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MEANING OF MOTHERHOOD AND MOTHERING FOR WOMEN WHO USE WHEELCHAIRS

*Significado da maternidade e maternagem para mulheres que usam cadeira de rodas**Significado de maternidad y maternidad para mujeres usuarias de silla de ruedas***Nahalla Danny Jacome Rodrigues¹** **Kenia Anifled de Oliveira Leite²** **Aleksandra Pereira Costa³** **Ana Luiza Cabral da Cunha de Almeida Chagas⁴** **Danielle Figueiredo Patrício⁵** **Alexsandro Silva Coura⁶** 

ABSTRACT

Objective: to understand the meaning of motherhood and motherhood in women who use wheelchairs. **Method:** qualitative research involving six women in wheelchairs. Data were collected through semi-structured interviews, submitted to thematic content analysis. **Results:** the meaning of motherhood involves positive and negative feelings such as "fear" and "anxiety" and attributes such as "dream" and "wonderful". Regarding mothering, the participants understand that they are responsible for the care in the first days of the baby's life, and that throughout this process difficulties arise, but they realize that the results and benefits found are much more relevant. **Conclusion:** it is understood that the meaning of motherhood and motherhood in women in wheelchairs is permeated by ambivalent and concomitant feelings, which have been reformed with aspects of overcoming and self-esteem, especially the negative stereotypes outlined socially and culturally.

DESCRIPTORS: Disabled persons; Women; Pregnancy; Nursing;

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RESUMO

Objetivo: compreender o significado da maternidade e da maternagem em mulheres que usam cadeiras de rodas. **Método:** investigação qualitativa envolvendo seis mulheres cadeirantes. Coletaram-se os dados por meio de entrevistas semiestruturadas, submetidas a análise temática de conteúdo. **Resultados:** o significado da maternidade envolve sentimentos positivos e alguns negativos como "medo", "ansiedade" e ainda atributos como "sonho" e "maravilhoso". No tocante à maternagem as participantes entendem que elas são responsáveis pelos cuidados nos primeiros tempos de vida do bebê, e que ao longo desse processo surgem dificuldades, todavia percebem que os resultados e benefícios encontrados são muito mais relevantes. **Conclusão:** compreende-se que o significado da maternidade e da maternagem em mulheres cadeirantes é permeado por sentimentos ambivalentes e concomitantes, os quais foram reformados com aspectos de superação e autoestima, sobretudo aos estereótipos negativos traçados socialmente e culturalmente.

DESCRITORES: Pessoas com deficiência; Mulheres; Gravidez; Enfermagem;

RESUMEN

Objetivos: comprender el significado de la maternidad y la maternidad en mujeres usuarias de silla de ruedas. **Método:** investigación cualitativa con seis mujeres en silla de ruedas. Los datos fueron recolectados a través de entrevistas semiestructuradas, sometidas a análisis de contenido temático. **Resultados:** el significado de la maternidad involucra sentimientos positivos y algunos negativos como "miedo", "ansiedad" y también atributos como "sueño" y "maravilloso". En cuanto a la maternidad, las participantes entienden que son responsables de los cuidados en los primeros días de vida del bebé, y que a lo largo de este proceso surgen dificultades, pero se dan cuenta de que los resultados y beneficios encontrados son mucho más relevantes. **Conclusión:** se entiende que el significado de la maternidad y la maternidad en las mujeres en silla de ruedas está permeado por sentimientos ambivalentes y concomitantes, los cuales fueron reformados con aspectos de superación y autoestima, especialmente los estereotipos negativos delineados social y culturalmente.

DESCRIPTORES: Personas con discapacidad; Mujeres; Embarazo; Enfermería.

INTRODUCTION

Motherhood is defined as a woman exercising the role of mother. Being a mother is a social right that can go beyond a biological process, and because it is an event that originates in the body, motherhood and reproduction acquire different meanings depending on the time and socio-cultural context in which it takes place.¹⁻²

The exercise of motherhood in the 21st century is accompanied not only by expectations of fulfillment, but also by fear and anxiety, since the desire to be a mother is often postponed or questioned, due to the insecurity of not being able to cope with the roles already played by the woman, added to maternal responsibilities, as well as the fear of not feeling fulfilled in this role, since in order to fulfill her commitments, she will have to rely on the support of others to look after the child(ren).¹

On the other hand, diverging from this concept is the definition of motherhood, which in turn is achieved through the establishment of the affective bond between mother and child. In this, there is a peculiar definition, which is influenced by cultural issues, giving expressiveness to the relationship and care of the mother-child dyad, which is not the case with motherhood, as it is established solely by blood relations.³

Women with different types of disabilities and different cultural backgrounds are increasingly experiencing motherhood.⁴ This desire for motherhood, which can often be biological, is also directly shaped by individual issues and social influences. It's no different for women with disabilities, but family and society are often biased in their belief that women with disabilities and who use wheelchairs

don't have an active sex life and question whether they have the capacity to get pregnant, gestate and give birth.⁵

The ability to conceive is considered by a percentage of women to be an extremely significant fact, both from a physical and physiological point of view and from an emotional and social point of view. Pregnancy inspires preventive care to ensure good maternal and child health, so for women who use wheelchairs, this care must take into account the need for attention to communicational, attitudinal and architectural accessibility, considering the transversality of actions and the singularity of actions in health services.

Pregnancy and childbirth are events that demand knowledge, preparation and guidance from women, due to the social, physical and emotional changes. For women with disabilities, this reality is the same, plus the different circumstances they need to overcome, such as accessibility, socio-cultural prejudice and communication problems with health professionals.⁵

Concerns about the quality of care are common problems reported by women with and without disabilities, largely related to the attitude and behavior of health professionals who often discourage women from seeking maternal health services.⁷ Women with physical disabilities say that women in wheelchairs are discouraged from maternity care by some health professionals.⁸

This scenario led to the following question: what is the perceived meaning of motherhood and mothering for women who use wheelchairs? In view of the above, the aim of this study was to understand the meaning of motherhood and mothering for women who use wheelchairs.

METHOD

A descriptive study with a qualitative approach, carried out with women who use wheelchairs. The inclusion criteria were: women with physical disabilities who use wheelchairs, who became pregnant after their physical disability and who were in a state of self- and allopathic orientation, and the exclusion criteria were women under the age of 18.

The Snowball technique was used to select the sample. Data collection ended with the criterion of saturation, when it was possible to notice the repetition of statements and the achievement of the proposed objectives, which was noticed in the sixth interview.⁹

Due to the context of the COVID-19 pandemic, we initially used freely accessible resources on the Internet, such as the social networks Instagram, Facebook and Blogs, and contacted the probable first participant using the e-mail address provided on the website, or the possibility of messaging through the social network resource itself, which were obtained because they were already publicized on the Internet.

Next, contact was made by means of an invitation letter, in which it was possible to explain what the research was about, about the researcher, the institution to which the research is linked and the research proposal. At the end of the invitation letter, the prospective participant was asked to confirm whether or not she wished to take part. If they agreed to take part, they were asked to indicate a date for an online meeting using Google Meet. On this occasion, any doubts that had not been answered in the invitation letter were clarified and the research explained in detail.

After these explanations, the Informed Consent Form (ICF) was presented and sent to the prospective participant's e-mail address. After the participant agreed, as evidenced by marking the ICF in a specific field for this purpose (ticked) or by digital signature, the questionnaire was sent out with questions using Google Forms resources.

After obtaining the answers to the questionnaire and confirming that it had been received online, the online interview began, using a semi-structured script, with the first part containing closed questions to characterize the participants, with the following variables: age, marital status, level of education, type of paraplegia, obstetric history, number of prenatal appointments and the service where the appointments were made, and the second with open questions such as: what is the meaning of motherhood and maternity? The interview took place using the broadcast recording feature offered by Google Meet, with an average duration of approximately 60 minutes. The interviews took place between April and June.

The interviews were then transcribed in full. The speeches were subjected to thematic content analysis, as follows: pre-analysis, exploration of the material, treatment of the results obtained and interpretation. The first phase consisted of a floating reading of the material, construction of the corpus based on completeness, representativeness, homogeneity and

relevance, and the formulation of hypotheses and objectives. In the second phase, the context units were identified by categorizing them according to semantic level, and two categories were identified. In the third phase, the results were described by means of inference, and in order for them to have significant validity, they were based on the theoretical framework.¹⁰

The study was approved by the Research Ethics Committee of the Center for Higher Education and Development - CE-SED/FCM, and after appraisal and approval with opinion no. 44426921.1.0000.5175. The anonymity of the participants was ensured by the letter "C", referring to wheelchair user, followed by a number corresponding to the order in which the interview took place.

RESULTS

CHARACTERIZATION OF THE PARTICIPANTS

The participants' ages ranged from 26 to 40, with married being the most prevalent marital status. The majority had a university degree. All the women taking part in the study became wheelchair users after birth: all due to the after-effects of a car accident with traumatic injuries, leading to paraplegia. As for aspects related to disability and wheelchair use, all the participants reported paraplegia due to spinal cord injury, half of which was located in the T12-L1-L2 and T12-L1 vertebrae.

As for the length of time they had been physically disabled with a spinal cord injury, all the women had been using wheelchairs for more than 12 years. With regard to obstetric characteristics, more than half were primigravidas. As for the type of delivery they had experienced, all of them had undergone cesarean surgery. With regard to cases of abortion, they all reported that they had not experienced this. All the participants reported that their pregnancies occurred spontaneously, without the need to use mechanisms or resources such as artificial insemination or other methods.

With regard to prenatal care, all the participants reported having it, half of them in the private health network, with a number of appointments equal to or greater than nine, starting in the first trimester. Half of the participants received medical, nursing and physiotherapy appointments simultaneously during their prenatal care.

MEANING AND EXPERIENCE OF MOTHERHOOD: CONCOMITANT FEELINGS

The meaning of motherhood involved ambivalent or concomitant feelings, which is characteristic of this period in a woman's life, since there is a process of both physical and emotional changes in this experience of pregnancy. When describing the meaning of motherhood, they referred to expressions such as "dream"; "wonderful", which refers to feelings of joy, overcoming, self-esteem; however, along with these words there were also words that dealt with fear, anxiety and doubt.

In this set of feelings, we initially highlight the positive ones, as shown in the following statements:

For me, the experience of becoming a mother was wonderful, because it was a conscious choice. I got pregnant when I was thirty-five and my son was born when I was thirty-six, in 2016. So it was a planned pregnancy and... my year pregnant was a very wonderful year, right? I have the privilege of working for a company that includes people with disabilities, (...) so it gave me all the support, I had a lot of flexibility, especially in the last month." (C-4)

I think that from the moment you want to be a mother, regardless of whether you have a disability or not, it's already a process that really affects your feelings. I'm paraplegic because I had a motorcycle accident. Then I fractured my spine, at T12/L1, right in the lower back. I tried for a year to get pregnant, but I couldn't. Then I went for more detailed tests and discovered that I had a polyp in my uterus, so I had to have surgery to remove it. After I had the polyp removed, I got pregnant during my normal period, I got pregnant naturally. And so my son came! After three months of trying. For me, as I'd been trying for a year and three months, it was a very... good feeling, I can't even explain it! I just cried when I saw the positive test. (C-1)

Look, it's always been a dream of mine to be pregnant, to be a mother. So for me, being pregnant with my second is wonderful. Even though there's some discomfort, you know. It makes me a bit more limited, but it's only now that it's over... that I'm going through it too. I think that every sacrifice is worth it for me to have my son afterwards, right? So I don't have any...any, nothing to question, bad or anything that I think is bad. I think I only have positive points, both the first and the second, I had a bit of difficulty, one different from the other. But... for me it's wonderful, it's the realization of... (C-2)

On the other hand, the limitations brought on by disability have generated stigmas for these women over time. The negative points were also reinforced in the participants' speeches when they mentioned feelings such as fear and attributing greater anxiety to this process, considering possible situations directly related to the clinical conditions characteristic of the disability:

First I had a bit more anxiety like that, not knowing, being unknown. I hadn't studied what pregnancy would be like in my situation. It was all very new. So I was very anxious at first, until I spoke to my doctors and so on. And they reassured me, because there was also the factor that with a spinal cord injury, with the use of the brace, with the issue of neuropathic pain. There's no way of knowing if you're going to have pain or not. The neurogenic bladder, how it's going to behave, there's no way of knowing all that, right?

When I found out I was pregnant, I was close to three months along, and then... at first I was very scared, but... I still didn't believe it, I didn't know what I was going to do, you know. Continue because of the broken rods, but then I found... a won-

derful doctor, who looked after me very well, everything worked out, thank God! (C-3)

MOTHERHOOD: MEANING, DIFFICULTIES AND BENEFITS

The participants understand that, as much as they receive support and help, they are responsible for caring for the baby in the early stages of its life, and that throughout this process it is common for difficulties to arise, whether in caring for the child, related to the disability or both:

The care of the baby, since it's much more the mother's at the beginning, right... Because of the breast, because of everything, right. You have to change diapers, right, he's so tiny. And I ended up guiding him a bit more. But I think bathtime is a bit more difficult because it's... being a wheelchair user you have a certain limitation in terms of trunk balance, so going forward with your... without any weight is already difficult, even more so with weight, so, as light as the little baby is, it was a bit more challenging. (...) Now what I found most difficult about being a wheelchair user is that the Caesarean section hurt a lot for any woman and it hurt a lot for me too. (C-5)

However, one of the participants claims not to have found caring for the newborn difficult, despite her disability:

No, I don't think so. Even knowing that everything was an overcoming, or even having overcome it, I don't think there were any difficulties just because I'm a wheelchair user. I understand the difficulties I encountered during childbirth, pregnancy... every woman goes through these things. For me it is. I think... because even my family say they're surprised that I didn't feel anything during my pregnancy. And they felt... there was a problem and I had nothing, nothing, nothing, nothing. I didn't even feel any pain, and the birth too." (C-3).

Despite the difficulties encountered by most of the participants during pregnancy and in the postpartum period, they see that the results and benefits found throughout this process are much more relevant:

Ah... I don't know how to explain it... I can't imagine my life without him! It's very intense. It's... a great learning experience, especially about what love is, so true, great, in short... it's... I learn a lot from him. And we... there are things that only by living as a mother do you realize... that no, you have to give your child attention, love, affection and that too much lap doesn't mean they'll be spoiled. These are things I really learned later (laughs). (C-1)

What I experienced and had during this whole experience of pregnancy and with my son after giving birth, I say it was really... worth the whole experience of pregnancy... (...) And I think the end result was good for me, and as much as I have... because we always... think... I always try to think positively, right?

DISCUSSION

Motherhood is linked to women and their duties as mothers; it is emphasized that the practices involving motherhood are based on fundamental concepts that it is an instinct inherent to women, imbued with the myth of maternal love, seen as natural. It can therefore be defined as the exercise of the role of mother performed by women.¹¹

Another point that influenced the understanding of motherhood was the advent of the feminist movement in the mid-twentieth century, when motherhood began to take on a reflective dimension, to be analyzed with the economic, social and cultural conditions of women and couples in mind.¹²

During pregnancy, wheelchair users experience many difficulties, ranging from difficulties in getting around in search of health care, to the attitude of the health professionals who will be caring for them, which can affect both the quality of maternal health care and fetal health.⁵

When considering the characteristic feelings of accomplishment, studies show that motherhood for wheelchair users is the fulfillment of a dream and an affirmation of their femininity and self-esteem. However, they have to make great efforts to meet social expectations in order to become good enough mothers.¹³⁻¹⁵

This need to respond to social expectations has generated stigmas for people with disabilities over time, and was also reinforced in the participants' speeches when they mentioned feelings such as fear, doubt and attributing greater anxiety, considering possible situations directly related to the clinical conditions characteristic of the disability.¹⁵

The meaning of motherhood for the participants favored a greater relationship with overcoming, accomplishment and positivity, these aspects being strengthened by the breaking of paradigms or pre-formulated concepts, since according to Santos¹⁶, women with disabilities are doubly affected by stereotypes and discriminatory practices based on gender and disability. This combination generates a series of attitudinal barriers, which prohibit them from working, looking after a home, having a romantic or sexual relationship and experiencing motherhood, as they are unable to bear a child, care for it or educate it, among other things.¹⁵

In this respect, Santos and other authors⁸ consider that society's common sense in relation to wheelchair users is a vehicle for castrating roles and has sometimes led to the belief of incapacity. However, for the participants, the affirmation of motherhood as a disabled woman was always mentioned in a significant way.

Mondo and Sousa¹ describe that imposed social norms are capable of operating a series of psychological mechanisms so that maternal ideals are incorporated by women, and these mechanisms will often cause feelings ranging from guilt to fear.

According to Santos¹⁶, giving birth to a child is something that causes concern and fear in any woman, and it would be no different for a wheelchair user because she is a woman and this must be well understood. We mustn't let the adjective wheelchair user become more relevant and carry with it specifications that don't exist.⁵

However, what needs to be explained is that due to the singularity that permeates human subjectivity, emotions and actions, perhaps not every woman will be happy and satisfied with motherhood, in other words, everyone will have their own particularity, respecting their history. There will be factors that are contingent on the way in which she will signify her experiences and awaken her desires, fears and achievements.¹

It is understood that the process of motherhood is built up over the gestational period and that it behaves as a grouping of care dedicated to the baby in order to meet its needs.¹⁷ From this perspective, the participants showed awareness of their role in motherhood and of the difficulties throughout this process, despite the social support network.

In addition, despite the setbacks faced in motherhood, whether in caring for the child and/or related to the disability, the speeches denote the perception that the results and benefits found are much more relevant. This is because mothering awakens the sensitivity of the mother or whoever performs this function to understand and decode the child's needs, through a routine that offers protection against external dangers and favors the growth, emotional stability and development of this individual, consolidating the mother-baby bond.¹⁷

FINAL CONSIDERATIONS

It is clear that understanding the meaning of motherhood and mothering for women who use wheelchairs is indispensable, given that this relationship is permeated by ambivalent and concomitant feelings, which were associated with aspects of overcoming, self-esteem, joy, fear and doubt, as well as attributes such as dreams and wonder.

In addition, it was identified that motherhood and mothering reinforce important benefits and results for life, such as love, care and affection. Difficulties were still identified in some activities, such as bathing the baby due to limited balance in the trunk, and the pain of caesarean surgery.

However, through the understanding gained by defining the two classes related to the participants' speeches, we can see the need for spaces that provide qualified listening to women in the preconception, pregnancy and postpartum stages, in any area of health care, because by rescuing the subjectivity of these women, it becomes possible to favor holistic and unique care for this social segment about motherhood.

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