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Exploring professionals' views regarding prenatal counselling in congenital diaphragmatic hernia

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Abstract

Objectives: Congenital diaphragmatic hernia (CDH) is a congenital malformation in which the diaphragm and lungs are underdeveloped, leading to cardiorespiratory and other problems. This study aimed to explore professionals' views regarding prenatal counselling in CDH.

Methods: A qualitative study was performed among healthcare professionals involved in the care of CDH patients in Radboud university medical center Amalia Children's Hospital. Semi-structured interviews were conducted until saturation was achieved. Transcripts were qualitatively analysed to gain insight into professionals' views regarding counselling.

Results: Eighteen professionals with various backgrounds were included. The professionals agreed that the first counselling session should be soon after diagnosis and additional sessions should be offered. Concerning counselling content, participants considered explanation of the diagnosis, prognosis, short- and long-term consequences, treatment options and practical aspects important. As for decision-making about possible termination of pregnancy, all professionals emphasised the importance of the parental role, but the preferred parental involvement varied. Regarding practical aspects, preferred counsellors were a neonatologist, obstetrician, paediatric surgeon and/or medical social worker. Participants emphasised that the counselling should be adjusted to parents' needs.

Conclusions: This study gained insight into professionals' views regarding the timeline, content, decision-making process, and practical aspects of prenatal counselling in CDH.

Keywords: congenital diaphragmatic hernia; prenatal counselling; qualitative study

Introduction

Congenital diaphragmatic hernia (CDH) is a rare congenital malformation, in which the development of the diaphragm is incomplete, occurring in 1–4/10,000 pregnancies [1]. The defect causes abdominal organs to protrude into the thoracic cavity and is associated with underdevelopment of the lungs and pulmonary vasculature, which can lead to severe cardiorespiratory problems, as well as nutritional and neurocognitive problems. CDH is associated with serious morbidity and significant mortality above 30 % in live births [2].

CDH is diagnosed antenatally in more than half of the surgically repaired CDH patients in the Netherlands [3]. Antenatally, a crude estimation of the survival rate can be made using ultrasound based on the observed to expected lung-to-head ratio (O/E LHR): a smaller O/E LHR is associated with a more severe prognosis. Severity is categorised into mild, moderate, and severe [4]. Amongst other factors, this ratio can be used in the prenatal counselling to give an estimation of the prognosis. The goals of prenatal counselling are to inform parents about the possible outcomes in the (near) future, and to support parents in making a (shared) decision about further management, i.e., whether to continue or terminate the pregnancy when applicable [5]. In the Netherlands, termination of pregnancy (TOP) is permitted up to a gestational age (GA) of 24 weeks. Another potential prenatal decision is

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whether to conduct a foetal intervention to improve prognosis, namely fetoscopic endoluminal tracheal occlusion (FETO) [6].

Prenatal counselling increases parents' well-being and decreases anxiety in parents expecting a child with a congenital anomaly [7]. Even though prenatal counselling is very important in such a severe congenital condition; little is known about how to best counsel parents expecting an infant with CDH. Furthermore, there seems to be international variation in current counselling practices [5].

The main objective of this study was to explore professionals' views regarding prenatal counselling in antenatally diagnosed diaphragmatic hernia. We aimed to gain insight into several aspects: the goals and timeline, content, and decision-making process as well as practical aspects of prenatal counselling.

Methods

Study design and setting

We performed a qualitative single centre study in the Radboud university medical center (Radboudumc) Amalia Children's Hospital, a tertiary care centre and one of two Dutch referral centres for CDH. Semi-structured, individual in-depth interviews were conducted. The COREQ checklist [8] was used to report methods and results, see also Supplementary Material I.

Study population

The study population consisted of healthcare professionals involved in the care for CDH patients in the Radboudumc Amalia children's hospital. Through purposive sampling, we aimed to gain a broad perspective by including physicians and non-physicians from various specialisms. We intentionally also included professionals who were currently involved in CDH care, but not in prenatal CDH counselling. Participants were recruited through email and/or face-to-face (CdG, EK, RG). Reminders were sent (CdG, EK) to non-responding professionals. Informed consent was obtained from all participants prior to the interview. The local Ethics Review Board (file 2020–6949) judged that this study did not fall within the scope of the Dutch Medical Research Involving Human Subjects Act.

Data collection

Based on literature [9, 10] and professional experiences of the research team, an interview guide was developed.

During the interviews, the preferred timeline of CDH counselling was addressed, followed by participants' views regarding the topics they think should be discussed, the decision-making process and practical aspects regarding prenatal CDH counselling. Participants were asked in-depth questions regarding what they consider potential decisions and about preferred ways of decision-making. Regarding the practical aspects, participants were asked about their preferences regarding counsellors, duration of the counselling sessions and the use of supportive material. The interview guide was evaluated and updated in several rounds (CdG, EK, RG, RvdL, WdB). To test the interview guide and to train the interviewers (CdG, EK), two pilot interviews were held. The topic guide can be found in Supplementary Material II.

Digital video interviews were planned in October and November 2020 via Skype for Business and Zoom. Live interviews were not possible due to restrictions related to the COVID-19 pandemic. All interviews were conducted by two interviewers (CdG, EK); one had the role of main interviewer, the other made field notes. Recruitment and data collection proceeded until data saturation was reached (i.e., when no substantial new insights were gained).

Data analysis

All interviews were recorded audiovisually and transcribed verbatim (CdG, EK). The transcripts were inductively analysed using the constant comparative method (CdG or EK). Analysis of each transcript was subsequently reviewed by the other analyst, after which all discrepancies were discussed (CdG, EK and RG) until consensus was reached.

Codes were assigned through open coding, regrouped into higher-order themes and subthemes, and refined through multiple readings. The analysis was performed using ATLAS.ti version 8.4.20.

Results

Demographics

A total of 33 healthcare professionals was approached. Participants from nine professions could be included, and inclusions were stopped when data saturation was reached (n=18 participants). The interviews lasted 23–61 min (median 40 min). Main characteristics of the 18 interviewees can be found in Table 1.

Quotes

Table 2 provides participants' quotes concerning their preferences in various aspects of prenatal CDH counselling.

Views regarding the timeline and goals of prenatal CDH counselling

The professionals agreed that the first counselling session should take place as soon as possible after CDH is diagnosed, which is most often around 20 weeks' gestation. Later in pregnancy, after the legal time limit for TOP (being 24 weeks GA in the Netherlands) has passed, opinions differed on the preferred moment of follow-up counselling sessions: ranging from 26 weeks GA to just before birth. When FETO is an option, it should be taken into account that the optimal time period for balloon insertion is between 27 and $29^{+6/7}$ weeks GA [11].

Table 1: Demographics.

Profession (n)	Current role in CDH care					Any prenatal counselling experience
	Prenatal counselling	Postnatal	Clinical care during admission	Outpatient clinic appointments	Specialised CDH expertise team[a]	
Clinical geneticist (1)	✓	✓		✓		✓
Medical social worker (2)	✓			✓	✓	✓
	✓	✓	✓	✓		✓
Neonatologist (2)	✓	✓	✓	✓	✓	✓
		✓	✓	✓		✓
Obstetrician (2)	✓			✓	✓	✓
	✓			✓		✓
Paediatric intensivist (1)		✓	✓			
Paediatric pulmonologist (2)		✓		✓		✓
		✓	✓	✓	✓	✓
Paediatric surgeon (3)		✓	✓	✓	✓	✓
		✓	✓	✓	✓	✓
		✓	✓	✓		✓
Paediatrician (2)		✓	✓		✓	
		✓		✓		✓
Registered nurse (3)		✓	✓		✓	
		✓	✓			
		✓	✓			
Total, n (%)						
18 (100)	6 (33)	15 (83)	12 (66)	13 (72)	8 (44)	13 (72)
Gender male, n (%)	7 (39)					
Median age, years (IQR)	46 (41–53)					
Years of experience, median (IQR)	16 (8–19)					
Years of experience with CDH, median (IQR)	10 (7–16)					

[a] Specialised CDH expertise team: This team discusses every new CDH patient, starting prenatally (even though some members are not routinely performing prenatal counselling conversations themselves, they are being involved starting prenatally). CDH, congenital diaphragmatic hernia; IQR, interquartile range.

A summary of the views regarding timeline and goals of prenatal CDH counselling as suggested by the interviewees is provided in Figure 1.

The participants emphasised that the number of counselling sessions should be adjusted to parents' needs and wishes. Most of the interviewees stated that more than one session before the legal time limit for TOP should be offered. Reasons given were to support the process of decision-making and because parents need as much time as possible within the legal restrictions. Another reason provided was that additional ultrasounds may provide new information, for example about the prognosis, and that these findings should be explained. According to the interviewees, an important goal for follow-up conversations was to answer questions that parents usually have.

Views regarding the content of prenatal CDH counselling

Almost all professionals mentioned that the content of prenatal counselling should be personalised by exploring parents' needs and expectations. Parental values (e.g., what do they want for their child and their family, what do they think is important for a good quality of life) should be discussed. Interviewees stated that this is crucial for decision-making about continuation or TOP and for managing parents' expectations. Furthermore, the professionals wished to adjust the degree of medical detail to parents' wishes and to what they assumed parents could handle at that moment.

The importance of allowing parents to have hope and give them perspective on a normal life for their child, considering the prognosis, was emphasised by several professionals. One participant suggested to also focus on positive aspects next to the negative aspects associated with this severe condition. Participants thought losing hope would be the worst thing that could happen to parents and should be prevented, in particular when the legal limit for TOP has passed.

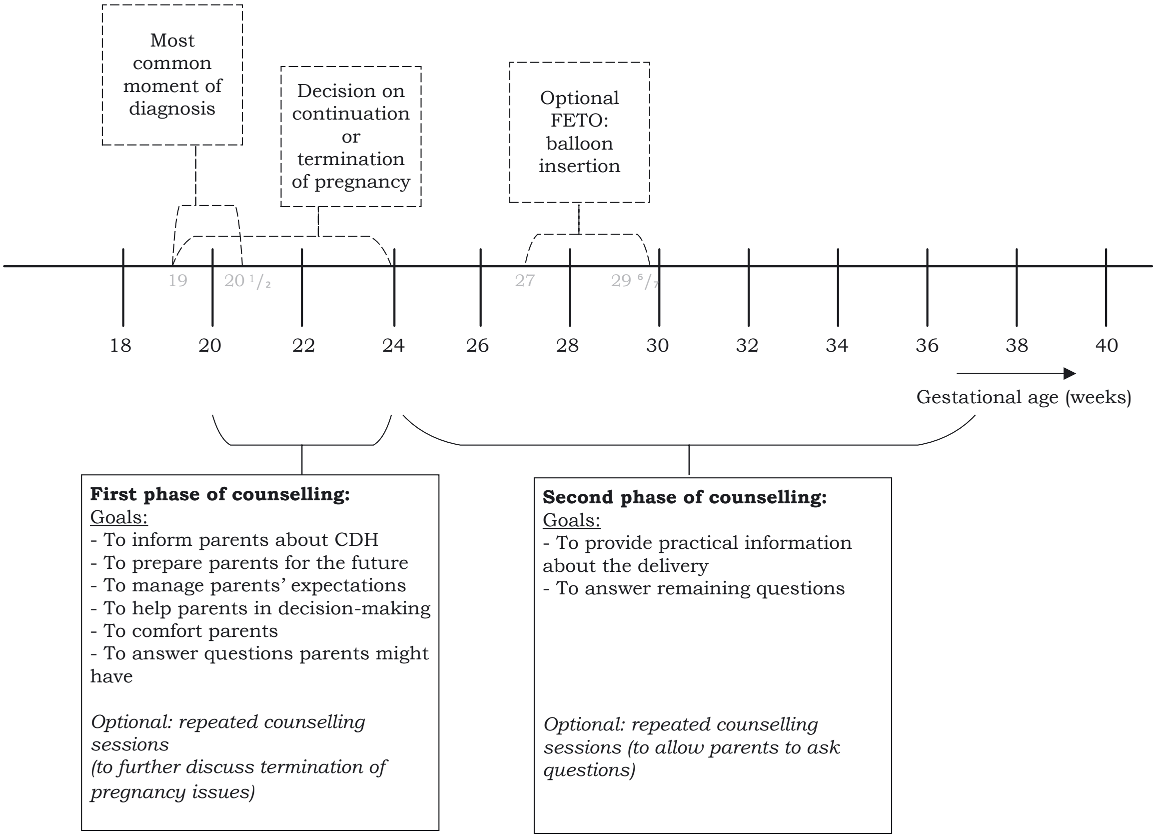
Most of the participants emphasised that to make an informed decision about continuation or TOP, counselling should contain at least the following topics: an explanation of the CDH diagnosis, what parents can expect in the short but also in the long term for a child with CDH, such as

Table 2: Themes and subthemes with participants' quotes regarding preferences in prenatal CDH counselling.

Themes and subthemes	Representative quote
Goals and timeline	
Number of counselling sessions	"In one single conversation a decision cannot be made. People sometimes need much more time, which is completely justified (…) and [it] should be tailor-made. For some, a single conversation is enough, but usually that is not the case (…) Others may need three, four conversations before 24 weeks, and two could be enough for someone else." (participant 6, obstetrician)
Content	
Degree of medical detail	"It does not make sense to just keep spouting information, just because you have to. The ultimate goal is that these people can benefit from this information, of course." (participant 7, obstetrician)
Personalising counselling	"You do follow-up ultrasounds, and growth ultrasounds, and you start monitoring that defect. You slowly but surely get a bit of a picture in those weeks. So, that means we have to adjust our "counselling", or gather guidance, accordingly." (participant 1, paediatric pulmonologist)
Hope	"I think it's important to allow people hope if that hope is actually there. As doctors, we actually are far too good at telling people how serious something is or what illness actually means, and then we sometimes forget that these children can go to a normal school." (participant 3, neonatologist)
Realistic information	"Because I really notice that people are misinformed, they think: the defect is closed, the child will go home after one week and that really is a misconception" (participant 9, paediatric surgeon)
Practical information	"People have to realise thoroughly that they will really be displaced from their home for the duration of about six months. And that this can be threatening for your family situation, for your marriage, for your career, for your work, pretty much for everything." (participant 3, neonatologist) "There is already so much uncertainty (…) that if all those kinds of practical things, if we can take away those questions by providing clarity, then we see that brings parents peace." (participant 10, medical social worker)
Use of statistics	"Then you mention numbers, which are actually for the whole group and therefore not per se for that individual child …" (participant 18, neonatologist)
Decision-making process	
Roles in decision-making	"By whom should it [decision about TOP] be made, well not by the neonatologist, not by the obstetrician, but by the patient. A patient has a choice and that is their own choice." (participant 6, obstetrician) "I think that the role of healthcare professionals is, of course, to counsel parents objectively, to the extent that this is possible, to provide parents with information to give them the option, (…), you hope that what is told is objective, to be able to make an objective decision." (participant 18, neonatologist) "So, I think that sometimes the healthcare professional should give a more pressing advice than in other cases. If parents are unable to make a good decision or weigh the options themselves, then, as a healthcare professional, I think you can steer them in a certain direction, in the best interest of the child." (participant 2, paediatric pulmonologist) "I do not think that you can leave a decision to parents on their own. (…). I do not think that is morally justifiable." (participant 17, paediatric intensivist)
Time pressure	"There is always a rush. Or rush, those people also need to be given some time about okay, uhm, what does this information mean to us and how do we proceed with that." (participant 7, obstetrician)
Practical aspects	
Counsellors	"We [obstetricians] often have the conversations with a neonatologist together, which I think is very nice, that you can complement each other and that you know from each other what has been said. Uhm, and the nice thing about it is that when you're not talking, you see how people react, and sometimes you don't realise that as much when you're talking." (participant 7, obstetrician)
Location	"But if they get information in another centre, I think they should get counselling again in XX [Dutch CDH centre of expertise], where ECMO is available. Because I do notice that it can be different from the counselling in other hospitals." (participant 11, medical social worker)
Supportive tool: decision aid	"What I notice myself, and also hear from patients, is that they don't really experience it as a decision aid but more as a list, uhm, what points are important to you. But it's not really a tool to help you choose. (…) Because, (…) you can't make a decision just on pros and cons." (participant 10, medical social worker)

CDH, congenital diaphragmatic hernia; ECMO, extracorporeal membrane oxygenation.

cardiorespiratory and nutritional problems and a prolonged hospital admission. Also the possible therapies should be discussed, e.g., surgery, extracorporeal membrane oxygenation (ECMO) and respiratory support. Many professionals also mentioned that the inability to predict an individual prognosis should be discussed with parents, just as a changing prognosis in case this occurs during pregnancy, which logically leads to adjusting the information discussed during the counselling sessions. Since participants experienced a lot of misconceptions in practice they thought this



First phase of counselling:
Goals:
- To inform parents about CDH
- To prepare parents for the future
- To manage parents’ expectations
- To help parents in decision-making
- To comfort parents
- To answer questions parents might have

Optional: repeated counselling sessions (to further discuss termination of pregnancy issues)

Second phase of counselling:
Goals:
- To provide practical information about the delivery
- To answer remaining questions

Optional: repeated counselling sessions (to allow parents to ask questions)

Figure 1: Summary of participants’ views on timeline and goals of prenatal CDH counselling. FETO, fetoscopic endoluminal tracheal occlusion; CDH, congenital diaphragmatic hernia.

information would help parents to gain a most realistic approach as possible about the future.

Opinions differed about the use of statistics to express the prognosis. Some preferred mentioning specific numbers like survival rates, others said to only use an outcome category based on the O/E LHR (mild, moderate or severe) and argued that specific percentages should not be mentioned. They thought statistics were too difficult to understand for parents, not useful for an individual prognosis and that parents could become preoccupied with the percentages. The same applied to discussing the statistics regarding the occurrence of potential complications: several professionals suggested that potential complications should be mentioned without using numbers.

In follow-up counselling conversations, according to the interviewees, information could be repeated or more detail could be given. Furthermore, additional explanations about the delivery and events immediately after birth could be discussed, participants thought that this was important for parents to prepare themselves. Participants explained the importance of practical information about the postnatal period, since having a child with CDH affects parents’ relationship, siblings, housing, and work. They thought that practical information could give parents something to hold on to in these uncertain times.

Table 4 presents a summarised list of the topics suggested to discuss in prenatal CDH counselling. In Supplementary Material III, a more extensive table including the subtopics can be found.

Views regarding the decision-making process in prenatal CDH counselling

Continuation or termination of pregnancy

The professionals stated it should be made clear that there is a decision to make, that information about continuation or TOP should be given and many said that this information should be objective. However, no further explanation of what they meant by ‘objective’ was given. All participants emphasised the importance of the parental role in decisions regarding continuation or TOP, because they felt that parental freedom to decide about this was important.

However, participants showed a great variety in the preferred extent of parental involvement, ranging from participants wanting parents to make the decision by themselves after being informed, to some professionals who wished to advise or even steer parents. Some emphasised the parental legal right to choose for TOP before the legal time limit.

A minority explicitly mentioned that doctors and parents should make this decision together. Furthermore, the importance of collecting information on parental preferences and values was mentioned by a few. One participant expressed worries that the burden of deciding should not rest on parents alone.

Time pressure turned out to be an important consideration, since professionals thought that parents should have enough time to make a decision. CDH is mostly discovered around 20 weeks GA and the decision should be made prior to 24 weeks GA in the Netherlands. Some professionals stated that this circa four-week period specific for the Dutch setting might be too short to make decisions for some families.

Table 3 summarises the different views regarding the decision-making process suggested by the participants.

Other prenatal decisions

Another prenatal decision brought up by participants is whether the foetus should undergo FETO or not if the foetus has an indication for this. Participants' suggestions for the decision-making process mainly focused on providing information to let parents decide. This information should make parents aware of the advantages and disadvantages (potential complications) of FETO, and of practical aspects like that the mother will be hospitalised and that they should be close to a hospital for a certain period.

Table 3: Participants' views regarding the decision-making process regarding TOP in prenatal CDH counselling.

According to the interviewees …:	
… the role of professionals should be	
	To inform parents[a]
	To advise parents[a]
	To check parental understanding
	To help parents in their deliberation
	To steer parents
	To explore parents' values and personal circumstances
… the attitude of professionals should be	
	Empathic
	Unbiased
	Accommodating with the parents
… the role of parents should be	
	To ask questions
	To make a well-considered decision

[a]Most often mentioned by the participants.

Table 4: Participants' suggestions of topics to discuss with parents in prenatal CDH counselling.

- Exploration of parents' needs and expectations
- Diagnosis (explanation of CDH)
- Short-term consequences (including events around birth, immediate cardiorespiratory and nutritional problems)
- Long-term consequences (including long-term respiratory and nutritional issues)
- Invasive diagnostic procedures
- Treatment options (including ECMO and CDH surgery)
- Prognosis (including uncertainty)
- Decision-making on continuation or termination of pregnancy
- Practical issues related to the hospital stay

CDH, congenital diaphragmatic hernia; ECMO, extracorporeal membrane oxygenation.

Finally, participants mentioned invasive diagnostic procedures (chorionic villus sampling and amniocentesis) as a prenatal decision and thought this should be offered to parents. Again, the interviewees viewed this as a parental decision after being informed by the professionals. Some emphasised that invasive prenatal diagnostics should always be offered since this can influence the decision about TOP.

Preferences regarding the practical aspects of prenatal CDH counselling

Counsellors

Four specific disciplines came up most often in the interviews as preferred potential counsellors: neonatologists, obstetricians, paediatric surgeons, and medical social workers (mentioned respectively by n=18, n=14, n=13 and n=9). Various professionals preferred joint counselling by a neonatologist and an obstetrician since this would allow them to complement each other and parents to ask questions regarding both disciplines in the same session. Another argument given was that better alignment of provided information is possible with joint counselling as compared to separate counselling.

The interviewees' preferred role of the paediatric surgeon was twofold; giving information related to surgery and about long-term consequences. Suggestions to ensure the prenatal provision of information on the long-term outcomes were to either include a clinician involved in follow-up in the prenatal counselling or to let this physician educate the main counsellors (as suggested to be the neonatologist and obstetrician). Alternative counsellors were mentioned by a few participants: a nurse practitioner as case manager, a clinical geneticist, or a paediatric pulmonologist mainly for parents with specific questions for these professionals. Several interviewees emphasised a limited number of counselling professions and individuals, to prevent parents from seeing too many faces and an overkill of counselling sessions and information. Moreover, they thought a limited group of counsellors would ensure experience with this counselling and potentially more uniformity among counsellors.

Duration, location

The participants could not express a preference for a standard duration of counselling sessions, since parents show variation in their needs. Several interviewees mentioned that it is important that the prenatal counselling takes place in a CDH centre of expertise to prevent misinformation.

Supportive tools

Table 5 shows suggested tools to be used in prenatal counselling. The use of tools to support prenatal counselling was generally thought to be of added value, although some indicated concerns about the generalisability of the information, because of a wide variety in CDH severity and uncertainty of the prognosis. The tools may have different goals; participants mentioned better understanding of the disease CDH, being able to revise information at home, or using it to discuss with others. Opinions on peer support and a decision aid were inconsistent. Some professionals stated that it would be useful for parents to hear other parents' experiences, others were reluctant and afraid of the creation of unrealistic expectations. When specifically asked about the potential for a decision aid regarding the continuation or TOP, some were positive and stated that it may help parents to get their thoughts together, but others believed that a decision aid does not make decisions easier, but only creates a list of positive and negative aspects. Also, some participants indicated to be unfamiliar with the use of decision aids.

Table 5: Potential supportive tools regarding prenatal CDH counselling, suggested by the participants.

- Website
- Hand-out with:
  - Explanation CDH (disease, consequences, treatment options)
  - Professionals' experiences with CDH
  - Peer support
  - Decision-making process in abnormalities
  - Roadmap: 'what to expect'
- Tour (NICU, delivery room)
- Peer support
- Video about:
- Explanation CDH, ECMO
- Patient's journey: first phase and long-term expectation
- Record conversation
- Parental notes and questions
- Decision aid
- Physicians' use of images or drawings
- Anatomical model
- Insight into personal electronic file: to reread information
- PowerPoint presentation

CDH, congenital diaphragmatic hernia; NICU, neonatal intensive care unit; ECMO, extracorporeal membrane oxygenation.

Discussion

This study provides insight into the preferences of healthcare professionals about prenatal counselling in CDH regarding the goals, timeline, content, decision-making process, and practical aspects. We used these to formulate recommendations to improve (local) practice of prenatal counselling, which are summarised in Table 6. These recommendations can be seen as a starting point for counselling conversations, which should be further personalised to parents' wishes.

Most suggested topics to discuss with parents are consistent with literature [7, 12], although the practical issues related to hospital stay, like the temporary influence on housing and the effect on parents' relationship, have not been reported so far. This is an important addition, since our study suggests that this can bring support and some guidance for parents in uncertain times. In CDH counselling an individual course can be even more difficult to predict compared to other congenital anomalies, due to the wide range of prognosis. Therefore, achieving some certainty about practical issues may be extra relevant and is supported by a very recent study among parents: "having an idea of what to expect helped parents to prepare themselves and gain a sense of control" [13]. Also, these parents would have appreciated more information on the long-term follow-up but had experienced a focus on survival [13]. This is in line with our study, where information regarding long-term follow-up was suggested. Our results mainly highlight the medical consequences of CHD and when asked about important aspects to tell parents, risks and complications of CDH were mentioned by most of the participants. Besides

Table 6: Recommendations for prenatal counselling in CDH summarised from the participants suggestions in this study.

Timeline
- Plan at least one conversation as soon as possible after diagnosis (mostly around 20 weeks GA) and at least one at 30–34 weeks GA. Offer additional sessions, according to parental or professionals' needs.

Content

It may be useful to adjust the content of the counselling session to whether a decision about TOP still must be made (first phase) or has already been made (second phase).
- For the first phase of counselling: aim to discuss at least the diagnosis and its explanation, the prognosis, long-term consequences of CDH, and invasive diagnostic procedures. Extend with short-term consequences and treatment options depending on parents' needs and wishes.
- For the second phase of counselling: aim to discuss at least the practical aspects, parents' remaining questions. Extend with short-term consequences and treatment options (if not discussed earlier), give more detail and/or repeat information.

Decision-making process
- Shared decision-making (SDM) will promote parental autonomy and allows for personalisation based on parental values and on the preferred extent that parents want to share in decision-making. Helping parents to discuss and sometimes even construct their values is useful. Also, providing guidance for some parents, upon their request and based on their values is not paternalistic [12–16].

Practical aspects
- The preferred counsellors are at least the neonatologist (or paediatric intensivist depending on local organisation of care) and obstetrician in a joint conversation and additionally medical social work. When indicated, also a clinical geneticist will inform the parents. Other professionals (such as paediatric surgeons, paediatric pulmonologists) may educate counsellors on specific expertise e.g., follow-up or could be asked when specifically needed.
- The preferred location of prenatal counselling is a CDH centre of expertise, so early referral is indicated.
- Supportive tools can be of additional value, but do not replace counselling sessions.

GA, gestational age; TOP, termination of pregnancy; CDH, congenital diaphragmatic hernia.

that, several professionals mentioned the importance of allowing parents to have hope e.g., by focussing also on positive aspects. Previous research in prenatal counselling regarding prematurity shows that hope helps parents to overcome the fear of the unknown and prepare for their family's future [14]. Thus, hope should have a place in prenatal CDH counselling.

An important finding of our study is the already mentioned importance of personalisation in prenatal CDH counselling, both in the parental need for information as well as in the decision-making. Because of a wide variety in the severity and outcomes of CDH [4], personalisation based on foetal and maternal characteristics is required. Statistics about the prognosis, like mortality, may give a prediction for a subgroup, but are still hard to apply for an individual child. It has been suggested to simply ask whether parents prefer statistics or not [10]. Furthermore, some parents want as much information as possible, but others quickly become overwhelmed by the amount of information, so the level of detail in discussed topics should be adjusted to parental capabilities for information absorption.

Regarding the decision-making process, the importance of exploring parents' personal values is known in the general field of prenatal counselling [15], although it was not yet confirmed for decisions regarding CDH. Parents' wishes for the extent of involvement in decision-making about continuation or TOP may differ and require a different type of counselling. However, our results show some potentially contrasting suggestions by our participants. An unbiased attitude when providing information was suggested by some, as well as a more steering role of counsellors by others. Furthermore, some suggestions seem unclear, e.g., the meaning of 'objective' decision-making. Exploring personal values – preferred by other participants – is not 'objective' as values are subjective in itself. Other authors emphasised to incorporate "not only the provision of information but also a conversation about existential life questions and values of life" in prenatal decision-making in congenital anomalies [16]. Participants showed varying preferences in whether the ultimate responsibility for decision-making should lie with the parents, physician, or both. It is essential to further explore whether these differences are based on unwanted physicians' bias on this topic, or on variety in parental decision-making preferences. This could for example be strong physicians' own values, or assumptions on patients' values or their capacity to make decisions, which could potentially hinder personalised decision-making and SDM [17]. Lack of knowledge on SDM by professionals has been shown in many other situations [17–19] and may also exist for some of our participants. Physicians' bias might also be influenced by whether the participant is usually involved prenatally, where the legal rights to decide on TOP are completely with the mother, or only postnatally involved, where the doctor also has a legal responsibility to ensure decisions does not cross a harm threshold, which seems to be supported by some of our data [20]. Various models for SDM allow for variation herein based on parental preferences. [21–25].

Concerning practical aspects, though multiple counselling sessions were recommended previously, it was not specified when these meetings should take place [6]. Our study helped to formulate a recommendation about the preferred timeline of the counselling sessions.

Supportive tools could support, although not replace prenatal counselling. Specific for CDH, a website with standardised information was found to be of additional value [26]. Expertise centres may want to develop supportive material matching the needs of their professionals and patients.

Strengths and limitations

A strength of this study is the inclusion of a diverse sample of healthcare disciplines, which improves the transferability of our results. Notable is that two-thirds of the interviewees were not currently involved in the prenatal CDH counselling. This may provide important new insights, but they could have unrealistic or even incorrect ideas on current counselling practices.

A limitation of this study is that although interview questions where open ended, the preselection of domains could have introduced a potential bias. The interview guide was developed with neonatologists and mostly focused on the child's healthcare perspective. Involving (e.g.,) an obstetrician, a social worker or parents could have led to a wider scope by e.g., including more questions regarding pregnancy or social aspects. Furthermore, this was a single centre study, so it is unsure whether the results are representative for other centres. Also, parents' views were not explored, however recently their experiences are described by others [18]. This study initiated a follow-up research collaboration involving a multidisciplinary expert panel including parents, who will formulate recommendations for prenatal counselling.

Conclusions

This study provides insight into the views of healthcare professionals regarding prenatal counselling in CDH concerning the goals, timeline, content, decision-making process, and practical aspects. For example, practical aspects related to the hospital stay deserve attention. Adjusting information during prenatal CDH counselling to parental needs and wishes is crucial and the decision-making process must be personalised.

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Informed consent: Informed consent was obtained from all individuals included in this study.
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