

Experiences and expectations of pregnant women in advanced maternal age with suspected or confirmed fetus malformation

Vivências e expectativas de gestantes em idade materna avançada com suspeita ou confirmação de malformação

Vivencias y expectativas de gestantes en edad materna avanzada con sospecha o confirmación de malformación

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This study aims at investigating the experiences and expectations of women in advanced maternal age, pregnant of children with a confirmed or suspected diagnosis of fetus malformation. This is a qualitative, descriptive and exploratory research, conducted from January to July 2016, including content analysis, in the thematic modality. Seven pregnant women were interviewed. Participants had to be 35 years of age or more and be monitoring their situation in the prenatal outpatient clinic of a specific federal public health unit, which is a reference for fetal risks. Two categories came to light: "The embarrassment of receiving and sharing the news"; and "Fears regarding the future". Tensions were found to exist among women regarding the social acceptance of their children, uncertainties regarding their professional future and expectations of overload in the care with the child. The conclusion is that these women should receive specialized care to deal with these issues.

Descriptors: Maternal age; Maternal-fetal relations; Gender and health.

O presente estudo tem como objetivo investigar as vivências e as expectativas de mulheres em idade materna avançada, grávidas de bebês com diagnóstico suspeito ou confirmado de malformação. Trata-se de uma pesquisa qualitativa, descritiva e exploratória, realizada entre janeiro e junho de 2016, com análise de conteúdo, na modalidade temática. Foram entrevistadas sete gestantes com 35 anos ou mais, acompanhadas no ambulatório de pré-natal de uma unidade de saúde pública, federal, de referência para risco fetal. Evidenciou-se duas categorias: "O constrangimento de receber e compartilhar a notícia"; e "Receios quanto ao futuro". Verificou-se que existem tensões das mulheres quanto à aceitação social da criança, incertezas quanto ao futuro profissional e expectativas de sobrecarga nos cuidados com a criança. Conclui-se que estas mulheres devem receber atendimento especializado para tratar estas questões.

Descritores: Idade materna; Relações materno-fetais; Gênero e saúde.

El presente estudio tiene como objetivo investigar las vivencias y las expectativas de mujeres en edad materna avanzada, embarazadas de bebés con diagnóstico sospechoso o confirmado de malformación. Se trata de una investigación cualitativa, descriptiva y exploratoria, realizada entre enero y junio de 2016, con análisis de contenido, en la modalidad temática. Fueron entrevistadas siete gestantes con 35 años o más, acompañadas en el ambulatorio de pre-natal de una unidad de salud pública, federal, de referencia para riesgo fetal. Se evidenciaron dos categorías: "El malestar de recibir y compartir la noticia" y "Recelos en cuanto al futuro". Se verificó que existe una tensión en las mujeres en cuanto a la aceptación social del niño, incertezas en cuanto al futuro profesional y expectativas de sobrecarga en los cuidados del niño. Se concluye que estas mujeres deben recibir atendimento especializado para tratar estas cuestiones.

Descriptorios: Edad materna; Relaciones materno-fetales; Género y salud.

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INTRODUCTION

Brazil has been going through a process of epidemiologic and demographic transition which is increasingly visible with the rise in the educational level of women who are mothers. These transitions were historically built and are related to a diminution of child mortality, an increase in the populational aging and a diminution of fertility rates¹.

The number of births during the so-called advanced maternal age – gestation by 35-year-old or older women² – has, in this context, expressively increased in Brazil. If, in the country, from 2000 on, a decline in the natality rates can be observed when the group of 35-year-old or older women is considered, a 32% increase in the number of births among women this age can be noted after 2000. The 275,277 births that took place in 2000 became 364,405 in 2014, a growth that was linear and stable from 2007 on³.

Late motherhood is articulated to social, economic, political and ideological dimensions, directly related to the changes in female sociability in the last decades. The motivations for delaying motherhood are many and can be linked to professional ambitions that demand investment, delayed marriages, the establishment of new affective unions, difficulties with fertility and the easy access to a vast number of contraceptive methods⁴.

These factors result from the changes in the job market, since women have been more and more present in public spheres and have an increasingly prominent role in the job market. Probably, this tendency will be maintained⁵, and that would require the health professionals to be prepared to offer qualified assistance to this segment.

Late female reproduction directly impacts the profile of child health and sickness. Late gestations are considered to be of risk, due to the repercussions they can represent for the life of the women and the fetus². Gestation after 35 years of age has a higher chance of leading to the birth of babies with malformation⁶.

A study⁶ regarding congenital malformations and risk factors in mothers in

Campina Grande – Paraíba, pointed out that advanced maternal age is a factor that may influence fetal malformation. Therefore, the chances for the baby to present with malformation are higher, as is their chance of developing chronic health conditions, reinforcing the chronic types of sickness that are in accord to the demographic and epidemiologic transitions.

Women are central figures in the care for children, even if they are in a context in which they have to work out of their houses⁷. If child care is already, quintessentially, taken on by females, this issue tends to be aggravated when the child has chronic health problems⁸⁻¹⁰.

Congenital malformation can be characterized as a morphological anomaly due to genetic, environmental or mixed motives, resulting from all defects present in one or many organs¹¹. Chronic health conditions are defined as long-term conditions, which can, sometimes, be permanent¹².

Malformation can, potentially result in chronic health conditions. When fetal malformation results in chronic health conditions for the child, it is possible to say that the maternal overload tends to increase, considering the specific demands presented.

This article is justified by the need to know the profile and the demands of this growing public, made up by pregnant women in advanced maternal age, increasing its visibility so that services adequate to their needs and their reality may be offered. Considering this context, this study aims at investigating the experiences and expectations of women in advanced maternal age, pregnant of children with a confirmed or suspected diagnosis of fetus malformation.

METHOD

This is a qualitative, descriptive and exploratory study, conducted from January to July 2016, including content analysis, in the thematic modality¹³.

Pregnant women under monitoring by the prenatal outpatient clinic of a federal public unit, a reference for high risk pregnancies, participated in the study, as long

as they were 35 years of age or more, and had a confirmed or suspected diagnosis of fetal malformation (FMF). This study did not include, due to ethical considerations, women with cases of stillbirth.

Data collection took part through semi-structured interviews. Data collection took place until data saturation, that is, it was stopped when the interviews were no longer offering new information and were then stopped¹⁴.

The research was conducted according to resolution n. 466/2012¹⁵ and was submitted to the approval of the Research Ethics Committee (REC), which it received, under protocol n. 51848015.0.0000.5269.

The interviewees were identified by aliases during the study, as to preserve their anonymity and the confidentiality of the study.

The research corpus was studied in three stages, which were pre-analysis, material exploration and analysis of the data obtained¹³.

RESULTS

Seven pregnant women took part in the study. The profiles of these women are presented in Table 1, so their reality can be better understood.

Table 1. Profile of women pregnant with children with suspected or confirmed malformation diagnoses. Rio de Janeiro, 2016.

Fictitious name	Age	Exposition to FMF or possibility of beginning of life with specific health issues
Frida	35	Microcephaly
Clarice	35	Diaphragmatic Hernia + Altered nuchal translucency + suspected Down Syndrome
Olga	37	Altered nuchal translucency + confirmed Down Syndrome
Marta	39	Hemolytic disease + pelvis dilatation
Dandara	41	Left kidney could not be visualized+ Congenital club foot
Cecília	41	Maternal sporotrichosis + multiple malformations
Tarsila	42	Magnetic resonance in pregnancy + HIV positive mother

Two categories of analysis were used to present the results of the study:

- 1) The embarrassment of receiving and sharing the news; and
- 2) Fears regarding the future.

The embarrassment of receiving and sharing the news

Women gestating babies with potential fetal malformation are subjects with previous experiences, which must be taken into account. It should be pointed out that, even if there were no confirmed malformations, a suspected one already changed the expectations of the mother regarding the birth of the child.

Interviewees did not seem to have assimilated much information regarding the health conditions of the baby, even when they were oriented by the health team, considering that they were also going through a process of

investigation regarding the health of the child. However, the fact that the exams presented alterations already was a reason for these women to feel tense.

Additionally, their expectations were articulated to their individual experiences and the social pressures regarding a certain lifestyle. In some cases, they did not want the pregnancy at first, and it had itself been difficult news to deal with, even before the suspicions of malformation:

It was a shock, because I didn't... Nor my husband, because of our current situation, you know?! Health situation... So we didn't want that... So I went to Fiocruz to say that I did not want that and all, so they sent me here. When I got here, I said again that I didn't want it... I went to maternity because I was bleeding, I think due to emotions, my pressure was 10x15, too high... (Tarsila, 42 years old).

Those who planned the gestation report a movement in both directions: happiness due to fulfilling their wish and

disappointment when they received the news of malformation:

Oh, we were very, very happy. Until the exams and complications started arriving, right?! [...] Then we felt that... It was that shock to the family, we were shaken. (Olga, 37 years old).

These experiences are oftentimes associated to a previous recognition of these women regarding prejudice and difficulties for the insertion of these children in society:

I'd never had any contact with Down Syndrome kids, although everyone thinks it's cute and says: - "Oh, how cute!", as if they were talking about a puppy... [...] - "But they are very loving!", you know?! [...]. But like, I still am really frightened (Olga, 37 years old).

Sharing the news is also not always a strategy that guarantees that they will receive support. These women are often confronted with curiosity and disrespectful actions from friends and acquaintances. The depersonalization of the woman in this context and the focus targeted at the malformation of the baby can be elements that motivate these pregnant women to redefine their actions and adopt the silence as a strategy to protect themselves:

[...] We, inadvertently, think that telling others will help... It does not, it becomes gossip. And even in the church I was going to, now I went back to another one, it... it's like: -"Hi! And the baby, what does it have?" [...] It's kind of like that... I'm fine, I'm alive... The baby... Is fine! [...] But they don't... Kind of, "if you died, whatever"... The baby is all there is. "And the baby, what does it have?" It was just that... Like, even today. But then, some time ago, I told my husband: "I'm not talking about it, tell them that!". If someone asks me, I'm going to say like: -"I'm fine, thank you very much!" (Clarice, 35 years old).

These experiences and the previous observations of these women regarding the routine of others in the same situation, are a serious source of preoccupation to them, regarding the acceptance of this baby in the social context and their possible overload and the re-planning of their future lives.

Fears regarding the future

The future tends to be established as a painful element. Many components that refer to the preoccupation with the specific health condition of the child are present. The preoccupation with the possibility that the child may not be able to live an independent life in the future is visible and concrete.

The reflections on the health conditions are associated to the stigma

according to which the child with possible malformations and/or chronic diseases could be unable to be autonomous and responsible for their own lives in the future. This idea is linked to the predominant social dynamic, which does not value diversity and is based on a fast society, on production, as it follows certain aesthetic and "health" standards.

But we're kind of like... that I would have a kid, who would grow up, go away, get married, be happy with his life, and then sometimes you find yourself thinking: "Man, my son [...], he's not going to get married, he's not going away". So, we're left wondering, like... You can't tell (Olga, 37 years old).

The health condition of the child is not the only factor that worries the woman-mother. In these cases, the aesthetics of the child, independently of their health conditions, are also expressive elements of acceptance or not of the child by part of the society and the father of the baby:

I think that, like... I think that hair, like... In the first days, if it's a beautiful child, perfect... He'll even be charmed. But if the baby's born with something, he'll abandon it (Cecília, 41 years old).

The fear that the child would "be born sick" tends to be a preoccupation that interferes in the acceptance of the child in the family nuclei. And the acceptance or not of the child by the members of the family group tends to be an issue that causes fear and insecurity among women, especially when there are no direct expressions of connection: *My husband was with me. [...] A nurse even talked to the doctor, because I was very shaken... So she went to talk to me, that the child might not be... Will not be born sick. [...]. My husband was not accepting it until last week. Now he's talking more about the baby, saying it's a girl. My kids are accepting it well... (Tarsila, 42 years old).*

The manifestations of support and affection from the family members can also be uncomfortable for these pregnant women. In these cases, the fear of disappointing and the suffering that the families can go through also tends to stress these women:

[...] They only talk about buying stuff for the baby, so I'm afraid they'll be disappointed, or something (Frida, 35 years old).

These two perceptions seem linked to the fact that women understand that theirs is the main responsibility for the care of the children, especially considering babies with specific health needs. Justifications for the other members of the family as to the financial

needs or gender characteristics seem to be used by them to explain this feeling they have of lack of future support:

[...] And I'll be alone again, because here's the issue: my daughter has to work to keep the house afloat, right?! If not, we'll go crazy... Because you know how boys are, right?! They arrive, give you a kiss and leave. It's just me... I'll be fighting alone again (Cecília, 41 years old).

Then, as good as your husband may be, as good as your family may be, you know that who's going to do everything is the mother and I'm perfectly capable to care for my daughter and I know that though the dad is a very good dad, a partner, but I know... I know I'll need more strength, more everything... So here I am, to fight (Olga, 37 years old).

The tension regarding the challenges seems to be the motivator that justifies the use of words such as "fight" or "war", when they refer to the challenge of caring for the child alone. The acceptance of caring for a child with special health needs by themselves is articulated to their previous motherhood experiences, considering that all those interviewed had children before.

The participants remembered raising their previous children, their experiences and challenges, emphasizing the little-to-no support they had from the fathers. These perspectives affect their expectation of going back to the job market:

[...] because I don't know how well he's going to be when he's born... That he'll leave and all, so based on all that... Also, if the case is more serious, I'm not even going to go back (Clarice, 35 years old).

When the child has specific health conditions, the challenge for the female public is increased, since the social tools that give support to the care of the child with malformation and/or chronic diseases are few and expensive, and the mother seems to be the person who needs to abandon her own wishes to care for the child. Additionally, maternal overload starts to take its hold.

Gender issues are also clearly present, since, when a woman abandons the job market, she becomes more financially dependent on her support network, on welfare and on the income of her partner (if she has one). Abandoning the formal job market is seen by women as something that can directly impact their autonomy.

DISCUSSION

Contact with the hospital environment and the results of the exams contribute for these women to understand better their reality, albeit may not be in line with what society seems to believe should be considered an ideally healthy child.

In a study¹⁶ conducted with pregnant women whose babies have some type of malformation, it became clear that their expectations changed as the results of their exams indicated the specific conditions of these children, which is in line with the results presented here.

When a mother receives a negative diagnosis regarding the health of her child, anguish, fear and uncertainties regarding the future are always present, as is the sadness for the loss of an idealized child¹⁷⁻²⁸.

As to the embarrassment to reveal the possible malformation diagnosis to the father of the child and the larger family, a study²² has found that women, at first, omit the news from some family members.

The weight of the notions of a "mother's heart" and of the "maternal instinct" are reported as factors that are oppressive to the rights and the quality of life of women^{19,23,24} and tend to be reproduced here, as women recognize themselves as those who will be the most exhausted by the responsibility of caring for the child^{23,24}. This may also be an element that explains the difficulties in telling the news to others and the silence as a strategy of protection and defense¹⁹.

Hardships related to the absence of the family have also been reported¹⁷. The restricted support network of these women^{20,24} may explain their distancing from the formal job market^{17,21,23,24}, which directly impacts the objective life conditions of women.

This is an essential element, since their social and family support can impact on the way these women deal with the malformation²⁸.

A new aspect found in this study is that these women seem not to have in mind the idea of distancing themselves from their other children in order to care for the child with

special health needs¹⁷. The fears mentioned here are more related to the future and to the independence of the child^{18,22,24,25,27}, perhaps motivated by the fact that these women, due to their age, already have older children.

Women in advanced maternal age also tend to believe that the responsibilities regarding the pregnancy are mostly going to be their own. Regarding this, the maternity of a child with special health needs becomes a hindrance to the insertion of females into public spheres of life^{23,24}, and it becomes necessary to delay or plan for the termination of their work lives.

CONCLUSION

This study makes it clear how necessary and important it is for health services to get to know the demands of women in advanced maternal age, who are gestating babies with a confirmed or suspected fetal malformation diagnosis, in order to adequately care for these women and their needs. Knowing the demands of this group allows for the offering of higher quality services that contemplate the realities of the population of users.

It is necessary to consider that the professional exercise should not be limited to a biologic approach. That goes to show how important it is for prenatal examinations to consider health in its entirety, including the social, economic, political and ideological aspects of these women and of the region they come from.

Despite their advanced age, they need to have their doubts clarified and to be embraced. Maternity is a unique experience, even if they have had children before.

Considering the health issues of these children, the need to offer quality monitoring articulated to quality listening and to the construction of future life projects for women themselves becomes clear, since the malformed child may not correspond to the health standards imposed by society.

It is necessary to understand that advanced maternal age and fetal malformation are not free from gender bias, since women are seen as the main caretakers of children in Brazil, which directly impacts their insertion in public and private spheres.

That is why, in these cases, health services must be willing to work closely with the men/fathers, both to generate deeper considerations regarding gender issues and to promote the establishment of stronger bonds between the man and the child.

Giving visibility to this theme and working intensely to this end in health services means offering better conditions for these publics to access the services and the many spaces of social interaction, which may have positive results in the indexes of quality of life of these women-mothers and of the malformed and/or chronically diseased children.

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CONTRIBUTIONS

Camila Rebouças Fernandes and **Aline de Carvalho Martins** contributed equally to the conception of this research project, data collection and analysis, result discussion and in the elaboration of the article.

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