Original Article

Shared decision making during antenatal counselling for anticipated extremely preterm birth

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Abstract

Objective(s): To explore health care providers' (HCPs) perceptions of using shared decision making (SDM) and to identify facilitators of and barriers to its use with families facing the anticipated birth of an extremely preterm infant at 22⁺⁰ to 25⁺⁶ weeks gestational age.

Study Design: Qualitative descriptive study design: we conducted interviews with 25 HCPs involved in five cases at a tertiary care centre and completed qualitative content analysis of their responses.

Results: Nine facilitators and 16 barriers were identified. Facilitators included: a correct understanding of this process and how to apply it, a belief that parents should be the decision makers in these situations, and a positive outlook toward using SDM during antenatal counselling. Barriers included: HCPs' misunderstandings of how and when to apply SDM during antenatal counselling, challenges using the process for cases at the lower end of the gestational age range, fear of the negative emotions and stress parents face when making decisions, and HCPs' uncertainty about their ability to properly apply SDM.

Conclusion(s): This study identified facilitators and barriers to use of SDM during antenatal counselling for anticipated birth of extremely preterm infants that can be used to inform development of tailored strategies to facilitate future implementation of shared decision making in this area.

Keywords: *Antenatal counselling; Extremely preterm infants; Intensive care; Implementation; Palliative care; Shared decision making.*

Antenatal counselling of parents facing the anticipated birth of an extremely preterm infant (EPI) (22⁺⁰ to 25⁺⁶ weeks gestational age [GA]) involves discussions that are ethically challenging for both parties due to the life and death nature of the decision being made (1–3). Each individual circumstance is unique (4,5), and the uncertainties surrounding prognosis at these early GAs create a situation where both intensive and palliative care options can be appropriate choices (5–7).

There is a shift within medical counselling toward the use of shared decision making (SDM) (8), where patients and their

families along with health care providers (HCP(s)) make decisions together about optimal care (9). The process of sharing information, asking questions, and clarifying values creates a common understanding between all parties involved and facilitates decisions that most closely align with patient and family preferences (10,11). SDM is the most appropriate approach for situations where multiple care options are possible without unified and clear evidence pointing toward a particular option, and is applicable in a variety of health care settings (12) including those involving the care of EPIs (7,13,14). National paediatric

organizations promote SDM during counselling with parents presenting with the possible delivery of an EPI (3,15,16), and our team followed this direction with the development and implementation of a local guideline (available at www.sdmforepi.com) to facilitate SDM with such parents (7).

Previous systematic reviews have highlighted commonly reported facilitators and barriers to SDM in multiple clinical settings (17–19), and factors that influence patient involvement in decisions regarding life support interventions (20,21). Although evidence demonstrates positive physician attitudes toward SDM in other clinical settings (22), it is unclear how HCPs conceptualize this approach to decision making for EPI care.

As part of a larger project evaluating the implementation of our local guideline, the objective of this study is to report HCPs' perspectives and perceptions of SDM and the barriers and facilitators to its use during antenatal counselling for anticipated extremely preterm birth.

METHODS

Study design

We used a qualitative descriptive study design as this method increases the understanding of poorly described phenomena that are not easily quantifiable. Ethics approval was obtained from the Ottawa Health Science Network and the Children's Hospital of Eastern Ontario Research Ethics Boards.

Participant recruitment

A research assistant screened hospital records daily for women admitted to the birthing unit (BU) or mother-baby unit (MBU) at the Ottawa Hospital General Campus who were likely to deliver or were in labour with an EPI. Five cases presented during the two months after implementation of the guideline and the HCPs involved in these cases were invited to participate in the study. Participants agreed to be contacted by our research assistant who then introduced the study, its aims and methods.

Data collection

A semi-structured interview guide (Figure 1), adapted from the GUIDE-IT tool and published framework (23,24), was developed and pilot tested with three HCPs. Modifications were made to the interview guide based on the feedback obtained. A female registered nurse (JR) with qualitative research and interview expertise and no relationship with the participants conducted single one-to-one interviews over the phone (n=11) or in person at the workplace (n=14). The 25 interviews ranged from 13 to 68 minutes, and were audio-recorded with consent and transcribed verbatim. Demographic data about each participant was collected and all but one interviewee consented to be audio-recorded. Detailed field notes of this participant's

responses were used in the analysis. No further comments or feedback were collected from participants.

Analysis

We used an inductive, content analysis approach to code, categorize, and thematically analyze the data. Transcripts of each interview were imported into NVivo 11™ and independently coded by two authors (JR and CB). The two authors individually reviewed and coded the first three transcripts, then met together and compared coding to ensure a uniform approach was being applied and resolve differences. At that point, a coding template was established and was continually updated as further transcripts were analyzed. Following the complete coding of nine transcripts, definitions, examples, and criteria of each code were established. Coding saturation (25) was achieved by transcript 18. An audit trail of each transcript's coding and code template development was maintained. Quotes to support the findings were chosen to give evidence and examples of the themes identified (26).

We used the Theoretical Domains Framework (TDF) to facilitate analysis and interpretation of the qualitative findings (27) (Table 1). We mapped the facilitators and barriers to the use of SDM during antenatal counselling for EPIs identified in our study against the domains of the TDF (27).

RESULTS

Demographics

From September to December 2015, 55 HCPs were contacted and 25 HCPs (16 physicians and nine nurses) participated in our study. Thirty HCPs did not reply to the invitation. Table 2 presents detailed demographic characteristics of the participants.

Facilitators and barriers to use of SDM

We identified facilitators and barriers to use of SDM during antenatal counselling for EPI and present them below within the TDF domains. Table 3 provides a sample of quotes that simply and directly demonstrate the themes identified.

Knowledge domain

All but one participant demonstrated that they were familiar with the SDM process during antenatal counselling. Twelve informants provided detailed descriptions of what they believed SDM encompasses. Seven of 12 described SDM as a process where the patient and HCP make a decision together that aligns with the patient's values and preferences. Conversely, 5 of the 12 described SDM as a process where the physician presents information to the patient who then makes an informed decision on their own. Three of the five participants who provided such description were nurses. Barriers in this domain were identified through several informants expressing uncertainties about specific concepts

1. When and how did you use the guideline? Please describe the scenario.
 - Probes: Tell me about your role when the guideline was discussed; when presenting the guideline to the family, who was present (i.e. who was involved in the counseling?)

*** If the participant's role was to do the neonatology consultation with the family (i.e. neonatologist or neonatal fellow), proceed to question 2. If not, proceed to question 3.*
2. Can you walk me through the process you used during the consultation with the family?
 - Probes: What coaching techniques did you use? Did you use the decision aid and cards? How did you assess the parents' knowledge and values? How did you assess the parents' desired role in decision making process?
3. Tell me about how you first heard about this guideline. What was your understanding of the guideline before you were involved in it?
 - Probes: how was the information communicated (i.e. in-services, email, etc.)
4. What do you think the recommendations are saying? Do you understand them? If not, what aspects do you find difficult or unclear?
5. What are the qualities of the guideline that made it easier for you to make decisions about how to manage this clinical situation?
6. What did you find most useful about the guideline?
7. Was this guideline difficult to use? If so, could you explain why?
8. Did following any of these recommendations evoke an emotional response? If so, what? Did your emotional response facilitate or hinder following the recommendation?
9. Is there additional information you would like to see in the guideline?
10. To what extent do physical (e.g. environment/setting) or human resource factors facilitate or hinder following the recommendation?
11. Would you change any of the recommendations? Why/why not? How would you change them?
12. Does this guideline conflict with others you are familiar with or have used?
13. Do you have any suggestions to improve the implementation of the guideline?
14. Is there anything else you would like to add that we have not yet discussed?

Figure 1. Semi-structured interview guide. This was used during participant interviews to guide general discussions and help direct further probing when required.

within SDM, including: who makes the final clinical decision, how physician advocacy and sharing of their opinions/recommendations fits into the SDM process, and how to proceed when the physician does not agree with the parents.

Skills domain

Participants provided two examples that illustrate how having the skills needed for SDM facilitated its use during antenatal counselling. First, several participants believed that parents who engaged in SDM were more confident and comfortable in making their own decisions and this ability facilitated their involvement in the decision-making process. Second, HCPs who perceived that they engaged in SDM thought they demonstrated and applied a consistent, unified approach when counselling parents.

One of the barriers described by participants related to the difficulties they encountered in trying to present unbiased, balanced information to parents to not unduly influence

their choice. The second barrier expressed by several participants related to the expertise needed to convey complex information to parents in an understandable way, especially regarding the low GAs and potential long-term needs of these infants. Finally, participants described the challenge they experienced in determining when both palliative and intensive care are possible options and SDM is appropriate to engage in.

Belief about consequences domain

Belief in the positive effects of SDM for parents and HCPs was viewed as a facilitator for the implementation of SDM. Participants perceived that practicing SDM helps remove potential guilt from parents as they are not alone in decision making. Several HCPs indicated that SDM improves counselling by increasing the extent to which HCPs listen to their patients. None of the three residents who participated in the study described benefits of using a SDM process.

Table 1. Outline of the theoretical domain framework (27)

Domain	Definition
1. Knowledge	An awareness of the existence of something
2. Skills	An ability or proficiency acquired through practice
3. Social/Professional Role and Identity	A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting
4. Beliefs about Capabilities	Acceptance of the truth, reality, or validity about an ability, talent, or facility that a person can put to constructive use
5. Optimism	The confidence that things will happen for the best or that desired goals will be attained
6. Beliefs about Consequences	Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation
7. Reinforcement	Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus
8. Intentions	A conscious decision to perform a behaviour or a resolve to act in a certain way
9. Goals	Mental representations of outcomes or end states that an individual wants to achieve
10. Memory, Attention and Decision Processes	The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives
11. Environmental Context and Resources	Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour
12. Social influences	Those interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours
13. Emotion	A complex reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event
14. Behavioural regulation	Anything aimed at managing or changing objectively observed or measured actions

Table 2. General demographic information of participants (N=25)

		n (%)
Sex	Male	6 (24)
	Female	19 (76)
Current professional role	Neonatologists and Fellows	8 (32)
	Maternal-Fetal Medicine Specialists and Fellows, Obstetricians	5 (20)
	Residents (Obstetrics and Paediatrics)	3 (12)
	Neonatal ICU nurses	5 (20)
	Birthing Unit nurses	4 (16)
Years in practice	<5	8 (32)
	5–10	6 (24)
	11–15	5 (20)
	>15	6 (24)
Parent	Yes	18 (72)
	No	7 (28)
Confidence providing counselling for parents of extremely preterm infants	Range (0 = no confidence, 10 = fully confident) *only completed by physicians (n=16)	3–9.5

One barrier identified is the perception that the use of SDM can complicate the decision-making process. The second barrier described by a number of informants related to the challenges HCPs faced implementing SDM with parents of extremely low GA infants and the ethical concerns and questions raised about the benefits of treatments,

specifically with respect to SDM being applied with EPIs of 22 weeks GA.

Emotion domain

Positive HCP experiences when using SDM with parents was a facilitator of this process. In addition, several participants

Table 3. Supporting quotes from HCPs corresponding to relevant facilitators and barriers

Domains	Facilitators	Barriers
Knowledge	<p>Awareness of SDM Responding 'yes' to being aware of guideline/SDM</p> <p>Correct understanding of SDM and how it is applied "... the goal would be to essentially figure out what the parents' knowledge is, invite their wishes and goals for their child's life if they were to deliver extremely prematurely into the conversation. And [...] decide with the parents about what would be the best way of managing premature delivery in terms of likely outcomes, what would it look like, what feels right to them, what might be best for their baby [...] we're here for open communication back and forth." (Res-2)</p>	<p>Misunderstandings/Misconceptions of SDM and how it is applied "... if we say we recommend palliative care, are we going to enforce palliative care or are we going to still with lots of discussion agree to [resuscitation] with certain provisos." (Neo-5)</p>
Skills	<p>Creates a consistent approach and removes HCP bias and judgement from discussion "I felt that the patients more than even before were counselled in a really systematic, consistent and appropriate way because prior to this, it was really the beck and call, the judgement, the bias of the providing physicians." (MEM/Obs-3)</p> <p>Parents more prepared and confident "We felt like the parents were being heard a little bit more versus being told of how it was going to be that we appreciate absolutely. And the parents feel much more comfortable in their decision-making as well, and supported, and heard." (RN BU-4)</p>	<p>HCP difficulty not persuading parents "... it's just hard to sort of not persuade them into one way or the other" (NICU RN 13)</p> <p>Parents cannot comprehend information due to its complexity "I know everybody has a different experience, but I don't think they really understand the process in hospital and then even the long-term if their babies do survive with the [...] that can arise there... once we resuscitate them they're successful for the first week and then things start to crumble, I think is difficult and sometimes parents get mixed messages and they hang onto the 1 per cent that their baby may survive." (RN NICU-5)</p> <p>HCP difficulty knowing what cases truly apply to SDM and how to align the prognostic factors with each family's values "I think that the most difficult part is to determine when you feel the options are equally valid. So it's the outside cases and where is the line and how firm you apply your line. I think that that's the struggle." (Neo-5)</p> <p>Increased difficulties created by SDM "Does it help it? I don't know, I actually think maybe it even can complicate it because the patients are thrown out options that they didn't even know are options before perhaps... So then they really have to start thinking about things..." (RN BU-1)</p>
Belief about consequences	<p>HCP belief in positive impacts of SDM for parents "so I think it will be very, very much valid when we hear more than to talk more with the patient, so I would totally agree that it will definitely help us listening more about the patient and that will guide us how I'm going to counsel her." (MEM/Obs-5)</p>	

Table 3. Continued

Domains	Facilitators	Barriers
Emotion	<p>HCP positive attitude toward SDM</p> <p>"I was quite excited actually, just because I was glad that our parents were getting really good visual aids and being presented information to allow them to make a decision regarding their child." (RN NICU-1)</p> <p>Positive hope for parents</p> <p>"... it allows for bringing more hope to the families in these situations when they're trying to make this difficult choice. I think it facilitates and really pushes that out there and expresses the importance of hope. And I don't just mean hope as in oh you should try early intensive care, that's not what I mean by hope. Hope can also be around hope for future pregnancies, hope for great comfort care or palliative care for their baby if that's what they choose. So I think that that is to me a really big positive" (Neo-7)</p>	<p>Uncertainty of using SDM at low GAs (specifically GA 22 weeks)</p> <p>"So even now, I find a lot of negativity surrounding the shared decision making process for these babies [premature infants around 22 weeks' GA] and a lot of the lines that you keep hearing often are oh you know, people can legally have an abortion up to this age and here we are resuscitating them. And I think because of the last two that we've seen, people have been so negative in saying oh they just don't have the skin, they're just not big enough, their lungs are just so premature, like why are we even doing this? At whose cost, is this selfish, you know it just seems to be we can't shift our thinking which is hard." (NICU RN-13)</p> <p>False hope experienced by parents</p> <p>"I'm worried to build up too much hope for the parents... My worry is that my patients, as a mother and parents, and whether they actually build up false hope... I am not sure if the patient at that time will have the ability to make the right decision." (MFM/Obs-1)</p> <p>Stress of decision for parents</p> <p>"I felt like that could very overwhelming for parents if they come in at we'll say 22, 23-weeks not even having a thought about having a pre-term baby because they assume everything's going to be normal with their pregnancy and then all of a sudden they have to make that decision. I felt like that was really stressful" (RN BU-1)</p> <p>Parental emotions driving their decision making</p> <p>"They have this vision of their child being healthy in the future and they're willing to—as some good parents will do, you know, I'll put my child through anything as long as they come out okay in the end. And I think they're holding onto that. And I think they may be sometimes too close or too invested or too optimistic or—I don't know, if at the end of it all, if they truly knew. We don't say your baby's not going to survive because we always hope that they will, right? (Neo-17)</p> <p>"They're thinking about the here and now, we don't want to lose our baby, but they're not thinking ooh that baby's going through a lot of pain, that baby's not supposed to be here, that baby's getting infections, that baby's being poked over and over again, all of that stuff. And in the long-run, statistically, is that baby going to be okay? What are we as parents going to have to deal with in 15 years? For themselves, they think about the here and now, they don't necessarily think about what the quality of life is going to be for everybody down the road... They're thinking more about what they're losing." (RN NICU-3)</p>

Table 3. Continued

Domains	Facilitators	Barriers
Environmental context and resources	<p>Time of day (day time)</p> <p>... I think that the reception of the conversation is sometimes better in daylight hours where you can also take a break because at night, it's really hard if you start at 2 am to say okay, well let's take a break, it seems like your emotions are—it can be a really overwhelming conversation..., but if you do it at 1 pm, okay you know what, let's get a tea, let's relax. We'll come back at around 2:30 and let me know how you're feeling and if you're haven't made a decision, that's okay." (Res-2)</p>	<p>Time of day (night time)</p> <p>"... what I've observed is that emotions run higher when you're tired and also there's a sense that when things happen overnight that they're more dire. Like I've had parents mention that like everything changed overnight and they feel like things start to spiral..." (Res-2)</p> <p>Increased amount of work</p> <p>"So then they really have to start thinking about things and we're giving them more support and I feel like there's going to be more teamwork between us and NICU; where I feel like I may have to in the future, call them more often to come and re-counsel the patients, especially as they continue on with the pregnancy at an early age because it does change so much on a day-to-day basis on the very, very early pre-term." (RNB-U-1)</p> <p>Communication challenges (multicultural context)</p> <p>"And from a communication point of view, we live in a multicultural society and to do this effectively, like you really should be speaking the same language and ideally you would not be relying on a translator as a mediator because I think it takes away a little bit of the person-to-person connection and it also leaves room for errors in translation about really pertinent pieces of information that you want to get across or that the parents want to get across" (Res-2)</p>
Social/ Professional role and identity	<p>Choice should be families to make (align with their beliefs)</p> <p>"I think that is an important idea that families are the ones who are going to live with these choices for forever and so it should be their choice, and making sure that that's a universal philosophy." (Neo-4)</p>	<p>HCP uncertain of skill and proficiency</p> <p>"... that's what perpetuates the worry ... am I doing the best thing, did this really go as well as it could have, and those sort of thoughts" (Res-9)</p>
Belief about capabilities	<p>HCP belief that SDM prevented use of their knowledge and expertise</p> <p>"I feel that with this shared decision making, we're expected to less give our opinions and leave it a little bit more open to the family, which I think families can struggle with and then I kind of have trouble." (Neo-4)</p>	

Table 3. Continued

Domains	Facilitators	Barriers
Intention		<p>Parents cannot shift decision making to HCP if they desire “And some families need me to make the decision... but in knowing the family and not having a strict guideline where I’m supposed to do this and say this and do that, I think was better for the family.” (Neo-6)</p> <p>HCP feeling inclined to provide intensive care due to SDM “It’s harder to have parents [involved] in shared decision making when the question is palliative care in higher gestational age compared to having to do a resuscitation in very low chances of survival. So it’s easier for saving life than a companion to that.” (Neo-3) “... usually before, depending on the neonatologist, before 24-weeks they’re often were more prone to palliative care.” (RN NICU-1)</p>

BU Birthing Unit nurses; HCP Health care provider; Neo Neonatologists and Fellows; NICU RN Neonatal ICU nurses; MEM/Obs Maternal-Fetal Medicine Specialists and Fellows, Obstetricians, RN; Res Residents (Obstetrics and Paediatrics); SDM Shared decision making.

perceived that the consideration of multiple options during SDM offered hope to some parents and noted this as an enabler of SDM.

In contrast, some participants expressed concern about creating ‘false hope’ for parents by presenting multiple options and identified this as an emotional barrier. Two other barriers were: the perception that engaging parents in the SDM process places an unnecessary and potentially inappropriate burden on families facing this very difficult and stressful decision, and the perception that SDM may result in decisions driven by only parental emotions and not based at all on what may be best for the infant from a professional medical perspective.

Environmental context and resources domain

The time of day that the counselling occurs was perceived by different participants to be either a barrier or a facilitator for SDM. One participant felt that the time of day affects the state of each party participating in SDM, and choosing a time that may be more stressful, such as at night, could limit the effectiveness of the approach and outcome. Potentially scheduling and postponing the counselling session during the day was perceived to be better.

The amount of work and coordination required to conduct a proper counselling using the SDM approach was expressed as a potential barrier. Communication in a multicultural context when language differences exist presented challenges to SDM and was viewed as a potential barrier to its use.

Social/professional role and identity domain

A facilitator to the use of SDM was the belief that parents’ preferences are more important than a physician’s professional opinion when it comes to making decisions about the management of an EPI if birth occurs. Some nurses as well as some neonatologists felt that the choices being made during these consultations are those the family will have to live with, so that the best option is the one that aligns with the parent’s values and preferences, even if that choice is different than the physician’s professional opinion.

Belief about capabilities domain

Participants indicated that HCPs who are uncertain in their skills and proficiency with SDM will be less likely to engage parents in this process of decision making. In addition, several participants felt that SDM actually impedes the HCP from inputting their knowledge and expertise in the decision-making process, which was a barrier to proper parental engagement. Finally, several participants felt that some parents want care decisions to be made for them by a physician, and engaging these parents in SDM may be more challenging and prevent this from occurring.

Intention domain

Some informants perceived that it was difficult to apply SDM, especially in higher GAs range, as physicians’ attitudes are more

inclined toward saving life by providing intensive care at this stage. Others also noted that a HCP's preference for one type of care over the other (i.e., intensive care versus palliative care) prevents proper SDM, as options may not be presented to parents in an unbiased way.

DISCUSSION

The results of our study provide insight into how HCPs from different professions perceive and conceptualize SDM during counselling of families anticipating the birth of an EPI. Although our results are consistent with the factors identified in a previous systematic review (18), our findings are novel in the specificity and detailed description of how a variety of HCPs who work in this very specialized area perceive SDM.

Almost all participants in this study indicated that they were aware of and familiar with SDM as a means to support parents' participation in decision making. Both correct knowledge of SDM and belief in its benefit are required for this approach to perform as intended. Although many participants correctly defined SDM according to the Charles et al. model (9), several described characteristics of an informed decision model when illustrating SDM. This inconsistency in understanding SDM has also been reported by others (10,28,29). HCPs' misunderstanding of decision-making models is an insidious barrier for using SDM. The need for adaptation to a new decision-making process from a more traditional well-established approach and the social construct of HCP identity as the primary decision-maker might explain this misunderstanding (12,14,21).

The challenges of patients understanding medical information related to their condition (30) was also identified as a barrier in our study. HCPs' use of lay language when speaking with patients or their families and verification of the families' understanding of complex medical information may not be well integrated in their practice (4,31). Focusing physician education on how to explore parents' learning needs and how to present complex information using nonmedical terms to ensure parents understand the information presented is essential. Building trust with parents is also important and may be more critical in the decision-making process than full understanding of all the medical facts (31,32). Well-designed decision aids (33,34) can facilitate delivery of clear, unbiased, and balanced (32,35) information to support SDM.

Participants described ethical issues surrounding SDM during counselling for the anticipated delivery of EPIs. It can be challenging to determine whether the infant is medically too immature to consider intensive care, or in the reverse situation, if the infant's prognosis is positive enough that commencing with intensive care is in the newborn's best interest. Many participants identified that clinicians struggle to balance parental autonomy and the best interest of the child in clinical decisions

for EPIs. HCPs struggle to determine when the prognosis for an EPI is such that SDM should be used to support parents deciding between two equal options: palliative comfort care and intensive care. Additionally, applying SDM in the lower GA range made some participants believe they may be causing more harm than good. Creating opportunities for HCPs to discuss these challenging clinical cases among their peers and agree on potential outcomes for the anticipated EPI, as well as creating postnatal EPI care bundles before SDM for EPI guideline implementation, could help address these uncertainties.

Participants identified hope as both a facilitator and barrier to SDM. Hope may permit parents to feel they have provided their baby with the best possible care option. It is an important value for many parents when making decisions regarding care of their EPI (5,36,37). Some HCPs were concerned about creating false hope, which may lead to a sense of anger and distrust among parents (38). Others viewed hope as an emotion that may cloud parents from making rational decisions. Emotional decisions, however, are not necessarily inappropriate as important life choices are based on emotion (39).

HCPs 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. These findings are in line with the time constraints and pressures for decision making described in the literature (18,37), but this does not diminish their probable importance for good clinical decision making.

There are several limitations to our study. The study involved only one institution and, although representatives from different HCP groups participated, full representation of all professions involved in the care of EPIs was not achieved (e.g., no social worker). Also, given the many potential clinical nuances in these complex antenatal consultations, the use of only five cases may have limited the data captured regarding barriers and facilitators to the use of SDM with families facing birth of an EPI. In addition, the participants that were selected had varying degrees of training and experience with SDM and this may have influenced their interpretation of and responses to questions about SDM. From the analysis of the interviews, it was not possible to find a strong trend between participants' demographic characteristics and their perception of SDM. The information obtained about parents' perspectives of the facilitators and barriers to SDM were limited to the HCPs' points of view since we did not directly explore parents' perspective about SDM. Finally, self-report bias may exist where the participants shared information they think the research team wanted to hear, even though our interviewer was not part of the guideline development team and was unknown to participants.

Embracing facilitators and designing tailored strategies to neutralize the barriers to SDM could help improve implementation

of SDM in high risk perinatal centres. This study highlights several important barriers and facilitators and presents implications for practice, education, and research regarding use of SDM with families facing anticipated extremely preterm birth.

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