

## Gestation and motherhood narratives of women with physical disabilities

*Histórias de gestação e maternidade de mulheres com deficiência física*

*Historias de embarazo y maternidad de mujeres con discapacidad física*

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### ABSTRACT

**Objective:** to analyze the life trajectories of women with physical disabilities who experienced gestation and motherhood.

**Method:** qualitative study with a historical-social approach, conducted by means of the life oral history technique. Fifteen women with physical disabilities were interviewed. Thematic content analysis was carried out with Atlas.ti® software, in light of the conceptual framework of vulnerability. **Results:** each woman's disability allows understanding of the obstacles faced regarding accessibility, image and identity, and vulnerability throughout the gestational and puerperal period. This emphasizes the significance of health care, valuing the right to experience gestation and motherhood with safety and inclusion. **Conclusion:** vulnerability was portrayed at different moments in the lives of women with physical disabilities, being similar among them yet distinctly unique for each one. These women's life trajectories reflect their way of confronting the barriers imposed by society and physical condition.

**Descriptors:** Nursing; Women's Health; Parenting; Health Vulnerability; Persons with Disabilities.

### RESUMO

**Objetivo:** analisar a história de vida de mulheres com deficiência física que vivenciaram a gestação e a maternidade. **Método:** estudo qualitativo com abordagem histórico-social, realizado pela técnica de história oral de vida. Foram entrevistadas 15 mulheres com deficiência física. Realizada a análise de conteúdo temático com auxílio do software Atlas.ti®, à luz do marco conceitual da vulnerabilidade. **Resultados:** a deficiência de cada mulher, possibilita compreender os obstáculos enfrentados pela acessibilidade, pela imagem e identidade, pela vulnerabilidade no período gravídico-puerperal. Isto reforça a importância da atenção à saúde, valorizando o direito de exercer a gestação e maternidade com segurança e inclusão. **Conclusão:** a vulnerabilidade foi retratada em diferentes momentos da vida das mulheres com deficiência física, sendo semelhantes entre elas e ao mesmo tempo muito particulares para cada uma. A história de vida dessas mulheres reflete seu modo de enfrentar os obstáculos impostos pela sociedade e pela condição física.

**Descriptores:** Enfermagem; Saúde da Mulher; Maternidade; Vulnerabilidade em Saúde; Pessoa com Deficiência.

### RESUMEN

**Objetivo:** este estudio analizó las historias de vida de mujeres con discapacidad física que experimentaron el embarazo y la maternidad. **Método:** se realizó un estudio cualitativo con enfoque histórico-social, utilizando la técnica de historia oral. Se entrevistó a quince mujeres con discapacidad física. El análisis temático de contenido se llevó a cabo con el software Atlas.ti®, desde la perspectiva del marco conceptual de la vulnerabilidad. **Resultados:** la discapacidad de cada mujer permite comprender los obstáculos que enfrentan en lo que respecta a la accesibilidad, imagen e identidad, y vulnerabilidad durante el embarazo y el posparto. Esto refuerza la importancia de la atención para la salud, valorando el derecho a vivir el embarazo y la maternidad de forma segura e inclusiva. **Conclusión:** la vulnerabilidad se manifestó en diferentes momentos de la vida de las mujeres con discapacidad física, fue similar entre ellas y, a su vez, muy particular para cada una. Las historias de vida de estas mujeres reflejan su manera de afrontar los obstáculos que les imponen la sociedad y su condición física.

**Descriptores:** Enfermería; Salud de la Mujer; Responsabilidad Parental; Vulnerabilidad en Salud; Personas con Discapacidad.

## INTRODUCTION

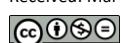
Historically, disability has been viewed by society as a disadvantageous condition. It refers to a state of imbalance when comparing groups of people with disabilities to those without. Therefore, it can be affirmed that the interactions and power relations present among individuals influence how a person with a disability constitutes themselves as a person in the world; however, their clinical condition also requires follow-up<sup>1,2</sup>.

Based on the International Classification of Functioning, Disability, and Health, the biopsychosocial model is considered the best framework for classifying disability. This model synthesizes truths found in both medical and social models. Disability is regarded as a characteristic of the individual caused directly by a disease (medical model) requiring medical treatment, but it is also perceived as a societal problem due to lack of inclusion and social policies (social model). This integrated model addresses various perspectives of health: biological, individual, and social<sup>3</sup>.

This study was financed in part by the Conselho Nacional de Desenvolvimento Científico e Tecnológico – Brazil (CNPq).

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Editor in Chief: Cristiane Helena Gallasch; Scientific Editor: Juliana Amaral Prata



Another concept discussed by the Pan American Health Organization defines people with disabilities as a risk group, having higher chances of infection for various reasons. Among them are difficulties accessing public health, implementation of basic hygiene measures, and difficulty maintaining social isolation due to the need for a support network<sup>4</sup>. For women, physical disability frequently signifies exclusion from femininity, active sexuality, and denial of motherhood opportunities<sup>5-7</sup>. Furthermore, many are characterized by functional disabilities of extremities that limit their mobility. As such, many feel shame, low self-esteem, and insecurity<sup>8</sup>.

Motherhood is experienced by women with physical disabilities amid limited accessible services and inadequate reproductive support. Health service access is constrained by physically inaccessible facilities, insensitivity among health professionals, and limited knowledge about disability<sup>5,6</sup>.

A study conducted in Australia with women with motor or sensory disabilities revealed that during the gestational and puerperal process, they perceived a discriminatory environment and lack of confidence in their ability to fulfill the role of mother. Additionally, they reported verbal and emotional violations, reflecting professionals' insecurity in handling their particularities<sup>7</sup>.

People with disabilities face gender difficulties, higher poverty or inequality rates, stigma, and discrimination. These external factors shape experiences of shame, asexuality or hypersexualization, and lack of confidence. Women with disabilities have a higher chance of rape, molestation, and violations of reproductive human rights. This characterizes this population as a vulnerable group<sup>6-10</sup>.

In Brazil, the health system aimed at people with disabilities is still generally characterized by fragmentation and discontinuity of care, arising from weaknesses in coordination between managers and the frontline professional teams<sup>11</sup>. Additionally, health professionals have difficulties seeing the needs of people with disabilities beyond their physical limitations<sup>11,12</sup>. At the end of the 1980s, with the Brazilian Federal Health Constitution, people with disabilities were mentioned and contemplated in the three spheres of government: care and public health assistance, protection, and guarantee of people with disabilities<sup>13</sup>. Subsequently, other legislations were enacted to adapt the inclusion of people with disabilities in society, such as Law No. 7,853 of 1989, which guarantees access for people with disabilities to health services at all levels of complexity; Law No. 10,098, which establishes general norms and basic criteria for promoting accessibility for people with disabilities or reduced mobility; and Law No. 10,048, which establishes priority groups for service, such as older adults, pregnant women, and people with disabilities, including guaranteeing specific seats on public transport for these groups<sup>14,15</sup>.

It is worth mentioning that the Brazilian Health Policy for People with Disabilities seeks to reverse the fragmentation and discontinuity of care, affirming that assistance to these people is based on the assumption that besides the need for attention to the specific health of their own condition<sup>13</sup>, these individuals may also be affected by common diseases and conditions, requiring other types of health services beyond those strictly linked to their disability, such as women experiencing the gestational and puerperal cycle<sup>14</sup>.

Health policies for the inclusion and quality of life of women with physical disabilities who have gone through the gestational and puerperal period, progress in legislation to achieve equal opportunities and good social coexistence are fundamental. However, it is understood that the support network plays an essential role in facing this process. Its role is to support and welcome women with physical disabilities, so they feel empowered to overcome their limits and vulnerabilities due to their physical limitation and conditions related to gestation and motherhood<sup>5,16</sup>. Vulnerability associated with lack of information, support, and disbelief about the ability to gestate, give birth, and care for a child shows the fragility of women with disabilities. For some, experiencing motherhood enables the recapturing of feminine identity lost before society. Additionally, social difficulties include access to health services, quality and specialization of care, integrated and referenced networks of care. Thus, the conceptual framework of vulnerability was chosen to reflect on this theme<sup>17</sup>.

Starting from the assumption that women with physical disabilities face difficulties related to social recognition of their figure as women and mothers, lack of accessibility and information, it can be affirmed that they have various social vulnerabilities.

Therefore, the objective was to analyze the life history of women with physical disabilities who experienced gestation and motherhood.

## METHOD

Historical research with a qualitative approach, which understands human groups in their temporal space discussing various social aspects<sup>18,19</sup>. To ensure accuracy and rigor, the Consolidated Criteria for Reporting Qualitative Research (COREQ) instrument was followed in all stages of reporting the study. The study context for initial capture of oral sources was a State Public Maternity Hospital in southern Brazil, a referral center for high-risk prenatal care.

Eligibility criteria for participant selection were defined as women with any type of physical disability aged 18 or older, who had been pregnant at least once and had had the physical disability for at least one year before becoming pregnant. Women with any cognitive or sensory disability that hindered communication between the researcher and the participant were excluded.

Initially, 25 participants were selected, but one was still pregnant and did not meet the inclusion criteria within the data collection period. Of the remaining 24 participants, two did not have updated contact information, four did not respond, and three withdrew<sup>20</sup>.

Data collection was carried out by the principal investigator from July to December 2020, using an interview guide with questions about childhood, adolescence, pregnancy, as well as perceptions of self, access to health care, family role, and women's self-assessed limitations and potentialities related to physical disability. The guide aimed to establish a timeline for the sequence of reported events. At the time, the principal investigator worked as a nurse at the study institution, facilitating access to the outpatient clinic where pregnant women received prenatal care.

Recruitment initially occurred through consultation of outpatient service records provided by the institution, seeking women who met study inclusion criteria after ethical committee authorization for consultation of these data. Subsequently, telephone contacts were initiated to invite participants to an introduction to the researcher and explanation of study purpose, stages, and interest in research participation. Snowball sampling technique was then employed<sup>21</sup>. Data collection started only after this stage.

Interviews were conducted virtually due to Covid-19 social restrictions and scheduled according to interviewees' availability. Each interview lasted a mean of 40 to 100 minutes and was recorded, transcribed, and underwent *copidesque*, transforming colloquial language into formal language.

Transcribed interviews were thoroughly reviewed for data analysis using thematic qualitative content analysis<sup>22</sup>. This step was performed by the principal author and reviewed by the other authors. Atlas.ti 9® software was used for data organization and systematization. After transcription, the interviews were returned to participants for information validation and authorization to use content in the research.

Transcriptions were uploaded to Atlas.ti® as primary documents, where sequential coding was created, followed by associations, divisions, or code changes. Codes were assigned to speech, paragraphs, or words according to meaning and theme. Each code was described, facilitating grouping. Memos were created in Atlas.ti® to record researchers' reflections aiding data discussion processes.

The research protocol was approved by the Human Research Ethics Committee of the university via *Plataforma Brasil* in May 2020. All participants received a digitized Informed Consent Form and declared verbal and/or written consent before data collection. Participants are identified in quotations by E (interview) and sequential interview number to ensure anonymity.

## RESULTS

A total of fifteen women participated in the study, identified with relevant sociodemographic information for developing and understanding their life stories in the study, which facilitates understanding of the final study results together with the objectives. The data are presented in Figure 1.

ID	Age	Schooling	Municipality of residence	Type of physical disability	Classification	LB	Delivery type (n)	MS	Ocup
E 1	39	Complete High School	Florianópolis	Sequela of cerebral palsy (prematurity)	Congenital	3	cesarean (3)	Married	A
E 2	30	Incomplete Elementary School	Paulo Lopes	Diastrophic dysplasia (dwarfism)	Congenital	1	C-section (1)	Single	L
E 3	52	Complete High School	Florianópolis	Sequela of infantile paralysis	Acquired	1	C-section (1)	Single	A
E 4	48	Complete High School	Florianópolis	Spinal cord injury – tetraplegia (car accident)	Acquired	2	Twin cesarean (1)	Married	A
E 5	50	Complete High School	Florianópolis	Sequela of infantile paralysis	Acquired	1	C-section (1)	Married	L
E 6	29	Complete High School	Florianópolis	Sequela of cerebral palsy (prematurity)	Congenital	2	C-Sections (2)	Single	T <sup>+,+1</sup>
E 7	25	Incomplete High School	Florianópolis	Spinal cord injury – paraplegia (car accident)	Acquired	1	C-section (1)	Married	L
E 8	50	Complete High School	Curitiba	Sequela of infantile paralysis	Acquired	3	C-Sections (2)	Divorced	A <sup>+,II</sup>
E 9	50	Complete Elementary School	Curitiba	Sequela of infantile paralysis	Acquired	2	C-Sections (2)	Married	A
E 10	61	Incomplete Elementary School	Florianópolis	Sequela of infantile paralysis	Acquired	2	C-Sections (2)	Widowed	A
E 11	30	Complete High School	Gov. Celso Ramos	Friedreich's ataxia	Acquired	1	Vaginal delivery (1)	Married	L
E 12	42	Graduate studies	Florianópolis	Spinal cord injury – paraplegia (car accident)	Acquired	2	C-Sections (2)	Married	L
E 13	24	Undergraduate	São José	Spinal cord injury – paraplegia (car accident)	Acquired	1	C-section (1)	Married	S
E 14	38	Undergraduate	Juazeiro Norte	Diastrophic dysplasia (dwarfism)	Congenital	1	C-section (1)	Married	T <sup>+,III</sup>
E 15	43	Incomplete Elementary School	Florianópolis	Sequela of infantile paralysis	Acquired	1	C-section (1)	Single	L

**Notes:** ID – Identification; LB – Live births; MS – Marital Status; Ocup – Occupation; A – Retired; L – Housewife; T – Working; E- Student; \*Receptionist; <sup>+,+1</sup>Intern; <sup>+,II</sup>Athlete; <sup>+,III</sup>Banker

**Figure 1:** Sociodemographic and personal profile of study participants. Florianópolis, SC, Brazil, 2020.

The results of this study were divided into two thematic categories to facilitate in-depth understanding of each aspect for building the proposed scientific knowledge: “*Nobody will stay with me because I have a disability*”: identity and self-image of women defining their attitudes toward society, and “*I think they believe that wheelchair users, disabled people, cannot be mothers*”: ignorance of health professionals and lack of institutional accessibility as limiting factors.

#### **“Nobody will stay with me because I have a disability”: identity and self-image of women defining their attitudes toward society**

This category addresses aspects of the image of women with physical disabilities, how they see themselves and how society views them. Many did not accept themselves due to their differences, limitations and fear of how others might perceive them.



*Adolescence was difficult because I did not accept myself. I thought nobody would stay with me because I have a disability. (E1)*

*At 18 years old, I started to have a life of going out, flirting [...] I had prejudice against myself, shame. I thought nobody would want to date me because I use a wheelchair, because I am disabled. (E8)*

*I thought I would never have children, never date, never marry. Since then, I always have had depression [...]. I did not accept myself, cried, and panicked. (E11)*

Some women say insecurity and lack of acceptance have lasted for years; because of this, many thought they would not be mothers or that their partners would not accept them. The statements highlight how women feel different from other women and their difficulty in accepting themselves, explaining their disability, and even believing people could be interested in them.

*He was very patient with me about me being a virgin before we dated; he was too. There is the whole neurogenic bladder and intestine issue, which functions when it's not supposed to. [...] It has happened several times that I have evacuated during sex, which is normal. People who have sensation can stop and hold it, but in my situation I cannot. I have gotten to know myself, discovered myself, and I'm fine. (E13)*

There is a mixture of feelings in the women's statements corresponding to self-acceptance, feelings of incapacity, lack of knowledge and (re)discovery of sexuality after acquiring a physical disability.

#### **"I think they believe that wheelchair users, disabled people, cannot be mothers": ignorance of health professionals and lack of institutional accessibility as limiting factors**

This category addresses the discovery of motherhood for women with disabilities, as well as their pregnancy, birth and puerperium. The statements show a new universe, sometimes "uncommon" to the eyes of society, lack of accessibility in health institutions and absence of health professionals trained to deal with mothers with physical disabilities.

*This was a more complicated pregnancy. I was consulting another doctor. I ended up having a high-risk pregnancy because my placenta detached. I had to stop college, had to stay on bed rest, and it was much more tiring. I could not do anything alone. I was much heavier, much more tired and I needed help with everything. At eight months, I could no longer bathe alone, transfer myself, or get into bed by myself. I was very dependent (E12).*

*I looked for the best gynecologist in my city. She followed me every fifteen days and during the end of pregnancy, weekly. She recommended a diet so I would not gain weight nor would the baby. Because I have dwarfism, my torso is smaller and since the baby was normal size, my belly was going to grow a lot, so the bigger he got, the harder it would be for me. I was the first pregnant woman with dwarfism that she attended. (E14)*

Pregnancy for most women with disabilities was classified as high-risk and they were followed by specialist doctors - gynecologists and obstetricians. However, some say pregnancy was high-risk not necessarily because of the disability, but due to other factors like recurrent urinary infection, high blood pressure or twin pregnancy.

*Everyone was surprised and happy because, at the time, no one in a wheelchair had children. I don't think I knew anyone in a wheelchair, let alone twins. Nowadays it is common; I have met several people who had children in wheelchairs, but back then no one did, so everyone was surprised. (E4)*

*When I found out I was pregnant, it was terrible (laughs), because I had been dating for one month and my father was in jail. My mother went crazy, wanted me to abort because she would not be able to take care of me, and it would all fall on her. When I was about to take the abortive pill, my father got out of jail and said I would not take it, that I would only have an abortion with a doctor's authorization. So I did not abort. (E6)*

The discovery of pregnancy was a surprise to women, their families, and society in general. Many people doubted the capacity of women with physical disabilities to gestate, give birth, and care for children, including the women themselves. Abortion was mentioned in one statement, with discourse that the responsibility would fall on the family, since the mother was disabled. However, abortion was not performed as there was no medical indication or guidance.

*After I found out I was pregnant, I attended checkups. It was possible to know the baby was fine then. When he was born, they did tests and the doctor said he was perfectly normal. (E9)*

*Cesarean was my only option because I could not risk it. It would have been a risk for me and my baby. So, there was no other doctor here [...] with experience in pregnancies of people with disabilities. I ended up choosing and accepting it. The doctor gave me confidence due to his track record and all the recommendations I received; I accepted what he said. (E12)*

Cesarean prevailed as the birth method, due to the individuality and physical limitation of each woman, as it was considered the safest option according to medical guidance. It is noteworthy that tubal ligation was performed on eight women, making it impossible for them to become pregnant again due to gestational risk.

*The room was whichever was available. But there was also the matter of having a private room for me for catheterization, and so on. They did that too; they had never done it before. It was my request, and they created a new one at the Hospital. (E13)*

*She was losing weight. The doctor scheduled delivery for a week later so she would not be born at 34 weeks and taken to the incubator, and also to allow lung maturation. (E14)*

*I had gestational diabetes, high blood pressure... He was born at 7 months; they had to deliver him at 32 weeks. I stayed in the hospital from 5 months until 7 months pregnant. He was born weighing 1,230 kg and 38 centimeters long. (E15)*

The puerperium is marked by phases, beginning in the maternity ward during the postpartum period where health professionals' guidance is fundamental in seeking autonomy and self-confidence, extending to daily life at home. Breastfeeding was, according to the testimonies, a challenge; besides the physical difficulty, for some women, the lack or insufficiency of a support network further impaired the process.

*I did it like this; I would pick them up, put them in the crib, and prepare their bath first. I bathed them on top of a bed. Everything done very carefully. (E1)*

*I could change diapers, but I was afraid, because I did not have much strength in my arms, so I could drop the baby. (E9)*

*At first, I slept with her in the crib because I couldn't get up to calm her down, so the baby's father wouldn't keep waking up. I slept in the crib because I fit there. (E14)*

According to the descriptions from women with physical disabilities, they developed their own strategies to care for their children. Due to their limitations, they sought to carry out basic caregiving tasks, such as breastfeeding and bathing, in a way that was safer and more comfortable for mother and child.

*The maternity ward was badly arranged. There was a shower stall and a bathroom but no wheelchair fit in the shower stall for me to take a bath. I bathed sitting on the floor on those hard plastic sheets, like a tarp. Later, they saw that my cesarean had opened; there was a huge hole, and liquid was leaking from my belly. When the nurse went to check my cesarean, my belly was almost rotten [...] Then they removed the shower stall from the bathroom, and after all that, they found a wheelchair for me. They said I fought too much, but I just wanted my rights. The right to come and go. Just because I'm a wheelchair user doesn't mean I had no place. I felt like an alien at the maternity ward. It was a very painful moment in my life because I struggled so much, my God, how I suffered. (E15)*

Women with physical disabilities were often judged and underestimated about the possibility of undergoing a pregnancy, being a mother, and breastfeeding their children. This caused strangeness in the eyes of society and health professionals. It is important to highlight that many of these thoughts came from close people or health professionals.

## DISCUSSION

Vulnerability and being vulnerable, within the nursing field, are related to the fragility of people across groups, communities, regions, and to illnesses or damage caused by natural disasters. This condition may be linked to life cycles and preexisting social situations, varying according to the individual's perception of the health-disease process and their capacity for decision-making power<sup>23</sup>.

People with disabilities are also part of the group considered vulnerable. The history of disability is marked by isolation, incapacity, institutionalization, inferiority, and social exclusion. Although Brazil has formulated social inclusion policies and programs, their practical implementation remains inefficient, and society does not welcome and include people with disabilities equally. The vulnerability of people with disabilities occurs within the socioeconomic context in which they live, which may result in vulnerability in various ways, due to unfair inclusion in society<sup>24</sup>.

In this study, some social barriers were identified that hinder and result from the vulnerability of people with disabilities, particularly women. It is understood that low schooling attainment resulting from school abandonment caused by lack of accessibility, both within schools and public transportation, may lead to deficits in knowledge about access to health care and their rights as citizens<sup>22</sup>. Furthermore, vulnerability is also portrayed, making women more fragile and susceptible to mistreatment and humiliation in certain relationships.

Considering definitions and the general context of vulnerability, its influence on the female gender and on people with disabilities, it is understood that a dual vulnerability exists for women with disabilities. The situations experienced by women with disabilities are invisible to health services due to difficulty in being approached by professionals and due to the lack of recognition of female identity<sup>25</sup>.

This dual vulnerability has led women with disabilities to experience family overprotection or rejection, whether due to difficulty accessing health and rehabilitation services or due to lack of material resources that foster their autonomy. Lack of autonomy was characterized by insufficient encouragement and investment in their schooling and professional training, as well as environments that disqualify women and people with disabilities.

In Brazil, health institutions providing care to women with physical disabilities during gestation and the puerperium confirmed the aforementioned, as they were generally unsatisfactory and inaccessible to attend to the different particularities of each woman. This is also due to being perceived with strangeness when experiencing pregnancy and due to the lack of recognition as women and mothers because of their physical appearance and idealized beauty.

A study conducted in Cambodia identified that women with physical disabilities did not consider themselves beautiful because of negative social norms specific to gender and disability, and that men did not see them as attractive and/or desirable, nor capable of reproductive health and motherhood<sup>26</sup>. For women, the aesthetic ideal is often constructed through advertising and the overexposure of a beautiful and fertile body. Such stereotyped thoughts are present in various daily spaces, including family settings, and exert different perspectives on female and male sexuality<sup>27</sup>.

Vulnerability associated with lack of information, support, and disbelief in the capacity to relate, be attractive, and experience motherhood results in the devaluation of the female identity of women with physical disabilities. They also have greater chances of being sexually abused, offended, and assaulted<sup>8,10,26</sup>. Some studies indicate that investing in sexual education and explicitly stating the sexual and reproductive rights of women with physical disabilities would benefit this social group and the health services, which would be prepared and demystified regarding this reality<sup>26,28-30</sup>.

Moreover, many women with physical disabilities have low socioeconomic status, dependent on public services for health access<sup>1,2,6,16</sup>. The majority of women in this study reported using public health services, whether for rehabilitation, primary health care, or maternity. Those who chose or could use private health services generally had a higher level of schooling.

Vulnerability is also tied to different social groups with varied conditions and is discussed in terms of minorities, being seen as a socially less dominant group, which strongly influences how they interact with health services and vice versa<sup>31</sup>.

In Brazil, despite the Care Network for People with Disabilities being established as public policy since 2012, difficulties persist in the integration of teams working at various points of care, revealing that the policy still lacks attention and investment, both structurally, regarding better technologies for adequate service to this population, and in training health professionals to provide capacitation and knowledge about these limitations<sup>11,12</sup>.

Additionally, the social belief that women with disabilities are asexual or sexually incompetent beings, incapable of caring for themselves or others, confirms the notion that they cannot be mothers<sup>2,10,28</sup>. Conversely, by marrying and having children, they fulfill a sociocultural norm as wives and mothers<sup>5,26</sup>.

This study addressed several aspects of motherhood practiced by women with physical disabilities, something visibly "strange" to society and even health professionals, yet it must be normalized and respected. The perception that women with disabilities do not have an active sexual life often reflects limited access to sexual and reproductive health services<sup>32-34</sup>. Legally, the right to access health services with the same quality and ease is granted to people with disabilities; however, environmental barriers, negative social attitudes, and services result in marginalization and social exclusion<sup>16,29,32</sup>.

Access to services for people with physical disabilities is hindered by inaccessible facilities, health professionals with limited knowledge on disability, and lack of adaptation according to each individual's health needs<sup>29,35-37</sup>. These characteristics were identified in the study results, further complicating gestation and delivery processes, causing insecurity, lack of autonomy, and embarrassment in health environments.

Gestation is a process provoking various physiological and psychological changes in women that requires a support network and must be accompanied by a health professional. For women with physical disabilities, gestation requires somewhat more attention, even if they have adapted well to the demands of motherhood and gave birth to healthy babies. However, there are high rates of miscarriage, cesarean sections, and low contraceptive use. Increased gestational risk and adverse pregnancy outcomes are also observed, mainly low birth weight usually due to premature delivery or the development of comorbidities such as preeclampsia or increased thrombosis risk, due to limited

mobility<sup>6,9</sup>. Hence, it is essential that health professionals be qualified to handle various types of clinical situations with technical expertise and free from stigma and discrimination.

Supporting this finding, a study conducted in Vietnam regarding health service access for women with physical disabilities concluded that specialized information on pregnancy and delivery for this group was limited. Additionally, women reported being influenced by health team attitudes due to lack of experience with this clinical condition. They also reported that certain protocols were confusing and health institution installations were inadequate for people with disabilities<sup>38</sup>.

The conduct of health professionals from prenatal to maternity care directly affects patients' well-being and safety, whether delivered by doctors, nurses, midwives, or other professionals<sup>39</sup>. Lack of preparation and experience forms a widespread barrier to quality care, but is reported by health professionals as precarious at all schooling levels, whether undergraduate, residency, or postgraduate. Obstetric doctors and nurses affirm they often assisted women with physical disabilities upon request from other colleagues without any specific technical guidance. Nevertheless, they report these experiences as highly gratifying and enriching, emphasizing the importance of listening to each woman's desires and limitations, empowering her as protagonist of her own life<sup>33,40,37,41</sup>.

Fear of labor and delivery also persisted, higher when women lacked necessary information, leaving them more insecure about this moment. Most women with physical disabilities were aware that cesarean section would be their delivery option but did not feel part of planning or decision-making, accepting only what was imposed due to fear of gestational risk. This was identified in the women's testimonies, who reported obstetricians recommended cesarean delivery and performed tubal ligation to prevent further pregnancies. Additionally, they criticized the anesthesia types, lack of dialogue, and communication, where many "lost consciousness" and missed seeing their children born<sup>8,34</sup>.

Postpartum experiences for women with physical disabilities were primarily characterized by difficulty accessing health institutions and by challenges in breastfeeding. The presence of a support network was also important during this period, both within health institutions and at home. Early baby care was often provided by a third party due to insecurity, clinical condition after delivery, or significant interventions on the newborn<sup>38,39</sup>. These experiences align with women's testimonies, who also highlighted that due to puerperal complications or newborn health status, they stayed long periods in maternity wards, enduring greater suffering and sacrifice due to lack of accessibility and inclusion<sup>40,41</sup>.

The vulnerability of these women is evident from their life stories, experiences of family overprotection or rejection, and lack of access to health services. Furthermore, lack of investment and access to schooling and frequent hostile family environments deprive them of material resources to acquire equipment and treatments, harming their autonomy<sup>5,42</sup>. Over time, they begin advocating for themselves, knowing and defending their own needs. This empowerment and overcoming is often linked to support networks that help reduce stressors associated with living with disability<sup>40-42</sup>.

Contributions of this study to nursing practice include knowledge about the trajectory of women with physical disabilities during the pregnancy-puerperal period, highlighting positive and negative aspects of clinical practice. These contributions serve to improve care, reflect upon the current reality, and adapt health service accommodations to include women with physical disabilities.

Furthermore, it is necessary to understand and implement sexual and reproductive health policies and provide health education focused on family planning and contraception, starting from nursing undergraduate courses and continuing through ongoing schooling in health services. This limits vulnerability and offers comprehensive, inclusive, and dignified care to these women.

### Study limitations

As study limitations, the experience of motherhood in different times is considered, having distinct health policies and social inclusion. A limitation is also recognized in the various types of physical disabilities encountered, since, although some share the same diagnosis, their health conditions, gestational risks, and support networks are individual. Lastly, the data collection being conducted virtually could have caused greater distance between the researcher and participants, hindering bond formation and possibly limiting information exchange.

## CONCLUSION

Discussing the life history of women with physical disabilities highlights a trajectory marked by stigmas, judgments, and overcoming. Vulnerability is portrayed in different life stages, influenced by social, biological, and individual factors, both very similar and unique to each woman.

The study also reveals that health institutions generally do not practice inclusivity and are unprepared to accommodate all types of populations and their particularities. The lack of health professionals' preparedness to care for these women indicates the need to address this topic starting from undergraduate schooling and to deepen it in specializations in obstetrics, gynecology, and other health fields.

This study offers expanded and reflective views on organization of health services and care flows in Brazil, revealing gaps and opening new perspectives for inclusion and individualized care for each woman with physical disabilities. The entry point for health care should welcome these women and their families, providing appropriate assistance, community inclusion, sexual and reproductive health education, and guidance on social rights. It is expected that this study's results contribute to ensuring improved access to integral health with an interdisciplinary approach. Thus, they are essential to the social inclusion process of these people beyond their disability.

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#### Use of artificial intelligence tools

Authors declare that no artificial intelligence tools were used in the composition of the manuscript "*Gestation and motherhood narratives of women with physical disabilities*".