j.semperi.2021.151532).

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