From powerlessness to empowerment: Mothers expect more than information from the prenatal consultation for preterm labour

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BACKGROUND: Guidelines recommend supportive care for all newborns >26 weeks' gestational age and recognize the importance of prenatal consultation by a neonatalogist for mothers at risk of premature delivery. These recommendations are drawn from medical expert opinions and emphasize informing parents about prematurity. The literature regarding parents' perspectives of prenatal consultation is lacking.

OBJECTIVE: To explore mothers' concerns about preterm labour and their expectations from the prenatal consultation with a neonatologist.

METHODS: Interviews of women hospitalized for preterm labour (26 to 32 weeks' gestation) were conducted before they met with the neonatologist. The analysis was informed by grounded theory.

RESULTS: The women's stressful experience was their main focus; they expressed a strong sense of loss of control and powerlessness. The consultation was perceived as an added source of stress, but they all hoped that it would reassure them. They wanted information about prematurity and the roles they would play for their baby. They expected the neonatologist to be supportive, open and trustworthy.

CONCLUSION: Prenatal consultation is perceived as a source of both stress and reassurance. Women believe the latter can be achieved through a supportive consultation with the neonatologist, during which tools providing them with a sense of empowerment are presented.

Key Words: *Autonomy; Bioethics; Informed consent; Neonatology; Prenatal consultation*

De l'impuissance à la prise en main de son destin : les mères s'attendent à plus que de la simple information lors de la consultation prénatale au sujet du travail prématuré

HISTORIQUE : Selon les lignes directrices, on recommande des soins d'entretien à tous les nouveau-nés de plus de 26 semaines d'âge gestationnel et on souligne l'importance de la consultation prénatale avec un néonatologiste pour les mères vulnérables à un accouchement prématuré. Ces recommandations sont tirées d'opinions d'experts médicaux et font ressortir l'importance d'informer les parents de la prématurité. Il n'existe pas de publications sur les points de vue des parents à l'égard des consultations prénatales.

OBJECTIF : Explorer les préoccupations des mères au sujet d'un accouchement prématuré et leurs attentes à l'égard de la consultation prénatale avec un néonatologiste.

MÉTHODOLOGIE : Les chercheurs ont effectué des entrevues auprès de femmes hospitalisés en raison d'un travail prématuré (de 26 à 32 semaines de grossesse), avant leur rencontre avec un néonatologiste. L'analyse était appuyée par une théorie d'ordre empirique.

RÉSULTATS : Les mères se préoccupaient d'abord de leur expérience stressante; elles exprimaient un fort sentiment de perte de contrôle et d'impuissance. La consultation était perçue comme une autre source de stress, mais elles espéraient toutes que cette rencontre les rassurerait. Elles désiraient de l'information au sujet de la prématurité et de leurs rôles auprès de leur bébé. Elles s'attendaient que le néonatologiste les soutienne, serait ouvert et digne de confiance.

CONCLUSION : La consultation prénatale est perçue autant comme une source de stress que d'apaisement. Les femmes pensent qu'elles peuvent être rassurées par une consultation de soutien de la part du néonatologiste, pendant laquelle celui-ci leur présentera des outils qui leur donneront l'impression de prendre leur destin en main.

Prenatal consultation with a neonatologist is recognized as an important step in preparing parents who are at risk of having a premature baby (1,2). Current guidelines (1) and some neonatologists (3,4) recommend discussing current and local survival rates, possible short-term and long-term complications of prematurity, and anticipated hospitalization length. Neonatologists who have been surveyed view their primary role in the prenatal consultation as providers of factual information, but they inconsistently address social and ethical issues related to the situation (5).

However, studies have shown that parents' priorities often differ from the neonatologists', and that the issues discussed are not always those that are most important to them (6-8). They want detailed information about the care their baby will receive, admission to the neonatal intensive care unit (NICU) and their baby's chances of survival or possible morbidities (6,9). Parents hope neonatologists will consider the impact of the information being given and recognize the stressful situation surrounding them. More precisely, women are often preoccupied with their own health (10) and with issues unrelated to the pregnancy such as financial or housing difficulties (11). Furthermore, doctors' sympathy during a consultation has been shown to be the best predictor of parental satisfaction (12). At the limits of viability, parents hope to find a common ground in which both parties' expectations are taken into account, and they call for a more caring relationship in which physicians also explore individuals' values and expectations (13).

Survey studies designed by medical teams have tried to identify parents' needs and the efficacy of the prenatal consultation (7-9). Sociologists (11) and psychologists (6) have sought to identify parents' perspectives through qualitative studies, without being

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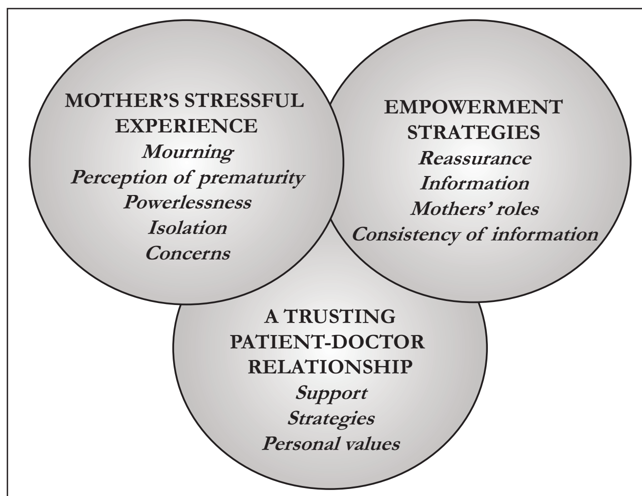

Figure 1) *Main themes identified by data analysis*

directly involved in prenatal consultations. No study has examined whether mothers and fathers have the same expectations and concerns. The objective of our study was to assess the maternal perspective of the prenatal consultation with a neonatologist for preterm labour, to identify their main concerns, questions they have about prematurity and what they expect from the consultation.

METHODS

The present study was qualitative in design. Hospitalized women were interviewed before they met the neonatologist to identify their own, uninfluenced point of view. Participants then met with the neonatology team as planned. The institutional ethics review board approved the study.

Sampling

Sampling was determined by inclusion and exclusion criteria; then, participants were chosen using purposive sampling (14,15). A sample of maximal variation (in age, gestational age, reason for admission and socioeconomic background) was sought to identify themes common to a diverse group of women (14,15).

The study was conducted in a tertiary care, high-risk obstetrics ward, within a mother-infant university hospital. Patients who met the inclusion criteria were adult women, with a gestational age of between 26 and 32 weeks, who were admitted to the obstetrics department for preterm labour, had no contact with the neonatology team, were able to read and write basic French or English, did not have an active psychiatric disorder and had no previously identified fetal malformations. Women with pregnancies of less than 26 weeks' gestation were excluded to avoid discussions about level of care (2).

Data collection

The study used a qualitative approach informed by grounded theory (16-18). In-depth interviews, using a semidirective format and lasting 30 min to 60 min, were audio recorded. Women were encouraged to speak freely about their situation and to elaborate on the following: main current concerns and stressors; topics the neonatologist should discuss and explain; expectations from the consultation process; and roles they believed the neonatologist should play for them. Information drawn from each interview was analyzed before the next participant was recruited, and women were enrolled until no additional themes were identified.

Analysis

Interviews were transcribed in their entirety and coded using the constant comparative method of content analysis (16). As such, transcriptions were coded, line by line, by the main researcher to construct themes. Each interview was reviewed independently by the second researcher. Codes and themes were systematically discussed between both researchers to confirm uniformity of analysis or until consensus was reached.

Validation

Identified themes were used to construct a survey addressing women's expectations about the prenatal consultation for preterm labour. This tool was sent for correction to the initial participants six months after their interview. Women confirmed that the main themes, their concerns and their expectations had been identified and represented in the survey.

RESULTS

From January to June 2007, seven women were approached for participation in the study. One woman agreed to participate, but she was discharged before an interview was possible; another initially agreed to participate, but withdrew after meeting her physician, stating that she was too overwhelmed. Five women were interviewed. Participants varied in age (ranging from 24 to 36 years) and gestational age (from 26 weeks to 30 2/7 weeks). They were from different social backgrounds and professions. The reasons for hospitalization and outcomes were also diverse: two women had their babies within days of the consultation, and the other three had full-term pregnancies after hospital discharge. Data analysis identified three main themes (Figure 1).

Mothers' stressful experience

Mourning: Women faced bad news regarding several aspects of their health or pregnancy. They tried to adapt quickly from living a healthy pregnancy to preparing for the challenges of prematurity, and found this to be difficult; the roles they had been preparing to play as parents changed. Some women at risk of a hysterectomy faced the possibility of no longer being able to bear children.

Perceptions of prematurity: All women had negative views about prematurity; several of them compared it with 'horror stories' or 'hell'. They all wished to avoid delivering prematurely.

Isolation: Women felt isolated from their usual support systems: four had been transferred from another hospital and their families lived far from the institution used for the present study. They expected their hospitalization and bed rest to become prolonged, which was perceived as another difficult challenge to overcome. Furthermore, although isolated from their loved ones, participants believed that they had lost their intimacy or privacy during their hospitalization experience.

Powerlessness: Women expressed a strong feeling of powerlessness and loss of control. They believed that they had to accept all treatments offered to them to obtain the best possible outcome for themselves and for their baby:

> There is nothing we can do. We're a little powerless in all this. So we let ourselves go. We let go and we let them do anything to us. (Mother 5)

They were overwhelmed by the number of events experienced in a short period of time; the uncertainty of these events added insecurity and stress:

> Uncertainty, it's like vertigo or a precipice. And there is a lot of uncertainty. We don't know when I will deliver. We

don't know how I will deliver. We don't know how it will go for the baby. We don't know what awaits the baby after. And we can get surprises, good or bad, for months after that. So it's a lot of uncertainty for a long time. (Mother 3)

Main concerns: The baby's health and outcome were the main concerns for most women. One was most worried about her own medical condition. Another had been born prematurely herself, and focused on potential attachment difficulties as a parent and on a prolonged separation from her other children. All participants expressed some concerns about organizing their families' lives around a prolonged hospital stay:

Yesterday, I was preparing my children's things, but I didn't know what to prepare. I had to give them extra everything because I didn't know when I would be back. One of my children goes to school, one goes to daycare and the third one stays at home (...) and he's having his first birthday tomorrow. Now they are staying in two different households. One child is at my mother's house and two children are at my mother-in-law's. (Mother 2)

Consultation as a stressor: Women were generally informed by the obstetrical team in charge of their medical care that they would meet with a neonatologist. However, one woman had not been told this and found out only when approached about participating in the present study; she asked to partake in the study and was, therefore, included after she met with the team responsible for her care. Similar to other participants, she perceived the consultation as an additional source of stress:

Simply knowing that we'll meet the neonatologist is a stressor in itself. It's something really big (...) The fact that I am being offered to meet the neonatologist before anything else makes me realize that, in my case, it is highly probable that I will deliver prematurely. (Mother 5)

However, all of the participants looked forward to the consultation so that their questions would be answered; they also hoped that the neonatologist could somehow reassure them, although the information they sought was not perceived as reassuring in itself:

I think that the more the neonatologist will tell me, the more stressed I will be. But I don't like (...) not knowing the answers. (Mother 1)

I am looking forward to meeting them so that they can reassure us. Well, maybe not so that they can reassure us, but so that they can tell us the truth. (Mother 2)

Empowerment strategies – expectations from the consultation

Reassurance: Being reassured was the most important objective of the prenatal consultation. Women realized that they might receive worrisome information about possible complications related to prematurity. They hoped that the neonatologist would find ways to reassure them:

Being reassured and just knowing what to expect. Because right now, I don't really know what to expect. So it's those two aspects, I think. (...) And what I can do as a mother to make sure, really make sure, that my baby is healthy and happy. Because that's really what I want. (Mother 4)

Information and content: All women expected to receive clear, precise details and statistics about short-term and long-term complications of prematurity specific to their medical condition and related to gestational age. Some anticipated themes were respiratory distress, neurological complications, sepsis, feeding difficulties and length of hospitalization. They hoped the neonatologist would describe some of the technology in the NICU. They reported having learned about prematurity and its complications from friends working in health care, from the media or from their own physicians. Only two of the participants underwent active follow-up for high-risk pregnancies before their enrollment in the present study. One woman suggested that parents visit the NICU before delivery, and believed that written documentation or pictures could be helpful.

Parental roles and responsibilities: Women expected the neonatologist to explain what their responsibilities would be and what would be expected of them. They wanted help organizing their professional and family lives so they could be available for their baby. They wanted to know how they would be allowed to touch or hold their babies, and wanted to discuss breastfeeding and feeding strategies.

Some wanted to know how they might participate in decision-making processes regarding their baby's treatment plans. One woman expressed concern about excessive care and had prepared questions to ask the neonatologist about her legal rights:

I'm not sure the neonatologists would make the same decisions that I would and I am worried they might impose their decisions on us. (Mother 3)

Consistency of information: Women expected all of the different medical teams involved in their care to communicate among one another to hold consistent discourses about their situation. They reported inconsistency between health care providers' messages as an added source of stress.

A trusting patient-doctor relationship: Expectations from the neonatologist

Structure of the consultation: Women who were interviewed believed that the best time to meet the neonatology team was before labour and delivery. They hoped their spouse would be present. They believed that the neonatologists should explain their role first, and then volunteer information about prematurity and its possible complications. One woman suggested that they sit down during the consultation. They all expected the neonatologists to be open to listening to their concerns and to provide time to answer their questions:

Sometimes, I find it goes fast, that we don't have time to ask our questions. (...) It would only take the doctor an extra minute or two, but it would save us from being anxious and having unanswered questions. (Mother 3)

Trust: It was very important that the neonatologist instill a feeling of trust. Women wanted to know that they were in the best place for their baby and themselves to receive optimal care:

We are handing over our lives and our baby's life into the hands of people we've never met before. So, if there's no trust, it's impossible. (Mother 3)

Support and strategies: Most women expected the neonatologist to offer support and help them develop strategies to cope with their situation:

It's very important to have a good doctor who can answer your questions and reassure you. (...) I mean, at least they're there to answer your questions and be supportive. (Mother 4)

TABLE 1
Expectations from the prenatal consultation for preterm labour

A trusting patient-doctor relationship – physician attitudes
Setting
Before delivery
Presence of significant other
Sufficient time
Sitting down
Trust and support
Openness to listening to concerns
Answering questions
Honesty
Engendering trust
Supportive
Content for the consultation
Empowerment strategies
Information
Coherence of information within the health care team
Description of initial care and admission to the NICU
Precise, detailed information about complications of prematurity (written information, suggest visiting the NICU, pictures, etc)
Roles for parents
As caregivers (feeding strategies, touching baby, dressing baby, visiting schedules, etc)
As decision makers (include parents in decision processes regarding their baby's health care)
Mother's stressful experience
Explore and address immediate and future social concerns (travelling, prolonged hospitalization of mother and baby, financial difficulties, other children, etc)
Offer consultation with other members of the neonatology team where applicable (nurse, social worker, psychologist)

NICU Neonatal intensive care unit

Some also thought that neonatologists should refer them to other members of the health care team to explore various aspects of the problem. One woman, who had undergone in vitro fertilization and fetal reduction, would have preferred to be referred to her own obstetrician for additional information and support.

A summary of potential recommendations based on these interviews is presented in Table 1.

DISCUSSION

The present study was the first to directly explore the maternal perspective of the prenatal consultation for preterm labour. Women were interviewed before any contact with the neonatology team and, therefore, without the encounter's potential influence. Several studies have tried to identify mothers' needs (7-9), but these involved women who had met the neonatologist (7) or who had already delivered prematurely (8,9). Furthermore, previous studies of mothers' perspectives have used surveys constructed by medical teams in which medical perspectives are represented (7-9). However, our qualitative study enabled us to identify mothers' expectations without this potential bias.

Previous studies have found that women at risk of delivering prematurely want a detailed description of the initial care their baby will receive (6,8,9). In our research, participants also hoped to receive precise information about prematurity, and they identified the neonatologist as being the best resource to inform them. However, our study demonstrated that mothers expected more than this type of information from the prenatal consultation.

Women in our study described a very stressful situation in which they felt a loss of control and powerlessness. Although such findings recall results from a study by Arockiasamy et al (19), in which fathers expressed feeling a lack of control during their experience in the NICU, the present study was the first to identify such feelings in women. Participants in our research suggested empowerment strategies to deal with their situation. Such an approach to the prenatal consultation, in which women are facilitated in developing strategies of empowerment, has not been previously described in the literature.

First, in our study, women hoped the neonatologist would actively address a variety of topics during the consultation. Alderson et al (11) described parents at risk of having a premature baby as passive recipients of information who seek guidance from their health care providers. By conducting exploratory consultations and addressing varied topics, participants believed that the medical teams might identify each woman's needs, answer her questions and offer adequate support, thus helping them develop strategies to be better prepared for their premature baby's hospitalization.

Also, our participants' common main objective was to be reassured by the consultation, although they reported that being informed about possible complications of prematurity could not, in itself, achieve this goal. To be reassuring, the consultation had to strive to be comprehensive and address other topics.

Finally, mothers hoped to develop a sense of control and empowerment by understanding the roles they would play for their baby; neonatologists were expected to explain these roles of caregiver and decision maker. In the study by Alderson et al (11), parents wanted their consent to be sought out for simple nursing care. Similarly, we report that participants wanted to know how they would play an active role in their baby's treatments and treatment plans.

Furthermore, in our research, the prenatal consultation was perceived as an added source of stress. Nonetheless, all of the women regarded it as an opportunity to be informed, reassured and better prepared. The women interviewed hoped that the neonatologist would strive to develop a trusting relationship with them. This was important in other studies, in which 70% of parents believed that a truthful and open physician was an important characteristic of a successful consultation (6,13). By giving women the time they needed to discuss their preoccupations and by being open to answering their questions, participants in our study expected the neonatologists to be able to reassure them and give them confidence in their health care team.

Finally, we report that neonatologists are expected to explore and address immediate and future social concerns. Another study also found that parents were often worried about travel costs or organizational issues, and that they may have previous financial or housing problems (11). In our research, the prenatal consultation was seen as an opportunity for the neonatologist to identify such concerns and help mothers cope with them by referring to different members of the team such as nurses, social workers or psychologists. Participants perceived the physician to be an essential link between health care providers.

Limitations

The small size of the study sample does not enable associations between various medical and sociodemographic data and women's expectations to be described. Given the single-centre design of the study, it may not reflect the situations encountered by women in

other settings. However, because the present study explored women's expectations, it likely reflected those of women at risk for premature delivery in similar high-risk obstetrical wards.

CONCLUSION

Women in our study anticipated the prenatal consultation for preterm labour as an added stressor, although they all looked forward to it and hoped to be reassured by it. They expected the consultation to be both informative and supportive. By addressing women's concerns broadly, the neonatologist might help them identify coping mechanisms and facilitate the development of empowerment strategies. This could be achieved through a multidisciplinary approach.

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