

“Preterm birth risk, me?” Women risk perception about premature delivery – a qualitative analysis

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Abstract

Background: Risk perception is based on collective indicators, but it is influenced by the individual's self-perception of his health-disease process. This study aims to investigate the risk perception of pregnant who were identified as high-risk for premature birth and to seek strategies for better management of such cases.

Methods: This is a cross-sectional study where women who had completed their participation in P5 trial were contacted and invited to answer a structured questionnaire with open questions. Data were collected by telephone and analyzed using thematic analysis. The analysis categories were defined, and all the answers were reviewed, categorized, grouped, and a descriptive summary was prepared.

Results: 208 Brazilian women have participated. Three categories were identified: 1) Risk perception mediated by health professionals; 2) Self-perception of risk through personal experiences and relationships; 3) Perception of treatment success. After receiving an explanation from a healthcare professional about short cervix and premature birth, women understood the risk of premature delivery, recognizing the importance of early diagnosis to prevent premature birth. Unsuccessful previous experiences in prior pregnancies influenced women's risk perception. Patients believed in the success of the treatment performed, placing their hopes on the treatment even without research guarantees about benefits.

Conclusion: Pregnant women's risk perception regarding prematurity is based partly on personal and family experiences but mainly on information given by healthcare professionals. The risk perception about preterm birth may contribute to healthy pregnancy, guiding necessary interventions and preventing adverse outcomes. Prevention studies on prematurity should thus focus on neonatal outcomes.

Background

The epidemiologic conception of risk entails establishing a causal association between risk factors and events connected to health-disease process (1). It is possible to perform a collective analysis and measure the event probability (disease) by using statistical analysis with a risk mathematical expression, where a patient is treated as part of a populational group (2). However, it is difficult to associate and to scale this risk analysis strategy and the influence of beliefs, values, meanings, attitudes, aspirations, motives, meanings and personal relationships, all of which are essential to human collectivity (3). This way, the development of risk perception is influenced by the individual's self-perception of the health-disease process, which is characterized by the association with personal factors related to cognitive capacity, affective and biological aspects, and ability to read and interact with the environment. Thus, understanding and confronting risk will depend on one's social and personal context and environmental pressures and demands (4).

The identification of a risk factor and notice to a patient is part of the routine of healthcare professionals. A patient's risk perception of his health guides his decisions, openness to the proposed treatment and the

results achieved with said treatment. In critical situations, a patient's self-perception of risk can further influence his decision. As an example, a woman can experience a critical situation during pregnancy. Preterm birth, in turn, is one of the most important potential risks faced during pregnancy. Prematurity is the main cause of infant morbimortality, and it places a significant economic burden on the family and healthcare system due to the newborn's demand for higher levels of complexity in the provision of healthcare (5).

Epidemiological studies in several countries have detected an increase in preterm birth rate in recent years (6), and it is a cause of great concern for the authorities and entities responsible for promoting maternal-child health in the public and private sectors. In 2012, the World Health Organization (WHO) published a report (Born too soon) in which Brazil ranked 10th among the countries with the highest number of preterm births, with a rate of 9.1% in live births in the country (279,300 premature births per year) (7). The "Multicenter Study on Prematurity Research - (EMIP)" carried out in Brazil found a national prevalence of preterm birth of 12.3% (8) .

The high risk for preterm birth diagnoses during pregnancy can have negative effects on a woman's quality of life, generating fear and anxiety about her future and her baby (9). In view of the potential adverse events connected to premature births, this article aims to present the risk perception of pregnant women with high clinical risk for prematurity. Our sample of female patients participated in a clinical trial that compared two interventions for preventing premature birth in order to identify possible strategies which could help in the management of patients exposed to risk situations.

Methods

This was a cross-sectional study based on the qualitative analysis of two open questions used to evaluate risk perception of preterm birth with pregnant women who participated in a clinical trial entitled "A randomized controlled trial on the use of pessary plus progesterone to prevent preterm birth in women with short cervical length (P5 trial)" (Trial registration RBR-3t8prz).

The P5 trial

P5 randomized controlled trial involves pregnant women at a high risk of preterm labor and has been ongoing since July 2015 in 17 Brazilian centers, distributed in five different geographic regions. The main objective was to compare the efficacy of progesterone alone versus progesterone associated with cervical pessaries for the prevention of preterm birth in pregnant women with a short cervix. All pregnant women from 18 to 22 weeks of gestational age attending antenatal care clinics at referral facilities were invited to participate in the study. The research team offered a transvaginal ultrasonography scan to identify shortening of cervical length and according to the identification of a short cervix, an important risk factor for preterm birth, women were randomized to two treatment options. Following randomization, women are followed up until 10 weeks after the infant's birth to evaluate neonatal outcomes. During recruitment for the clinical trial, all eligible patients received information on the risk of preterm birth by the research

assistant and by the staff medical doctor. All those who agreed in participating have signed out an informed consent form. The Brazilian National Review Board (CONEP) approved the P5 trial under the number 1.055.555.

The cross-sectional qualitative study

In order to identify possible barriers to implementing a screening program for preventing prematurity, a descriptive cross-sectional study adhering the STROBE guidelines [Additional file 1] was conducted within the P5 clinical trial by applying a structured questionnaire with 36 queries, which included 8 open questions [Additional file 2]. These questions related to women's understanding of the doctor's explanations, prematurity, risk perception, experiences of her participation in the study, doubts about whether it was appropriate for the woman to participate in the study and her perception regarding the success of the treatment provided.

All patients who accepted to participate in P5 trial were contacted after labor by telephone and invited to participate in the cross-sectional study. For those who did agree to participate, an appointment was made at a convenient date and time for each woman. Since the interviews were conducted by telephone, informed consent was given verbally and recorded after any doubts were clarified (10).

The interviews were conducted between January and July 2017 by investigators with experience in this interview technique, and each lasted 10 minutes on average. The women's answers were recorded and registered in a digital version of the questionnaire, where the responses to the open questions were transcribed *ipsis litteris* into the database.

For the purpose of the present study, two open questions were analyzed: 1) What made you finally decide to undergo the proposed treatment? and 2) In your opinion, did the treatment work or not? And why?

Data analysis was conducted according to the guidelines proposed by Patton (11). The text corresponding to the two questions was read several times by two of the investigators to identify the units of analysis in the women's answers that would meet the proposed objectives. Based on the defined set of units of analysis, categories of analysis were then proposed. After the categories had been defined, all the answers were read again, categorized and grouped together. A descriptive summary of the content of each category was then built. This study was approved by the local and national Institutional Review Boards (CAAE 5592.3016.1.0000.5404).

Results

A total of 208 participants answered the full questionnaire. Three categories of analysis were identified to explain how the women identify and understand risk for preterm birth. We present the results obtained for the following categories of analysis:

- Risk perception mediated by health professionals

- Self-perception of risk through personal experiences and relationships
- Perception of treatment success

Risk perception mediated by health professionals

Overall, after a healthcare professional provided a clear and detailed explanation about the diagnosis of short cervix, the women understood both the information given and the preterm birth risk factor. These women were able to recognize the association between short cervix and preterm birth and the importance of the early diagnosis for preventing premature birth. Moreover, they were also able to understand that there are other risk factors for premature birth, such as twinning or other maternal morbidity, which together increase the risk of prematurity.

"Oh based on what the doctor said, he said that my cervix is low and could not hold the weight of the baby" (patient 60)

"...although I had a premature birth because of twinning and all that, so it was already expected". (patient 2)

Participants reported that the information given by health professionals involved in the P5 trial was impartial. The health professionals clarified that P5 trial was a clinical research and that accepting to participate in it would not guarantee that the woman would have the delivery at term. Participants reported that doctors said that *"....there is no conclusion if it [treatment] really works"* and that *"...maybe the treatment could not keep the pregnancy [the baby in the womb]"*.

The well-established relationship between the healthcare professional and the patient brought confidence in the treatment and safety to the patient on several occasions. Care, attention, answers to questions, trust and the excellence of the medical team were mentioned, including mentions that the doctor was always very concerned about the patient, the feeling that the doctor was her *"lifeboat"*, and that having access to the doctor by phone at any time solving patients' doubts, was a good experience. One woman even considered that all monitoring and perinatal care from P5 trial health professionals was as responsible for the baby's health as well as the treatment itself.

"...the doctor's quality, treatment, care, the way he explained to me about the treatment, his follow-up for months and after the treatment. For me, I think he was the main responsible because of his treatment, care, concern and guidance. Do you know what I mean? For me, in addition to progesterone, it made me successful". (patient 170)

Most women reported feeling gratitude for the health professionals who accompanied them during pregnancy and the opportunity to participate in the P5 study.

"I have to say that it was an amazing experience [the treatment], I really appreciate it. The doctors are all attentive, they are wonderful, the medical team is to be congratulated, the study team either". (patient 160)

Many women also thanked for the opportunity to receive a short cervix diagnosis during their first pregnancy, without having to go through the experience of having a premature child before being diagnosed.

"I would like to thank for this opportunity...it helps me a lot because I even know that I had a short cervix, it was something new to me and I received help...thank God I got to the end and I didn't have a preterm baby".(patient 116)

Self-perception of risk from personal experiences and relationships

Having had an unsuccessful experience in previous pregnancies, such as miscarriage, stillbirth, neonatal death, premature birth or having the baby admitted in to a Neonatal Intensive Care Unit (NICU) led women to associate their history with the informed risk in the current pregnancy, influencing their self-perception of risk. This created concern and anguish, because these women did not want to go through that suffering again. One woman reported that "*my other babies [previous gestations], it was so hard following them in the NICU*", so her wish was "*leave [the hospital] with the baby in her arms*".

Family experiences also influenced the patients' decision to accept treatment. Having someone close to them who had had an adverse outcome during their pregnancy, helped women to recognize the preterm birth adverse events, and it stimulates a fear felling that something similar could happen to their baby.

"...I had a case of preterm birth in my family and the baby died because he was born with 5-6 months, so I didn't think twice. I accepted right away(to participate in P5 trial), I said that if it is to keep my baby inside my womb I will accept it until the end". (patient 78)

Perception of treatment success

Although this study has not yet demonstrated higher efficacy of one treatment in relation to the other, and considering that literature is controversial regarding the effectiveness of treatments used to reduce premature birth incidence, overall, patients considered that the offered treatment to avoid premature childbirth had a positive result, and that it worked properly. Even those who had a premature birth considered that the treatment worked, because without this treatment the birth would have happened earlier than it was. The feeling of successful treatment is clear in phrases like "*it worked because if I hadn't done it I could have lost my son*" or "*I felt like it was my salvation*". Patients seem to project their hopes on the treatment, waiting for any benefit that it may bring to their pregnancy.

For some women, even without reaching a term pregnancy, the treatment was able to prolong the gestation, and this gained would have brought many benefits to their babies' survival. Women comprehend that neonatal outcomes influenced for prematurity depend on gestational age at the time of delivery and the closer to a term gestation, the lower risks would be involved.

"Because I had a previous pregnancy and I hadn't done this treatment, so I hadn't even get 30 weeks. Thus, I lost my baby. In this gestation I kept my pregnancy until 33 weeks with the treatment and my baby

was born, now he is fine, he is very strong".(patient14)

Most women reported that the treatment proposed was able to "*keep the baby until the appropriate time*", others mentioned that having their baby healthy at the moment of the interview is already the answer to the question, because "*it worked because my baby is in my arms right now*". Another reported factor was a decrease in some patient symptoms such as pain, bleeding and an increased feeling of security and tranquility. These feelings were cited not only as a consequence of performed treatment, but also as responsible for the treatment success.

"It worked [the treatment] a lot. It worked because I have my son with me, well and healthy, without any risks. Do you know what I mean? It worked because I kept my pregnancy until the end". (patient 47)

After I have just started [the treatment,] the bleeding has stopped, the pain also has stopped. So it worked for me. And one more thing, I left the risk area and my pregnancy became stable".(patient 64).

Women stated that they had a successful treatment mainly comparing the current pregnancy with their previous experiences. They also reported their personal experience in having a previous baby in a NICU and all suffering linked to this uncertainty moment, regarding if the premature newborn would survive. Many women reported that with the managed treatment they could carry the gestation until term. Few patients considered that the performed treatment did not work, and all of them had stillbirth or neonatal death as the final result of pregnancy. Half of these neonatal outcomes were linked to extreme prematurity. Therefore, the perception of failure is strongly connected to the baby's death.

"No, it didn't[the treatment didn't work]. Because I have not been successful . If I hadn't done this treatment, the same thing would have happened". (patient 29)

Participating importance in the research was also emphasized, due to the possibility of receiving adequate treatment. Some women said that they would redo the treatment and others reported that they would recommend the treatment to relatives or friends.

Discussion

Overall, pregnant women participating in this study recognized the preterm birth risk which they were exposed from personal experience and information provided by the health team. This combination allowed patients to establish a relationship between pathology and disease. The image of good health and female fullness associated with the pregnancy process is broken after a risk condition diagnosis, breaking projections and expectations launched to an expected positive birth outcome. Recognizing illness is different from recognizing the presence of a disease, and it will influence how the patient will follow the proposed treatment.

It is clear that, in this study, knowledge about the risk of prematurity was also influenced by their own previous experience and / or relationships (12). Especially when a patient has a history of premature birth, it is natural that she asks the doctor about prematurity and the possibility of going through this

negative event again, since she brings with her a risk perception of prematurity formed through this previous experience.

Having access to medical criteria defined by doctors as a disease condition and the way they were informed interfere in the process to recognize or not this risk condition and it brings the patient's perception of illness closer to the illness process (13). In addition to easy understanding of the information, patients in the present study also praised the way it was transmitted. The study results reinforce the need to invest in health education as a way to offer autonomy, empowerment and health literacy (14)(15). Within the collective, the external social influence on the individual's risk perception can be perceived in the valuation or not of certain diseases. Most frequent with high mortality can be underestimated while others that are uncommon can be overestimated due to people's lack of knowledge. Considering pregnancy, we can exemplify the need for health education with the current Brazilian population perceptions of risk on prematurity and the congenital Zika syndrome. Although prematurity is the main cause of infant morbidity and mortality in the world, currently in our country one of the greatest fears of families is linked to the possibility of Zika virus infection during pregnancy, or more directly, linked to microcephaly, despite the lower incidence (16).

Developing a risk perception about prematurity, patients understood the information about the diagnosis, they individually recognized the disease and chose to participate in the research accepting the proposed treatment based on their self-perceptions of risk. In this study, it is noteworthy that pregnant women develop an appropriate knowledge about prematurity. They were able to understand that the closer they were to a term gestation, the lower associated risks would be the risks.

The participants who, even with the treatment, still had a premature delivery, giving birth to a healthy baby and who had a premature birth at a lower gestational age in the past, attributed this gain in time and better outcomes at birth to the offered treatment, even though they had not achieved a term gestation. Expecting for positive neonatal outcomes, women may believe that any performed intervention is beneficial and capable of reducing the risk.

The follow-up throughout this study provided a good doctor-patient relationship, strengthening this bond and reducing, within the patient condition of vulnerability, the fear and anxiety created by the pregnant woman's knowledge about her high risk of preterm birth. Many women who firstly felt fearful about the future of their pregnancy, considered the medical follow-up and treatment offered by the study as a divider - changing their position as a high-risk pregnant woman to a situation where this risk could be "controlled" or even "take away" (17). On the other hand, participation in a study or acceptance to use some treatment, even without clinical evidence, can create a false sense of security.

Although pregnant women were informed that this treatment was not proven to be effective and that participating in the study would not guarantee positive results regarding their health or their fetus, many of them still considered that from the moment they started to receive the treatment, they would be out of the risk situation. During pregnancy, women can experience a critical and vulnerable situation and they

can have their actions driven by anxiety and fear. In this way, women put hope and faith in the health professionals and in the treatment offered by them, although there were no guarantees of results.

This fragility associated with lack of health professional proper conduction can increase the number of interventions and over-medicalizations in pregnancy, often unnecessary and even harmful (18,19). Examples of damage to the patient's health are situations in which their decisions were guided by a false perception of risk, based and induced by knowledge from health professional information that was not based on scientific evidence, such as unnecessary cesarean sections, so common in Brazil (20). Therefore, it is important that health professionals are clear and individualize each patient risk situation, avoiding unnecessary interventions without scientific evidence looking for an unfounded protection to their patient health.

The searching for health protection also emerges as the patient's focus. The child's good health at the time of interview was cited as proof of the achieved success. However, women who had stillbirths or neonatal deaths considered the treatment ineffective, even though their gestational age at birth were higher than expected. These results describe the real primary outcome expected by patients exposed to the risk of prematurity: a healthy baby birth. For women who had babies still premature, regardless of gestational age or length in the NICU, but that had a positive neonatal outcome, the association with satisfaction and success is clear.

This identifies an important fact: studies for preventing preterm birth must consider neonatal outcomes as the primary outcome, and not just focus on higher gestational ages at birth. It will increase quality and importance to these studies (21,22). In practice, increasing gestational age as a primary outcome for prematurity studies is an intermediate outcome that does not achieve study participants goals. Thus, we believe that studies to prevent premature delivery should bring neonatal outcomes as primary outcomes, achieving in their results the desire of pregnant women exposed to prematurity.

Health professionals are the most important element in the pregnant women risk perception and must to consider that the concept of risk involves failures. In this sense, communication about risk must be careful and not to cause alarm and suffering. We must consider how much it is worth it to pattern all behaviors to avoid a future risk that we do not know if it will occur. It is important to recognize that there is a need to establish a more fluid and horizontal relationship between patients and health professionals. Therefore, patients will have more autonomy in this relationship, incorporating their risk perception and opinions to their decisions, respecting patient individuality and leading to a more satisfying experience (23).

Regarding limitations of this study, it is a qualitative analysis with an exploratory characteristic and the results should not be extrapolated beyond its limits. Although we observed that women reported that they understood the information about preterm birth risk, this information was not checked in a systematic way. It can also be considered a limitation the fact that patients were interviewed weeks or months after delivery, which can limit their memories about occurred facts and, therefore, their comments. Another important issue is the fact most patients who refused to participate had a negative outcome (miscarriage,

stillbirth or neonatal death), which reduces the number of women interviewed who had an unfavorable outcome.

This study brings with a large sample of patients a new perspective to understand the pregnant risk perception. There are still few studies about pregnant risk perception in the face of a critical situation such as prematurity and, therefore, it is not known how they understand and experience this risk yet. Recognize an existing risk in pregnancy can further increases pregnant vulnerability, creating a stressful and anguish situation, regarding uncertainties about the pregnancy future, as well as it can help to find the best way to deal with the risk condition, giving the possibility to receive an adequate prenatal care, sharing decisions and responsibilities and increasing proposed treatments acceptability.

Conclusion

Pregnant risk perception about prematurity is based in personal experiences and mainly by health professional clarifications. This professional assumes the role of knowledge about risks involved in pregnancy. However, it is important to emphasize that the concept of risk is not limited to numerical calculations. Risk is a social construction and, associated to a possible unwanted event occurrence and its severity, risk cannot be represented only by collective, objective and numerical data.

Extrapolating risk use can generate distortions, misunderstandings and even suffering for women, creating a false sense of prevention and control of threatening situations in our lives and our health, and giving scope in this process for medicalization and unjustified interventions, which must to be avoided when considering the patient's individuality.

Risk perception, when it is well supported and reinforced by health literacy, can help to conduct pregnancy properly, where women can share decisions with the health team and implement necessary actions. Moreover, we recommend that new clinical trials to prevent prematurity must focus on neonatal outcomes in order to achieve families' expectations.

List Of Abbreviations

WHO - World Health Organization

P5 trial – Randomized controlled trial on the use of pessary plus progesterone to prevent preterm birth in women with short cervical length

CONEP - The Brazilian National Review Board

NICU - Neonatal Intensive Care Unit

Declarations

Ethics approval and consent to participate

The internal review boards of UNICAMP - Institutional Review Board, Faculty of Medicine, University of Campinas, SP, Brazil (CAEE 5592.3016.1.0000.5404) and IMIP - Institutional Review Board of Instituto de Medicina Integral Professor Fernando Figueira, PE, Brazil (CAEE 3841.7114.0.2005.5201) approved the study protocol. All the participants gave their informed consent verbally over the telephone, with their consent being recorded. The research followed the determinations of the Declaration of Helsinki, as well as the norms that regulate the research involving human beings in Brazil.

Consent for publication

Not applicable

Availability of data and materials

The datasets analyzed during the current study are available from the corresponding author upon reasonable request.

Competing interests

The authors declare that they have no competing interests

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Authors' contributions

RCP, TVS, SB and LK contributed to the conception and designed the study. TVS and SB collected the data. RCP, TVS, SB and LK analyzed and interpreted the data. TVS wrote the first draft and RCP, TVS and SB contributed to the final version. All authors read and approved the submitted version. All authors agreed to be personally accountable for the author's own contributions and they ensured that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature.

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