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Transition to motherhood and mothering for women in wheelchairs: a nursing perspective

Transição para maternidade e maternagem em mulheres cadeirantes: perspectiva da enfermagem

Transición hacia la maternidad y el maternaje en mujeres usuarias de silla de ruedas: perspectiva de la enfermería

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ABSTRACT

Objective: To discuss the process of transition to motherhood and mothering of women who are wheelchair users, from the perspective of Afaf Ibrahim Meleis. **Method:** Qualitative, descriptive, exploratory study conducted with six women in the state of Rio de Janeiro. The Life Narrative method was used, with thematic analysis in the light of Transitions Theory. **Results:** Developmental and situational transitions occurred and were influenced by personal, community and social factor. Moved mainly by ignorance and prejudice of family members and of the social network, these factors were not barriers for motherhood and mothering. **Final Considerations:** The reproductive rights of women with disabilities must be respected and, for this, inclusive policies focused on women with disabilities should be adopted.
Descriptors: Disabled Persons; Women; Pregnancy; Mother-Child Relations; Nursing Care.

RESUMO

Objetivo: Discutir o processo de transição para a maternidade e maternagem de mulheres cadeirantes na perspectiva de Afaf Ibrahim Meleis. **Método:** Estudo qualitativo, descritivo, exploratório, realizado com 6 mulheres cadeirantes residentes no estado do Rio de Janeiro. Utilizou-se o método Narrativa de Vida com análise temática à luz da Teoria da Transição. **Resultados:** Ocorreram as transições desenvolvimental e situacional, com influência de fatores pessoais, comunitários e sociais. Movidos principalmente por desconhecimento, preconceito da família e da rede social, esses fatores não foram impedimentos para o exercício da maternidade e da maternagem. **Considerações finais:** Os direitos reprodutivos da mulher cadeirante devem ser respeitados e, para isso, políticas transversais devem ser adotadas com práticas inclusivas às mulheres com deficiência.
Descritores: Pessoas com Deficiência; Mulheres; Gravidez; Relações Mãe-Filho; Cuidados de Enfermagem.

RESUMEN

Objetivo: Discutir el proceso de transición hacia la maternidad y el maternaje de mujeres usuarias de silla de ruedas según la perspectiva de Afaf Ibrahim Meleis. **Método:** Se trata de un estudio cualitativo, descriptivo, exploratorio, realizado entre 6 mujeres usuarias de silla de ruedas y residentes en el estado de Río de Janeiro. Se utilizó el método Narrativa de Vida con análisis temático a la luz de la Teoría de la Transición. **Resultados:** Se produjeron transiciones de desarrollo y de situación, influenciadas por factores personales, comunitarios y sociales. Movidos principalmente por el desconocimiento, el prejuicio de la familia y de la red social, estos factores no fueron un impedimento para el ejercicio de la maternidad y del maternaje. **Consideraciones finales:** Deben respetarse los derechos reproductivos de las mujeres con movilidad reducida y para lograr este cometido se hace necesario adoptar políticas transversales con prácticas inclusivas.
Descriptores: Personas con Movilidad Reducida; Mujeres; Embarazo; Relación Madre-Hijo; Cuidados de Enfermería.

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INTRODUCTION

The possibility of motherhood is no longer an obligation of the couple; it has become a social right, regulated and modulated by social expectations of how it should occur, which conditions are most appropriate, and, without a doubt, who can ideally be a mother[1].

Motherhood is a right that transcends biological processes. Because it is an event that originates in the body, reproduction acquires different meanings depending on the period and sociocultural context in which it happens. It has particular nuances according to the conditions of each woman[1].

Mothering, unlike motherhood, occurs through the development of an affective bond between the mother and her child. It carries a particular meaning, influenced by cultural issues, which give expression to the relationship and care of the mother-child dyad. This does not occur with motherhood, which is established by blood relation[2].

Likewise, the mother-child relationship took on new configurations. The binomial motherhood-mothering, as a social and historical construction, can explain the contemporary conceptions of motherhood[3].

Factors such as age, socioeconomic status, mental health and physical and functional status lead to a process of social appraisal, which influences women's capacity to fulfill the responsibilities of being a mother. This is enhanced for women with disabilities (part of the groups traditionally considered unfit for motherhood), because they do not fulfill the social expectations of health and independence to perform this function[1].

Contemporary society knows little about pregnant women with mobility difficulties[4], and even less about wheelchair users who have become mothers. The few publications directed to this population address biological aspects and difficulties inherent to the limitations imposed by the disability.

A study conducted in Turkey with 326 midwifery students found that they cannot communicate or experience difficulty in establishing communication with women with disabilities. And, 96.9% of these students did not take courses about disabled women's reproductive health problems[5].

Nursing professionals have an important role in this scenario because, in addition to providing comprehensive care to attend the needs of these women, they are also concerned with the interference of socio-cultural relations in their decision-making process and with the autonomy of the disabled woman, thus providing a support network[6].

From this perspective, the transitions theory, elaborated by the nurse Afaf Ibrahim Meleis was used as a theoretical support. It defines transition as the passage from a state of stability to another state of stability, with an in-between phase of instability. For nursing care purposes, this period of instability is divided and analyzed in several parts, the main ones being: transition types, facilitators and inhibitors and patterns of response[7-8].

It is important to carry out qualitative studies addressing aspects related to motherhood and mothering, not only for women who are wheelchair users, but also for women with any type of disability.

OBJECTIVE

To discuss the process of transition to motherhood and mothering of women who are wheelchair users, from the perspective of Afaf Ibrahim Meleis.

METHOD

Ethical Aspects

This study is part of the master's dissertation entitled: "Pregnancy on Wheels: health care for the women in wheelchairs during prenatal, childbirth and puerperium", that related the issue of maternity to disability, defended at UFRJ/EEAN. The broader study was approved by the Research Ethics Committee of EEAN/HESFA on March 29, 2011. All ethical requirements recommended by Resolution 466/12 of the CNS/MS were followed. After the presentation of the objectives and clarifications about the research, the study participants signed the Informed Consent Form.

Theoretical and methodological framework

The life history approach, with the methodological framework of Daniel Bertaux was adopted[9]. The theoretical framework was the Transitions Theory, elaborated by Nurse Afaf Ibrahim Meleis[8].

The flowchart of the Transitions Theory comprises: the type of the transition experienced by the individual - which can be developmental (related to the life cycle), situational (change of social roles of family conditions), health and illness (process of illness) and organizational (social, economic and organizational influences on the individual).

The patterns of the transition, which can be single or multiple, sequential or not and related or not[7-8].

The properties of the transition, which include: awareness, engagement in the process, change and difference, time span and critical events[7]. Facilitators and inhibitors include personal conditions (meaning, beliefs, values and socioeconomic conditions), community conditions, and social issues of the individual. Patterns of response evaluate progress and outcome indicators within the transition process. Progress indicators analyze feelings of integration with social networks, trust and coping. Outcome indicators are related to the abilities and the identities that the individual assumes in the process of transition[7-8].

Type of study

Descriptive, exploratory, qualitative study.

Study participants

The Snowball technique was used to select the participants. This is a technique widely used in social research, in which one individual indicates another and so on, characterizing a snowball shape. It is adopted to establish connections between the members of a given group, and thus obtain a sample[10].

The study sample consisted of 6 participants. Inclusion criteria were: women who are wheelchair users and who became pregnant after the disability (regardless of the cause); being a resident of the state of Rio de Janeiro; and being oriented to person, place and time. There were no inclusion criteria related to civil status or age of the children. The exclusion criteria were: being under 18 years of age and having any mental illness.

Data collection and organization

Data collection occurred through an open-ended interview with the following question: describe your experience with your

gestation and the health care received during prenatal, childbirth and puerperium. The interviews took place in the household of the respondent, from May to August 2011, and were carried out until reaching saturation point (when the researcher has the impression of not apprehending anything new referring to the object of study after a certain number of interviews). The interviews were immediately transcribed so that the saturation point could be identified[9]. The participants' anonymity and privacy were guaranteed. They were identified by the abbreviation W (Women) and arranged in sequence, according to the order of the interviews.

Narrative analysis

The thematic analysis was the analytical process used[9]. The transcribed empirical material (narratives) were read and grouped by similarity, allowing the emergence of common themes. After grouping the themes, the narratives were reread and synthetized, which gave rise to one analytical category and three subcategories: Category 1- From woman in wheelchair to mother in wheelchair: assuming new roles; Subcategory 1-Facilitators and inhibitors in the transition to motherhood/mothering for women in wheelchairs; Subcategory 2 - Patterns of responses in the transition to motherhood/mothering for women in wheelchairs; Subcategory 3 - Nursing Therapy for women in wheelchairs in the transition to motherhood/mothering.

RESULTS

All women participating in the research became disabled after their birth. Three were in wheelchairs due to sequelae of polio, two due to traumatic injuries and one due to cerebral palsy, leading them to paraplegia and quadriplegia.

The narratives showed that the society and some professionals in the scientific community discourage these women to become mothers, as happened with the first participant interviewed. She was stabbed at age nine and suffered a spinal cord injury.

> *I thought I would never be able to have a baby, because on my last day at the hospital the orthopedic doctor who took care of me said so to my mother: mother, your daughter can walk again and stop wearing a diaper, but she will never be able to be a mother* [...]*That was imprinted in my mind since I was 15 years old.* (W1)

Four women said that their first disincentive to motherhood was the orientation of health professionals, justified by their deficiency. The stereotype of incapacity for motherhood interferes with the judgment and clinical diagnosis of these women, compromising their therapeutic care.

> *They did a transvaginal ultrasound and they saw the gestational sac, but they said it was my probe balloon.* [...]*They returned to do a new ultrasound. The same doctor who did the other said that he had made a mistake, that it was a child, that perhaps he had used his emotion instead of reason because he did not believe that a quadriplegic could be pregnant.* (W2)

The society's common-sense regarding women in wheelchairs is a barrier that has sometimes led to the respondents' belief in their incapacity.

> *When I got pregnant* [...] *everyone thought I was ill. I felt very sick and I lost a lot of weight* [...]*And everyone said, you're going to die! You're sick, you're not pregnant!* (W1)

Although the narratives of the six participants present a normative and repressive society, they received congratulations from their families after the announcement of the pregnancy. However, the women's narratives revealed, along with the manifestation of joy from their families, feelings such as fear and apprehension due to their condition. For some participants, the low expectation led to the disapproval of their pregnancy, culminating in marriage dissolution.

> *I have already decided. I want my child, I choose him, and if you don't want to be with me you can follow your destiny. It was the first time we split up* [...]. (W5)

Even with the obstacles faced by these women, comforting and warm-hearted narratives based on faith were observed. The great desire to be a mother, the certainty of pregnancy and even the choice of the child's name, showed the influence of religiosity. The participant W5 did not have the support of her husband, who said he was not prepared to be a father. Faith was a powerful foundation for these women, encouraging and stimulating the completion of their journey as mothers and their choice of having her child without the presence of the father and assuming this responsibility alone.

> *I got pregnant and that day I knew I was going to get pregnant because I wanted to be a mother. And that very day I knew it was going to be a boy. And that very day I had already chosen the name. I'm a devotee of Saint George, because I'm a spiritualist and that day I told myself, I'm going to get pregnant and my son's name will be Jorge.* (M5)

Regarding the process of maternal care, the majority of the participants were desirous of motherhood and confident about the perspective of caring for their children. Only one of the participants mentioned in her narrative the fear and apprehension of not being a good mother. Even after getting pregnant, she still did not want to have children. Her pregnancy was not planned, she became pregnant from a friend and hid the pregnancy for a while for fear of the reaction of her family and the father. Her disability was not pointed as the reason for not wanting children.

> *When I discovered that I was pregnant with my first daughter, I did not want it.* [...] *Until my eighth month it consumed me. I did not feel like a mother.* (M6).

Three women experienced more than once the experience of having a child. One was enthusiastic, unlike in her first pregnancy, when she was afraid of not being a good mother. The other two were startled by the news, not because of their disability, but due to the age of their firstborn.

After the gestation process, there was their desire to have healthy children. People close to these women tried to dissuade them from the idea of bearing unhealthy children; however, these concerns were present and generated negative expectations in relatives and health professionals, including the possibility of not having a full-term pregnancy or of fetal death.

> *People thought they were all going to be born crippled (laughs), all of them walking in crutches in the streets* [laughs]. *I think people believed that my babies were already coming from the maternity in a wheelchair, using crutches.* (W3)

The narratives of the interviewees refer to a feeling of mothering, represented by the mother-baby bond and by the force of overcoming the obstacles imposed by physical limitations, such as fulfilling socially constructed maternal demands. Denying that their disability is a limitation for the care of their child reinforces the feeling of mothering, which is fully exercised by the interviewees.

> *You're crazy, how are you going to take care of a child? How are you going to hold her to breastfeed? Even me, disabled* [...] *I can do much more for my daughter than many people. If she wants to nurse at dawn and I'm lying down, I have to have someone to help me.* (M2)

Despite of their confidence, the participants reported difficulties to return home with their child, mainly in relation to maternal care. Their narratives show that this is a moment of mother-child adaptation, as it happens with non-disabled mothers, who may sometimes need the help of another person or a professional.

> *We need someone to help, to take care of the baby during feeding, to change the diapers. Because there's no way, especially if we have a C-section. How does a person in a wheelchair, who makes a gigantic force to get up, to sit down, is going to make an even bigger force to get up after a surgery?* (M3)

DISCUSSION

We discuss the experiences of women in wheelchairs who have had children, and analyze them on the light of Afaf Ibrahim Meleis's Transitions Theory and its four pillars: the type of the transition, the facilitators and inhibitors of the transition, the patterns of response and nursing therapy.

Category 1- From woman in wheelchair to mother in wheelchair: assuming new roles

In dialogue with the theory, the terms motherhood and mothering were used as a way of distinguishing the physiological and congenital relationship between the mother and child from the emotional attachment developed during the process of reception and approximation between them[3]. From an early age, women are socially convinced that motherhood is necessary to make them feel complete. Culturally, motherhood is naturalized. Both as a biological destiny and as a social value, conception is part of the female universe[11]. The narratives showed that this is not the reality of women in wheelchairs.

In the Transitions Theory, the nature of the transition defines its type, which can be developmental (related to the life cycle), situational (change of social roles or family conditions), health and illness (process of illness) and organizational (social, economic and organizational influences on the individual). In this step, we also include the pattern of transition, which determines if the transitions are single or multiple, sequential or not and related or not. The property of transition includes awareness, engagement in the process, change and difference, time span and critical events[8].

The developmental transitions described in theory are the situations related to the life cycle[8]. This type of transition occurred in all women in the study and manifested with gestation, childbirth, caring for a child and with the passage from woman to mother, as occurs for non-disabled women[2-8].

All the women interviewed presented some type of physical disability, representing a special condition, an adverse situation. Two of the interviewees (W5 and W6) had to assume the role of mother and father, due to the absence of the paternal figure. W6 got pregnant from a friend and the birth led to a distance between them. W5 broke up her relationship because the father did not accept the pregnancy. These scenarios represent situational transitions, considering the changes of roles to be performed, as shown in Figure 1[8].

The condition of disability is not directly or physiologically related to the condition of being a mother; however, the correlation between motherhood and disability is undeniable and can be frequently seen in the narratives of the participants. This way, the patterns of transition are considered related and multiple, since there is more than one type of transition occurring. Also, we can consider them sequential, due to the experience of a situational transition during the developmental transition of gestation.

Awareness, the first property of transition, is consistently demonstrated, since the pregnancy is desired and even planned by some of the women. However, engagement is fragile ever since gestation. Consequently, the possibility of mothering has its effectiveness frequently questioned. And, if the person does not search for information, there is no way to debate these questions.

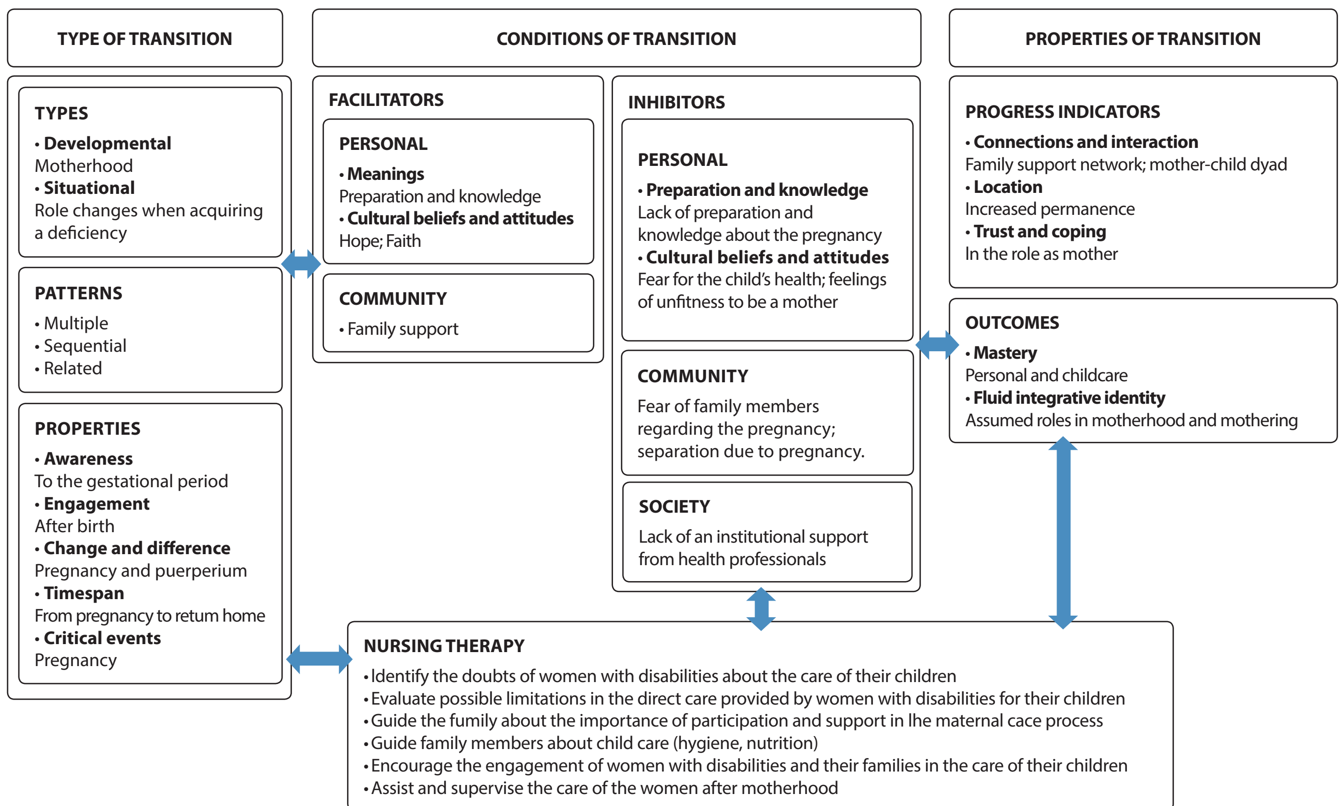
The health professional must translate the feelings presented by these women, whether or not they are ready for mothering. Progressive approaches and the clarification of their doubts, frustrations and longings will help the development of mothering[12].

Studies reveal that the pregnancy of women in wheelchairs is the realization of a dream and an affirmation of their femininity and self-esteem. However, they must make great efforts to respond to social expectations and become good mothers[13-14].

The properties of change and difference refer respectively to the disturbing elements in the transition process and the expectations created in the process, whether they are met or not[8]. The change of these women occurred with the confirmation of pregnancy and the development of concerns about pregnancy and puerperium. The difference properties observed were positive, related to the ability to procreate with the disability and to take care of their children.

The disability is a transition marker for the participants, considering the studied object reflected in maternal desire; however, the time span was between the discovery of the pregnancy and the return to routine activities at home, associated with the contact with the child. The critical events of the transition of these women were the pregnancy and puerperium processes, the mother-child bonding and the desire/fear of caring for their children.

Regarding the transition properties related to development and community conditions, the lack of a pursuit of knowledge to clarify doubts related to the pregnancy process, the arrival of a child and the becoming of a mother was evidenced. This lack of understanding generates fear in both the woman and the family.



Source: (MELEIS, 2010).

Figure 1- Stages of the transition of disabled women according to the flowchart of the Transitions Theory

Subcategory 1.1 - Facilitators and inhibitors in the transition to motherhood/mothering for women in wheelchairs

The transition conditions include personal, community and social conditions that facilitate or hinder the transition process. Personal conditions include meanings, preparation and knowledge for transition and socioeconomic status[8]. The meaning of both motherhood and mothering was a facilitator for all the participants, in view of their desire of motherhood (exercising their role of motherhood), as well as the desire for mothering (characterized by protection, care and bond with the baby).

The beliefs and values are factors that influence the cultural construction of the individual and his social context[8]. In the study, they were both facilitators and inhibitors, because despite of their hope and faith in a normal pregnancy and puerperium, the participants were also afraid for the child's health and of a possible inability to care for them.

Many women with disabilities may not feel prepared for motherhood, which they see as a challenge. They may deny the possibility of procreation or, when they are already mothers, they can feel guilty about their child's care[1].

Little-discussed issues related to the pregnancy and childbirth of these women exert a great influence on society and even on health professionals, raising doubts about the possibility of a woman with mobility disability bearing a child. Lack of preparation and knowledge were inhibitors of the transition. Inhibitors observed in the narratives of these women were related to the lack of information from health professionals regarding their gestation and labor, which puts them in a situation of vulnerability and passivity.

The community is understood as a social combination in which a particular social unit, non-egoistic and with a prominent emotional component, stands out. The family and other social groups are a support network that influence the desire for motherhood and mothering[14]. Some of the participants did not have the support from their family or their spouse in their motherhood. This is because these women do not fit imposed aesthetic standards and society does not believe that they can assume roles as wives, mothers and caregivers. These factors demonstrate a prejudiced view of the motherhood of women who are wheelchair users.

Society is considered complex and polysemous. It can be seen as structural, definer of morality and of intelligible standards, and as solidary, stimulator of connections between people[15].

The concept of society is related to the social issues that interfere in the motherhood of women in wheelchairs. The family, the spouse and most health professionals act as structural society and inhibitors in the transition process, perpetuating stereotypes of incapacity and prejudiced attitudes.

Although few, there were some family members and a single health professional who provided a support network that facilitated transition and solidarity. The narratives of Spanish women with disabilities pointed out to stereotypes rooted in society as generators of pressure in the family environment and even in health systems. The same thing happens in Brazilian society[16].

Subcategory 1.2 - Patterns of responses in the transition to motherhood/mothering for women in wheelchairs

Patterns of response to motherhood/mothering include progress and outcome indicators in Transition Theory. Patterns of response include progress indicators in the transition process (integration with the social network, trust, and coping) and outcome indicators (such as the abilities and the identities that the individual assumes to make the transition)[5-6].

Progress indicators evaluate the transition of women in wheelchairs through the connections, interactions and location of these woman in the transition process[6]. There was an attempt to develop support networks ever since the pregnancy process, and in motherhood and mothering.

The outcome indicators are related to the skills and behaviors required to deal with the new reality. The mastery of these skills is associated with healthy outcomes of the transition and redefinition of self-concepts[6]. Disabled women have proved to be extremely skilled and able to make adaptations to care for their children, albeit with help from family or caregivers. Despite several attempts of social repression of their motherhood, they assumed the identity of mothers.

The process of transition of women in wheelchairs showed that motherhood is a phenomenon still to be unveiled and that is not limited by disability.

Subcategory 1.3 - Nursing Therapy for women in wheelchairs in the transition to motherhood/mothering

Nursing professionals have an important role in the motherhood and mothering of women who are in wheelchairs. Nursing therapy is responsible for role supplementation, which is the name given to nursing care aimed at filling the gaps that are essential in the transition process[8].

Nursing professionals should, still in prenatal care, identify the demands of these women and guide the care of their child and family. Tasks such as placing the child on the lap may not be so simple when the mother uses a wheelchair, because the child must be attached to the mother's trunk to avoid falls[17].

The birth of a child requires a lot of care measures, and disabled women need to adapt to these new demands. Bathing the baby is a task that generates fear and dependence on other people[17]. The nurse, along with the mother and the family, must find strategies that increase their independence, such as placing the tub outside the shower and at a height that allow safe movements of these women

Traditional cradles and changers are inaccessible to these women. Cradles must be adapted with a lateral opening that gives access to the child. Changers need to have a space to accommodate the wheelchair. When it is not possible to buy adapted furniture, the baby ends up lying on the floor or in the bed[17].

Motherhood is not an easy task and disability can make it even more difficult. Therefore, support is an indispensable factor to exercise this role in a satisfactory way. The nurse should encourage the participation of the father and family in the care of this child and the engagement with this woman, so that this transition can be experienced in a healthy way.

Health professionals should take ownership of the care of the person with a disability and take actions that give these women confidence and strength, ensuring their social inclusion. In addition, these professionals should avoid communication barriers and information deficits in the pregnancy, delivery and puerperium of these women, providing accessible information and sensible care for this population[18].

The follow-up of this pregnancy should be carried out primarily by professionals who have experience in the care of people with disabilities and who are willing to walk side by side with these women. The women should seek support in other mothers with disabilities. The creation of conversation circles and meetings with these mothers is important in this process. In this context, it is necessary to give visibility to these women, stimulating the importance of being critical and believing in their potential[18].

Inclusive policies addressing the rights of women with disabilities, especially in matters related to motherhood, are necessary. The decision of having children or not and of how they to lead their lives must be respected, treating them with dignity[16].

Limitations of the study

A limitation of the present study was the difficulty to find women who were wheelchair users, regardless of the cause, and who became pregnant, which explains the reduced number of participants. It is necessary to carry out new research to complement and collaborate with the subject in question.

Contributions to the area of nursing, health or public policies

Through the understanding of each life narrative unveiled, nursing and other health professionals can create a place of respect for the subjectivity of these women, preserving their feelings and accepting their choices, their potentialities and their limitations, which will reflect in the care actions provided by the multidisciplinary team.

FINAL CONSIDERATIONS

Women who are in wheelchairs have a great challenge to face when it comes to motherhood and mothering, especially given the social and institutional conditions established in the health and family settings. The desire to be a mother was the main starter in the transition of these women, and it generated insufficiencies in the transition. Some limitations identified influenced the transition process of these women.

Motherhood and mothering were not limited by the disability of women in wheelchairs. The main obstacles were prejudice, creation of stereotypes of incapacity and the lack of scientific knowledge of health professionals. The reproductive rights of women with disabilities must be respected and, for this, inclusive policies focused on women with disabilities should be adopted.

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