ABSTRACT
Objectives: to discuss care needs of wheelchair pregnant women in the light of Collière’s Theory of Caring. Methods: qualitative, descriptive, exploratory, with eight women, between August 2014 and March 2015, in Rio de Janeiro State, Brazil. The method of data collection was the life history. The theoretical reference used was Marie-Françoise Collière’s Theory of Caring. The thematic type analysis identified three categories: pregnancy planning; support and prejudice of family and health professionals; and caring for the wheelchair pregnant woman. Results: prejudice, fear, lack of support, lack of knowledge about the maintenance of pregnancy and childbirth interfered negatively in the process of gestation. Participants had urinary tract infection, miscarriages and preterm birth. Final Considerations: gestation in these women should predict possible intercurrences, which makes it imperative to train professionals in integral care to promote and protect health.

Descriptors: Nursing; Disabled Persons; Woman’s Health; Pregnancy; Prenatal.

RESUMO

Descritores: Enfermagem; Pessoas com Deficiência; Saúde da Mulher; Gravidez; Cuidado Pré-Natal.

RESUMEN

Descritores: Enfermería; Personas con Deficiencia; Salud de la Mujer; Embarazo; Cuidado Prenatal.
INTRODUCTION

Pregnancy and childbirth are important events for women due to social, physical and emotional changes. For the disabled, this reality is the same, plus the different circumstances they need to overcome, such as accessibility, sociocultural prejudice and communication problems with health professionals(1).

The World Health Organization(2) points out that 10% of the world population lives with some form of disability. This situation pervades all social classes, age groups, ethnicities, races and sex. The Demographic Census in Brazil estimated the existence of approximately 13,265,599 disabled people. Of this total, 8,285,981 are women(3).

Since 2008, our country is a signatory to the Convention on the Rights of Persons with Disabilities, which represents a watershed in the incorporation of human rights dimensions(3). Its Article 25 reinforces the right of these persons to achieve a high standard of health care without discrimination. However, international studies(1,4-5) and Brazilian studies(6-8) show that maternal health issues related to disability need to be deepened, especially when it comes to wheelchair pregnant women(9-11). This is due to the need for greater professional care and to have a greater chance of obstetric complications, high rates of abortion, preterm deliveries, cesareans and low birth weight infants.

Historically, government programs in our country have privileged the female population with actions focused on maternal and child health and a restricted view of their social role focused on their reproductive function. However, social and political changes have occurred in the last decades, such as the inclusion of women prisoners, lesbians, indigenous and quilombolas (a “quilombo” is a resident of a “quilombo” in Brazil, which is a Brazilian hinterland settlement founded by people of African origin including the Quilombolas, or Maroons) with disabilities and who have begun to be seen as subjects of law because they have needs that go beyond pregnancy, childbirth and birth(12).

Speeches and social practices that exclude these women are the product of a historical and cultural construction that contributes to the definition of limits and possibilities for social inclusion(9). It is a segment of the population that has inexpressive actions of health services geared to their needs, especially with regard to accessibility in the gestational period(13-14).

The needs of women with disabilities at the time of gestation are numerous, ranging from the architectural surpassing of the city and particularly of hospitals. As an example, there is the adequacy of permanent material and the physical plan of outpatient clinics for prenatal consultations, the attitude of professionals who care in a prejudiced way, with stereotypes, without regard for precepts of humanization, which could compromise maternal and fetal health(6-10).

Family and society believe that wheelchair pregnant women have no active sex life and question whether they would be able to get pregnant and conceive. It adds to this belief, the lack of knowledge about their abilities and limitations to raise their children. This situation reinforces the image of fragility due to their physical limitations, which leads them to discourage their potentialities, conditioning them to domestic activities and thus leaving them submissive and exposed to physical and sexual abuse(4,8).

Care regarding sexuality and reproduction need to be approached from the perspective of public assistance, education and human rights policies, to ensure a broader view of their needs and desires. It is essential to sensitize and empower health professionals so that they can break paradigms and incorporate sociocultural values. Attention to the wheelchair woman should not be limited to biological aspects. It is necessary to ensure an individualized and comprehensive care, recognizing it as an active subject of sexual and reproductive health(9-12).

Thus, this research focused on the health of the woman in the gestational period. The theoretical framework of Marie-Françoise Collière’s Theory of Caring was used, whose precept is to support the nurses in the provision of individualized care, considering that in order to care, it is necessary to distance oneself from what is known and to understand the bonds of meaning, and to consider their personal experiences and sociocultural values in order to capture the needs of the person who is cared for(13).

The use of these theoretical principles allows us to understand the meanings, not to dissociate the facts from the emotions and to learn to perceive the emotions and feelings of both caregivers and caregivers. The theoretical framework is based on six areas of care: encouragement, comfort, life maintenance, opinion, compensation, and appeasement(15).

Encouragement is centered on the awakening of fundamental abilities. It is the case of sensation, of perception, of representation, in which the variety of care creates expectations, desires, interest, affective relations, being the starting point of the construction of thought. Comfort is understood by the attitudes that encourage, allow to acquire security, favor the change for the better and the assimilation of the experience. Life maintenance is understood as the capacity acquired throughout life to meet the needs of everyday life. Opinion is understood from those who contribute to build and enhance the image of itself and thus to emerge and strengthen not only the feeling of identity, but also that of belonging to a group. Compensation is intended to replace what has not yet been purchased or only partly because of functional damage or deficiencies. Appeasement means resting, releasing tensions that appease and bring tranquility(15).

Considering the nursing-related gap in the subject, this research aims to discuss care needs of the wheelchair pregnant woman in the light of Collière’s Theory of Caring.

OBJECTIVES

To discuss care needs of wheelchair pregnant women in the light of Collière’s Theory of Caring.

METHODS

This is a qualitative, descriptive and exploratory research. For data collection, the Snowball Technique was used, considering the reduced number of women who were pregnant on wheelchairs in a single research setting. This technique consists in the indication of another interviewer, made by one already interviewed, thus enabling the meeting of the researcher with the participants(16). The inclusion criterion was to be a woman who nursed on a wheelchair, regardless of what caused the disability. No demarcation was established for parity, nor age of children.
The starting point was the contact with two deponents indicated by the Centro de Vida Independente (freely translated as Independent Life Center), an institution located in the city of Rio de Janeiro, led by people with disabilities and adopting a transformative perspective in the life of the disabled, encouraging and fostering independence. Telephone and e-mail contacts were performed, totaling eight (8) participants.

For data collection, the life history method was used, with an open interview and a single question: ‘Tell me about your life, and that has a relation to its gestation.’ The interviews took place in their respective homes, in the period between August 2014 and March 2015. They were recorded in MP3 with the authorization of each participant and later transcribed in full by the researcher. In order to guarantee the anonymity of the interviewees, identification codes were adopted, using the letter W, meaning “woman”, followed by an ordinal numeral in ascending order (W1...W8), according to the interviews.

Data treatment occurred on the ethical precepts of the thematic content analysis. With the transcribed narratives, an exhaustive reading was made for codification, with 21 thematic units being constructed. Six clusters were carried out, including the recoding phase and, later, the synthesis that originated three thematic categories: pregnancy planning; support and prejudice of family and health professionals; and caring for the wheelchair pregnant woman. Data analysis took place in the light of Collière’s Theory of Caring.

The study complied with the provisions of Resolution 466/12 of the Brazilian National Health Board (Conselho Nacional de Saúde) of the Ministry of Health, which establishes norms for research with human beings, being approved by the Research Ethics Committee of the Universidade Federal do Estado do Rio de Janeiro (UNIRIO) on July 22, 2014, under CAAE (Certificado de Apresentação para Aprovação Ética - Certificate of Presentation for Ethical Consideration) protocol number 33343414.0.0000.5285.

RESULTS

Of the eight participants, the age ranged from 33 to 66 years, with an average of 42.1 years. In relation to the marital situation, six were married (W1, W2, W3, W5, W7 and W8) and two were single (W4 and W6). As for color, six self-declared white (W1, W2, W3, W5, W6 and W7) and two, black (W4 and W8). As for educational level, three deponents had higher education (W1, W2 and W5), one had completed high school (W4), another had completed elementary school (W7) and three had not completed elementary education (W4 and W6). As for profession/occupation, three had assured labor rights: federal prosecutor (W1), advertising and television presenter (W2), social worker (W5), one informally worked as a candle seller (W7), three stayed at home (W3, W4 and W8) and one pensioner (W6).

In relation to the causes of motor deficiency, five had childhood polio (W1, W5, W6, W7, W8), two were victims of motor vehicle accident (W2) and PAF (W3) and one suffered neonatal asphyxia (W4). Regarding obstetric history, all of them experienced gestations on the wheelchair, one primiparous (W5) and seven multiparous (W1, W2, W3, W4, W6, W7, W8). Three reported a history of miscarriage (W1, W3 and W4) and four pregnancies were planned (W1, W2, W5 e W8). All of them underwent prenatal follow-up, four in the public network (W3, W6, W7, W8) and the others in the private network (W1, W2, W4 and W5). The results showed that four women had health problems in the last pregnancy: one had pneumonia requiring orotracheal intubation (W2); two had edemas in lower and upper limbs (W3 and W8); three had urinary tract infection (W3, W4 and W8); one had preterm birth (W2) and one presented pregnancy-specific hypertensive disease, with outcome for eclampsia (W8) and hospitalization in the Intensive Care Unit.

Pregnancy planning

With regard to the planning of pregnancies, there were ambiguous feelings that involved the desire and the fear of becoming mothers in the face of the difficulties faced by the women in planning their pregnancies:

The decision was made and we were going to have our son regardless of any opinion. (W1)

I’ve always been a little afraid of pregnancy. When I became a wheelchair user, I thought I was not going to be a mother. (W2)

I really wanted to be a mother, but I was afraid, I had not planned. (W3)

Four women were surprised by the news of the unplanned pregnancy. Of these, two said they did not feel prepared because it was the first pregnancy. The other two justified the early age of other children.

I did not want to be a mother, because everything was very fast, I thought I was very young, I wanted to enjoy life. (W8)

The first child, as it was not programmed, when I got pregnant, I had no desire to be a mother, because I lived with my parents too. (W6)

The third pregnancy was startling because I was not planning to […] my daughter turned two, and I was already pregnant! (W4)

I discovered that I was pregnant, and she (another daughter) was only five months old! I panicked! (W5)

Support and prejudice of family and health professionals

All the participants experienced the support of family members, such as grandparents, mothers, sisters, sister-in-law and friends and/or companions.

My grandmother helped a lot and his family did too. My parents got scared, thinking that I would not be able to care […] the pregnancy even made my parents come closer to me, that was very good, because I missed it. (W3)

When I spoke to my family, they supported me because I am very determined, despite my disability, I am very independent. (W5)

My mother and my sister, at the end of the pregnancy, already almost close to being born, about 8 months old, went to my house to help me. (W7)
The following reports indicate that the family fears to support women in their decision to conceive because they do not believe they will be able to produce perfect babies and take care of their children independently.

When I got pregnant, I became scared, my family said that I could not get pregnant, that I was taking risks, they were starting to frighten me. They [the ex-husband’s family] thought the child was going to be born with the problem I had, to come dragging my belly on the floor. (W6)

I did not tell anyone I was going to try it the first time. I warned that I was pregnant already, it was a surprise for everyone, everyone was very scared at first, because no one knew what it would be like. (W2)

The lack of support from health professionals was perceptible, generating fear and insecurity, making visible the fragility of women and distancing existing during prenatal care.

The first doctor was scared, she said that I had better not try to get pregnant due to my disability. (W4)

The first three consultations were with the nurse and what he did was to weigh us, to ask about the diseases, it seemed an interview, but they did not orient in anything. The doctors did not pay attention, if they had given it maybe [eclampsia and premature birth] would not have happened. (W5)

I was there full of fear, full of doubt, it seemed that no one noticed it. He [doctor] said that he had never performed a wheelchair user’s labor. (W3)

Caring for the wheelchair pregnant woman

One participant reported that she received adequate prenatal care, which, for her, meant the success of pregnancy:

I had prenatal care right, they gave me guidance of everything. I had all the attention from beginning to end. (W4)

Four women reported intercurrences that occurred during the last gestation, which led them to feel insecure about the success of gestation and care of professionals:

I had a urinary infection with eight months and stayed five days in the hospital to get the treatment right, it was difficult because nobody there from the hospital helped me a lot. (W3)

At 29 weeks’ gestation I had pneumonia and was hospitalized for 3 weeks in the ICU. It was very difficult because I was very afraid of losing my daughter. (W2)

The others (4) lived the pregnancy fully, according to the following statements:

I had an excellent pregnancy, I did not have a nausea. I had a full-term pregnancy without feeling anything at all. (W1)

I had a little nausea and that drowsiness that every woman feels. But then I felt like the most powerful woman in the world! I felt very pretty. I had an incredible pregnancy. (W7)

DISCUSSION

Among the eight interviewees, the majority acquired some type of motor deficiency in childhood; had a low level of schooling; were married; white color; and half (four) had paid work and private health insurance. Although there are important differences between living with a disability from birth and a lifetime disability, the reports have indicated that socioeconomic characteristics are similar to other studies with pregnant women with disabilities[1,4,9]. It is noteworthy that three women had a higher level of schooling and private health insurance, evidencing a greater cultural and economic purchasing power to face the problems arising from disability.

Regarding obstetric history, the majority, six, were multiparous and underwent cesarean section; three experienced miscarriage and half, four, did not plan the pregnancy. In addition, half of the interviewees (four) had at least one obstetric complication during the gestational period. Of these, three had at least one episode of urinary tract infection. Therefore, it was evidenced that the health difficulties of these women do not differ from the results of other studies[1,4,9].

The results showed that, for some women, maternity was an option and, at other times, not. The difficulty both in having support to conceive and in avoiding an unwanted pregnancy permeated the universe of these women. Although maternity is culturally naturalized, not always the right to start a family, to have access to information about reproduction and reproductive planning, and to the means of exercising it to have a safe, socially supported and pleasurable gestation, was guaranteed[2,16]. Although women have the right to exercise their sexuality, it is very common for some women to face prejudices in order to experience it. For example, to be outside conventional aesthetic standards, they have to deal with myths that they can generate disabled children and will not be able to care for them[6-7], a situation that justifies the importance of empowering professionals and demystifying aesthetic standards to guarantee the right to exercise of sexuality and reproduction of disabled women. This so that they do not find the barriers of the prejudice of the society and they think that they are incapable to gestate, to give birth and to take care of its children, besides not being good wives and/or mothers[6-7].

Thus, the participants’ perception of their own body and how to deal with it to exercise their sexuality and to plan their pregnancies safely refers to the need for the nurses’ encouragement, compensation and comfort care[16]. Such care will contribute to the awakening of women’s sensations and expectations, in order to feel empowered and to be safe in order to conceive, give birth and care for their child. Thus, it is expected that with the nurses acting in these three areas of care, women will have a close relationship with professionals and identify in their bodies the possibilities and limitations for them to be able to capture their needs and, therefore, to seek and recognize the importance of each care offered based on reciprocity and humanization of care[19].

For women who did not plan for pregnancy, the importance of vocational guidance to ensure a full sex life without the risk of an unwanted pregnancy. When the decision to manage is taken, multiprofessional health monitoring will be essential to ensure its comprehensiveness, since studies show that women with physical disabilities are at greater risk of chronic diseases and complications during pregnancy, with a higher probability
of health outcomes unfavorable. Therefore, it is necessary the training and effective participation of the health professionals, in order to understand the whole problem of the wheelchair woman, to meet their specific needs with quality and safety. Thus, the expression “becoming close” is essential for there to be this close relationship between professionals and these women.

In the presence of the desire for pregnancy or lack of planning, the support received from the family was preponderant. For the women who lived with the disability from the first years of life, the support of the family was built before the gestation and extended during the reproductive period. The experiences were positive, especially that of the companion. A Brazilian study carried out in Rio Grande do Norte State, corroborates the findings of this research, when it reveals that the presence of relatives and partners helps positively in the comprehensive care, especially in its self-care and care with the newborn.

However, the concern of the family regarding birth of a child without physical and neurological deficiency appears with evidence in the narratives of the participants, a connection that families wrongly make of the maternal deficiency, with the increase in the probability of the woman to generate children with malformation. This initial preoccupation of the family may be related to the lack of knowledge and clarification regarding the capacity of the woman in charge of generating and conceiving perfect children, as well as to live her sexuality and motherhood in a pleasurable way, disregarding aesthetic standards that correspond to the expectations, such as taking care of mother and wife roles.

In the perspective of care of the opinion, revisiting Collière’s Theory, for the auxiliary nurse, the woman to invest of authority over her body, it is necessary to encourage the valorization of the image has of itself, so that it can rescue its identity and feel inserted into a group. This is so that these women may be able to live their sexuality, generate, give birth and care for their children with their partner and family. The nurse, in care, needs to transcend the biological, appropriating the singular feminine universe of the woman in charge, in order to seek new technologies and theories of care that help in the recovery of her feminine identity, in order to feel safe for conscious choices and to be able to exercise their sexual and reproductive rights.

Health professionals sometimes attempt to “protect” women’s health by not realizing that the person with a disability needs to have an affective bond and maintain their sex life. This means that there is a need for professionals to respect and value these sexual and reproductive rights. Moreover, since there is a common sense that disabled women, especially wheelchairs, will be incapable of gestation, that they will not be good wives and/or mothers, it is a situation that highlights the importance of a trained professional and sensitized to identify the subjective issues of these women. They attend to the continuity of care and to the learning of the received orientations.

Therefore, in first contact, whether for a pre-conception visit or for the beginning of prenatal care, assessment of the six dimensions of Care of Collière represents a tool for the care offered for the nurse, based on comprehensive health. This strategy would represent for nurses and other professionals to think about these women in their different dimensions of singularity and plurality considering that to take care of them it is necessary to look beyond physical alterations, care for the needs of information, reception and respectful care, in order to provide them with security and support in order to conceive and give birth in a safe and full.

Therefore, health professionals and wheelchair women need to strengthen the bonds of trust so that they can understand the possibilities and limitations of this relationship in order to be able to put into practice care of encouragement, comfort, life maintenance, opinion, compensation, and appeasement. These are intended to strengthen the physical and emotional security necessary to maintain existing capacities and to regain those that can be recovered in women, such as self-image, self-esteem, self-care and caring for others. Certainly, these dimensions will favor the professionals so that they can take care, encourage the potentialities and identify the fragilities of each woman, so that they can exercise with autonomy the sexuality, gestation, childbirth and maternity.

In this perspective, it is up to the nurses, when contacting a pregnant woman in the health unit or in the community, to understand the multiple meanings of pregnancy for this woman. Thus, an open listening, without trial and prejudice, will allow them to know the experience of each one of them, considering the socioeconomic and family contexts involved in care, contributing to a childbirth and birth of a healthy child. In this way, it is also necessary to welcome the woman’s choice companion, offering no obstacles to her participation, encouraging participation in prenatal care and ensuring her presence in labor, delivery and postpartum.

Gestation and childbirth are social events that integrate the reproductive experience of men and women. It involves expectations and fears that should be valued in providing care, as health professionals are supportive of this experience, and play an important role in this, since they have the unique opportunity to share knowledge with the woman, recognizing the moments in which their interventions are necessary to ensure quality assurance.

The results indicate that the majority of health professionals perceived gestation as a predominantly biological event, leaving in the background the real needs of pregnant women with poor care, evidencing the lack of knowledge and unprepared care of their gestation, a situation that represents a great challenge. Changing professional attitudes and practices requires that they are increasingly able to meet the specific needs, constraints and potential of this clientele. This should be based on guidelines that promote health, make it possible to resolve doubts during prenatal care and always encourage the autonomy of women, aiming at a better quality of care, thus providing not only the prevention of gestational problems, but a quality life during and after pregnancy.

It is noteworthy that, in this study, the insecurity of the interviewees was notorious in the face of the posture and the lack of knowledge of some health professionals about the gestating and giving birth of wheelchair women. Their actions were restricted to the treatment of signs and symptoms, being limited to the clinical practice circumscribed to the complaint-conduct. This attitude, based on the biomedical model, annihilates the physical, psycho-affective and social capacities, enhancing the feelings of fragility and incapacity of these women. In this sense, Collière points out that the professional, to take care of comprehensive needs to perceive emotions and to understand the lived facts of who is cared for.

Therefore, it is incumbent on nurses to establish an effective link to perceive the needs and capacities of each of the women in dealing...
with the process of gestating and giving birth, from their experiences, and empowering them. Therefore, compensatory care aimed at compensating for sensory and motor reflexes\(^{1(10)}\) can be applied to reduce the possibility of current and future complications in the face of the identified needs, thus ensuring an uninterrupted gestation.

Motherhood presupposes not only the ability to give birth to children, but the possibility of offering dedication to the other, developing patience, unfolding their time, seeing that the other is different, learning to wait, generating ideas, tolerating contrariety, and learning daily to love\(^{2(20)}\). This moment represents a complete emotional transformation, and these women need to feel capable of coping with the changing needs of everyday life; one of them to become a mother, which brings us to life-support care\(^{5(13)}\).

The ability to gestate is considered by any woman an extremely significant fact, both from the physical and physiological points of view as well as the emotional and social. Normal gestation inspires preventive care to ensure good maternal and child health, whereas in the nursing woman, such care should take into account the disability in gestation\(^{1(16)14}\). Specific guidelines for the pregnant woman to become pregnant and to gestate should predict the health problems that can affect this group, such as urinary tract infection, preterm birth, lower limb edema, thrombosis and scarring, all of which are potentiated by difficulty in locomotion but can be minimized also by the help of relatives attentive to the care of this pregnant woman.

It is important to note that in the gynecological and prenatal consultations, wheelchair women receive a specific care and information necessary so that they and their children are not exposed to the risks that their physical condition imposes\(^{13(14)}\).

Therefore, it is necessary that the actions of health professionals, especially nurses working in care of these women of reproductive age, respect their sexual and reproductive rights, rethinking ways of caring and being fully cared for, considering the social, economic and cultural aspects. However, it is imperative to train and sensitize professionals and managers in order to promote and protect the health of this population, enabling a care without prejudices and welcoming.

**Study Limitations**

The study's limitation is the number of participants, given the complexity and difficult access to the women in the study. Several attempts were made in blogs and rehabilitation centers to try to contact potential participants, but without success.

**Contribution to Nursing Health**

In this study, it was found that women in wheelchairs face difficulties in conception and pregnancy. Based on this panorama and on the six dimensions of care in Collière's Theory, as well as on sexual and reproductive rights, it was possible to describe guidelines of conduct, so that nursing professionals can rethink the practice of obstetric care, fully serving and respecting the differences that are imposed on this segment.

**FINAL CONSIDERATIONS**

The results of this study pointed out that the desire to be a mother was not always present in the interviewees' lives. Prejudice, fear, lack of support from family members, lack of knowledge about the possibility of pregnancy maintenance and childbirth success were feelings that permeated the women's reports and eventually interfered with this process.

It was notorious that common sense held the stereotype that the disabled woman is asexual and incapable of carrying on the gestation or even of giving birth to a healthy child. This thought, still present in society, shapes the ways in which a large part of the population is related to the different body, in addition to interfering in the behavior of health professionals.

Therefore, this theme needs to be discussed and deepened in an interdisciplinary and multiprofessional perspective, so that we can provide a care that should go beyond physical examination, anamnesis and medication prescription, welcoming this woman and her family in an individualized way, for through an open and unprejudiced listening.

This study, carried out in the light of Collière's Nursing Theory, represents a tool that will subsidize the professional practice of nurses, enabling the implementation of a comprehensive care based on respect and knowledge, which will certainly positively influence maternal and perinatal morbidity and mortality.

Despite the current visibility in relation to the problem of the disabled, in the media and also by government agencies, the gestation of wheelchair women needs to broaden spaces for discussion in universities and research groups in the area of Health, in order to expand the possibilities of accessibility and social inclusion.

Finally, the conclusions point to the need for new studies to complement the knowledge already acquired, in order to subsidize the public policies focused on the pregnancy-puerperal cycle of the woman.

**FUNDING / ACKNOWLEDGMENT**

A special thanks to Professor Doctor Fernando Rocha Porto, co-ordinator of the Master's Degree in Nursing at the Escola de Enfermagem Alfredo Pinto for the promotion granted through the edict E_22/2016-FAPERJ, and for the expenses with the article's proofreading and translation into English and Spanish.

**REFERENCES**

