

# ORIGINAL ARTICLE

# SIMPLY MOTHERS: SHARED ELABORATION OF TECHNOLOGIES ON PRENATAL CARE OF VISUALLY IMPAIRED WOMEN

#### **HIGHLIGHTS**

- 1. There are specificities in the prenatal care of visually impaired women.
- 2. Women with visual impairments want respect for their autonomy.
- 3. Shared construction of educational technologies is a successful strategy.

Geovana de Jesus Ferreira de Carvalho<sup>1</sup> Dheise Sandy da Cruz Tavares<sup>1</sup>

Nayara Costa Modesto da Silva<sup>1</sup> ©

Marcia Helena Machado Nascimento<sup>2</sup> ©

Elizabeth Teixeira<sup>3</sup>

Sílvia Teresa Carvalho de Araujo<sup>4</sup> ©

Fernanda de Nazaré Almeida Costa<sup>5</sup> ©

### **ABSTRACT**

**Objective:** To develop educational technologies on prenatal care with and for visually impaired women. **Method:** A methodological study with a participatory interface and qualitative approach. It was carried out at a Specialized Technical Unit in the municipality of Belém, Pará, Brazil. Data production took place between August and September 2021 with six women. DOSVOX was used as a communication resource for the participants to answer four instruments with a view to developing the technologies. The analysis was of the thematic content type. **Results:** Women with visual impairment want respect for their autonomy, inclusion, and information from the professionals. The technologies produced point to the specific demands of visually impaired women and to the importance of preserving autonomy during prenatal care. **Conclusion:** Technologies produced in a participatory way point out women's specific perspectives and needs regarding prenatal care and may support both the nurses' actions in consultations and favor women with visual impairment during prenatal care.

**DESCRIPTORS:** Educational Technology; Prenatal Care; Pregnant Women; Nursing; Visually Impaired People.

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<sup>1</sup>Universidade Maurício de Nassau, Curso de Graduação em Enfermagem, Belém, PA, Brasil.

<sup>2</sup>Universidade do Estado do Pará, Departamento de Enfermagem Hospitalar, Belém, PA, Brasil.

<sup>3</sup>Universidade do Estado do Pará, Programa de Pós-graduação em Enfermagem- Associado Universidade Estadual do Pará/

Universidade Federal do Amazonas, Belém, PA, Brasil.

<sup>4</sup>Universidade Federal do Rio de Janeiro, Departamento de Enfermagem Médico Cirúrgica, Rio de Janeiro, RJ, Brasil.

<sup>5</sup>Universidade Federal do Rio de Janeiro, Programa de Pós-graduação Stricto Sensu em Enfermagem, Rio de Janeiro, RJ, Brasil.

## INTRODUCTION

The World Health Organization (WHO) estimates that 2.2 billion people in the world are visually impaired; of this number, approximately 750,000 live with visual deficits in Brazil. In this context, there is no official statistics on this condition in our country<sup>1</sup>.

Women with visual impairment in transition to motherhood occupy spaces in health services; however, they are not yet perceived in their uniqueness because they represent a minority and, thus, still face situations of invisibility and prejudice, although it is asserted that the number of visually impaired women of all ages has been increasing<sup>2</sup>.

The singularities of pregnant women with visual impairments include the search for autonomy in performing the maternal function, in addition to overcoming fears and insecurities due to their new role, which includes the responsibility of taking care of themselves and conceiving another human being. Prenatal care is the ideal time to welcome these women, creating a facilitating environment to develop the ability to adapt and provide guidance that will contribute to their new role<sup>3</sup>.

Some studies indicate that these women usually lack family and social support, and that this is probably due to the prejudice and stigma related to visual impairment, as they are not recognized as capable of exercising motherhood<sup>4</sup>. Another aspect to emphasize is that these women are not always welcomed in a humanized way, with their autonomy respected, and this is oftentimes due to the professionals' inability of to serve blind people. Prenatal care is limited to routine physical examinations and there is no guidance on self-care, childbirth or newborn care, important information that end up compromising the quality of prenatal care for these women<sup>5</sup>. The aforementioned not only in the physiological aspects, but mainly subjective ones, with regard to emotions and consequences originated in this stage.

As one of the principles of the Unified Health System (Sistema Unico de Saúde, SUS), accessibility ensures that the supply of services is able to meet the demand with any needs. Thus, the pregnancy of a visually impaired woman requires a set of care measures that involves comprehensive and equitable assistance. Despite representing a minority of the served population, these women still face discrimination and are overlooked. They are not attended to according to their particularities, as they lack planned and individualized care that addresses their specific needs<sup>2</sup>.

Since 1961, December 13<sup>th</sup> marks the celebration of the National Day of the Visually Impaired, created with the objective of fighting against prejudice and discrimination. In addition to that, it also aims at ensuring the basic rights of social inclusion for visually impaired individuals in society.

In this context, prenatal care for visually impaired pregnant women requires a comprehensive and inclusive approach tailored to their unique needs. Nurses play a crucial role in prenatal care, as they are qualified to implement health promotion and disease prevention strategies, and to adopt humanization principles in the care provided. Such actions require safe and evidence-based actions in order to preserve women's autonomy<sup>1</sup>.

Prenatal care represents the first contact for these women with health services and, therefore, it should be systematized to address their real and special needs through the use of technical-scientific knowledge and appropriate resources, fostering a humanization and individualization context. With this perspective, the objective of this study was to develop educational technologies on prenatal care with and for visually impaired women.

# **METHOD**

A methodological study<sup>7</sup> with a participatory and high-intensity interface<sup>8</sup>, descriptive and with a qualitative approach. The *Consolidated Criteria for Reporting Qualitative Research* (COREQ) were used to guide the research.

It was conducted at a state Specialized Technical Unit, with over seven decades of existence and located in Belém, Pará, Brazil. This unit is focused on the pedagogical and social rehabilitation of individuals with visual impairment, low vision and/or blindness, serving approximately 300 students who receive specialized educational assistance through specific curriculum supplements.

The researchers' first contact was made through a visit to the *locus*, previously scheduled with the unit's management, to identify and select potential participants according to pre-established criteria. The inclusion criteria were as follows: pregnant women or mothers; visually impaired; over 18 years of age; who experiences or experienced prenatal care in the Unified Health System or Supplementary Health Service. In turn, the exclusion criteria were the following: women that did not present unfavorable clinical conditions at the selection moment and who did not have access to the Internet or to virtual platforms.

Sample composition was convenience-based, adhering to the established criteria. The "snowball" technique was employed, wherein the subjects were asked to recommend other potential participants. Three women were recruited, including two staff members and one user of the unit, who then recommended three additional women, who were contacted by the researchers through the *WhatsApp*® instant messaging app.

The invitation to participate in the research was made individually and formalized by signing the Informed Consent Form (ICF). For the women indicated in the "snowball" process, meetings were scheduled on the days they would be at the unit; thus, individual invitations were extended, and the ICF was signed. The final sample consisted of six participants: four female employees and two users. There were no withdrawals or refusals. After accepting the invitation, it was agreed that all contacts during the research would take place online via instant messages.

Data collection was developed between August and September 2021 using the DOSVOX communication tool. DOSVOX is a system designed to assist individuals with visual impairments in using computers, performing tasks such as text editing with regular or *Braille* printing, reading and listening to transcribed texts, and using spoken productivity tools (calculator, agenda, etc.), in addition to including various games. The system speaks and reads in Portuguese, using international computing standards. Through DOSVOX, data and texts generated by programs and systems in common use in computing can be read<sup>1</sup>.

Four links were sent via WhatsApp, and the reason for this format was in response to the participants' request to read and fill out the documents using voice commands with the assistance of DOSVOX. The links were sent in the following sequence: the first one contained the Informed Consent Form (ICF), sent during the in-person meeting and after presenting the research.

The second link comprised the instrument with two sections containing open-ended questions. In the first section, the following topics were addressed: demographic data, number of pregnancies, details about prenatal care, and the need to develop technology with diverse information about prenatal care. The second section addressed the women's perceptions and their needs during prenatal consultations, their experiences, feelings, and any absences and/or issues encountered during prenatal care.

This instrument sought to understand the participants' profile and their initial requirements regarding the need to produce this technology and identify their real needs. The data produced by them in this instrument supported the elaboration of the first version

of an educational technology on prenatal care for visually impaired women. Women also provided insights into diverse information related to Nursing assistance during prenatal care, leading to the development of a second technology product focused on Nursing assistance during prenatal care and addressing the specific needs of these women. It was produced on the CANVA® online graphic design platform.

In the third link, the women received both technologies in Portable Document Format (PDF), accompanied by two evaluation instruments containing questions regarding the content, presentation and organization of both materials. The instruments included open-ended questions with a space for contributions, possible additions and necessary changes to the material, as well as about the preferred format to be adopted in the final construction of the innovation product. In this option, formats such as PDF, podcast and a combination of PDF with podcast were included, along with the title proposed.

The fourth link consisted in presenting the final version of two technologies for the participants' approval, incorporating the adjustments they had suggested in the evaluation instrument sent with the third link.

The text content analysis was organized in line with the topics suggested by the participants in the first instrument (second link). These topics emerged from the needs identified and pointed out by these women based on their experiences in prenatal care.

Data production was initially organized into four main axes related to relevant information about pregnancy, information about childbirth, guidelines on breastfeeding, and care for the newborn. One of them was focused on diverse information for pregnant women and the other contained guidelines for nurses.

Based on the answers obtained in the second instrument (third link), restructuring instances of the technologies for women and professionals were carried out. Both proposals were appreciated by the participants in the fourth link.

The analysis of the answers obtained in all instruments was carried out through thematic content analysis operationalized in three stages<sup>9</sup>. In the first one, the pre-analysis, a floating reading was conducted, indicators were developed, and objectives were formulated to guide development of the technology through the information and organization of the corpus. The second stage, exploration of the material, involved segmenting the units of registration and context, followed by categorization. The third phase, treatment of the results obtained, included highlighting expressions to identify units of meaning and meaning nuclei. The analysis of all the information resulted in four categories, namely: Autonomy in childbirth, Respect during prenatal care, Assurance of their right to information, and Accessibility. Due to their affinity, two categories were created: Women with visual impairments want respect for their autonomy; and Women with visual impairments seek inclusion and information from professionals.

The research was approved by the Research Ethics Committee (*Comitê de* Ética *em Pesquisa*, CEP) of the Maurício de Nassau University Center in 2021, under opinion number 4,915,949. To ensure anonymity of the participating women, it was decided to identify each one with names of flowers. The chosen names were Lavender, Jasmine, Azalea, Sunflower, Daisy and Tulip.

## RESULTS

The participants' age varied from 23 to 39 years old; as for their occupation, two (33.3%) are students and, in terms of marital status, four (66.7%) are married. In relation to the number of pregnancies, half of the participants had only one and the rest reported having had two.

After a thematic analysis of the data they produced, two categories were created based on affinity and exclusion of topics. The categories that served as a basis for developing the educational technologies were the following: 1- Women with visual impairments want respect for their autonomy; and 2- Women with visual impairments seek inclusion and information from professionals The technologies produced from the participants' expressions were entitled "Simply Mothers", with one designed for women and the other for professionals.

# Women with visual impairments want respect for their autonomy.

During the prenatal consultations, the participants reported that they were not seen in their entirety and that their autonomy was not respected. They also mentioned that the health professionals never directly addressed them when discussing procedures and that they addressed their companion instead, thereby infantilizing them or not considering them capable of motherhood.

[...] Many times during the consultation, it was as if I weren't in the room; the doctor always directed the instructions to my mother, and I felt uncomfortable with the situation; they still infantilize us and doubt a lot about our capability. (Daisy)

The women had no choices regarding timing of their deliveries, and they did not receive guidelines on the matter. They were compelled to accept the medical decision for a C-section if the physicians deemed the pregnancy as of high risk, which affected them emotionally and psychologically.

[...] I had a healthy pregnancy throughout my prenatal care; however, when I talked to my obstetrician about my childbirth preferences and expressed my desire for a natural delivery, he told me that my baby was too large, that I wouldn't have a passage, and that I wouldn't be able to deliver naturally and that my baby would be in distress; I couldn't bear the thought of my child suffering because of my choice, so I accepted the doctor's decision. My son weighed 3,100 g. (Jasmine)

The health professionals at the maternity ward did not provide adequate assistance regarding the newborns and, during visits from the Nursing team, they addressed the companions as if the women were not present. They did not receive direct guidelines on breastfeeding, cleaning the umbilical cord stump, dealing with infant colic, or even changing diapers:

[...] I lacked guidelines, as that was my first delivery, they should teach the mother and not the companion about our first contact with the baby. (Tulip)

There was a moment when I had to assert myself, saying, "I'm here; I'm the one taking care of my daughter; it's me that should be given the guidelines". Everything was new for me, so I needed to know, and I felt invisible in those situations. (Daisy)

# Women with visual impairments seek inclusion and information from professionals

During the gestational period, women need care that promotes health and quality of life. It is known that Nursing consultations are moments for welcoming pregnant women, making communication a crucial ally. However, according to the women, some nurses rarely addressed them to provide guidelines on prenatal care, oftentimes leading them to seek information from other sources or individuals:

- [...] the nurses should offer more clarification about pregnancy and breastfeeding. (Lavender)
- [...] there was little guidance on how to proceed, and it was my boyfriend who took on

the task of finding out about inclusion in pregnancy groups for support and exchange; the nurse mostly covered the very basics, as if I already had experience, or as if it weren't relevant to address the prenatal care aspects more deeply and empathetically. (Sunflower)

[...] the nurses should provide guidelines on breastfeeding because, when the baby is born, the mother becomes very concerned about its nutrition because breast milk may not be produced immediately; then we already might consider turning to porridge and bottles right away; in this way, many issues such as allergies and obesity could be avoided. (Daisy)

Motherhood is a unique moment and each person will have different experiences and emotions; these situations can be more impactful in the pregnancy of a visually impaired woman, as she lacks a sense as important as her vision. This specificity requires greater sensitivity in care, encouraging their autonomy, but what they reveal are negative experiences as well as difficulties receiving diverse information during prenatal consultations:

- [...] Frustrating, in the sense of expecting to receive greater and better guidelines. I resorted more to reading and groups to inform myself. (Sunflower)
- [...] Ableism, lack of clarification about the types of delivery [...] without accessibility, and a deficiency in guidance from both nurses and the obstetrician. (Azalea)

Women indicate that nurses lacked proficiency in providing assistance during consultations, even failing to inform or describe what was happening during those moments or procedures:

- [...] it's important to have professionals that are trained to serve people with disabilities. (Daisy)
- [...] they had a look of pity, I don't know, maybe judging me like that, right, because I decided to have a child and so on. (Azalea)
- [...] it is necessary to describe the procedures and everything that is visual, covering more about the trimesters of pregnancy, from the physiological to the psychological aspects. I believe that the disability itself wouldn't be an obstacle, but it ends up becoming one due to the barriers of lacking or absent inclusive actions as well as communication technologies, and most importantly, lack of attitudes. (Sunflower)
- [...] I felt lack of guidance, especially because I was a first-time mom and. during consultations, the nurse rarely directed information to me. There were also no guidelines about the type of delivery, so I had to turn to mothers' groups to learn and get some tips. (Lavender)

# "Simply mothers": Participatory development of the technologies

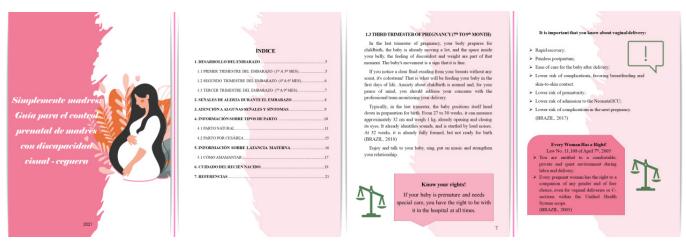
Based on the participants' expressions in the second instrument, the first version of a technology for women with visual impairments about prenatal care was developed. It consists of 21 pages covering the following topics: (1) Gestational development; (2) Warning signs during pregnancy; (3) Attention to some signs and symptoms; (4) Information on types of delivery; (5) Breastfeeding information; and (6) Newborn care.

After the women's review, suggestions for developing the technology were included in the third instrument. Regarding all the information, they requested adding details emphasizing signs and symptoms that serve as alerts for gestational risk. Additionally, they suggested replacing technical terms with everyday words to enhance clarity of the information. As for the organization, the women defined the sequence of the topics. No design adjustments were requested.

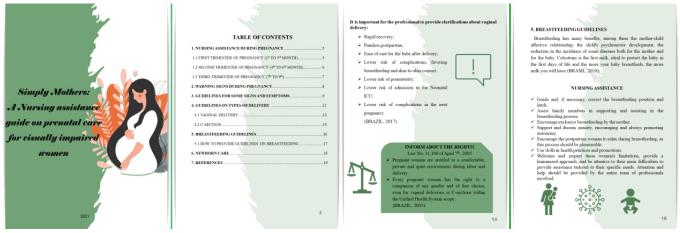
The women opted for the PDF format since, as reported, it is easily accessible with the DOSVOX tool. The researchers also suggested formats in Braille and podcast; however,

some women reported that they did not master use of these tools. As for the title, they indicated "Simply Mothers". Considering the suggestions, in addition to restructuring the technology for women, a technology for professionals was developed under the same title, comprising 19 pages with the following topics: (1) Nursing assistance during the gestational period; (2) Nursing assistance regarding warning signs of gestational risk; (3) Guidelines on risk signs and symptoms; (4) Guidelines on types of delivery; (5) Nursing assistance on breastfeeding; (and 6) Nursing guidelines on newborn care.

The women' evaluation regarding both technologies in the fourth and final instrument indicated that they meet the prenatal care needs, considering the specificities of the target audience, and no alterations were made (Figures 1 and 2).



**Figure 1** – Cover, table of contents and two illustrative pages from the "Simply Mothers" Guide: Guidelines on prenatal care for visually impaired women. Belém, PA, Brazil, 2021 Source: The authors (2021).



**Figure 2** – Cover, table of contents and two illustrative pages from the "Simply Mothers" Guide: Information on the prenatal care of women with visual impairments for professionals. Belém, PA, Brazil, 2021 Source: The authors (2021).

It is noted that the distinctive feature of this production lies in the involvement of the target audience in all stages, with their main concerns emerging, ensuring autonomy and visibility for women, therefore allowing blind pregnant women to access material that can complement important information during prenatal care. The technology produced for health professionals brings the target audience's eyes on the needs identified during prenatal care and their main requirements.

# DISCUSSION

The loss of a woman's autonomy when giving birth violates every woman's right to receive information to exercise autonomy in her choices, receive good quality treatment, have the right to a companion during hospitalization in the obstetric unit, receive equal and discrimination-free treatment, and have her privacy and confidentiality respected<sup>10</sup>.

Autonomy as a value implies the democratization of relationships between professionals and users; it requires sharing knowledge, recognition, respect and appreciation for multiplicity, diversity and individualities, in addition to valuing subjectivities and, above all, the ethics of solidarity and responsibility. This includes people with disabilities, whatever they may be, as they require their specificities to be recognized and access to health actions targeted at their needs. Women with visual impairment can have children at some point in their lives; they are able to care for and monitor the development of their children, even if they need support from their families and health teams<sup>11</sup>.

Autonomy means the human competence to "give oneself one's own laws", acting in a sovereign way in relation to oneself. It is a way of being human and, therefore, needs to be considered in health services<sup>12</sup>.

Prenatal care is an opportune moment for welcoming, inclusion and effective communication with visually impaired pregnant women. The professionals conducting prenatal care need to create a facilitating environment and provide guidelines that will contribute to the gestational state, as well as help women cope with the feelings of fear and insecurity that pregnancy can produce<sup>3</sup>.

Prenatal care aims at ensuring healthy development of the pregnancies and at ensuring comprehensive care both for the mothers and for the newborns. Qualified prenatal care is associated with a reduction in negative perinatal outcomes such as low weight and prematurity, in addition to reducing the chances of obstetric complications<sup>13</sup>.

Care during pregnancy, early identification of warning signs for gestational risk, the importance of breastfeeding and techniques for its implementation, preparation for childbirth and newborn care are some of the themes addressed during health guidance consultations<sup>13</sup>.

The professionals that perform prenatal care need to provide assistance in an individualized way, with respect for women's autonomy and aiming at respecting and solving their problems. Strengthening the bond between health professionals and women is crucial to increase pregnant women's confidence and promote maternal-fetal care continuity<sup>14</sup>.

Health services that offer prenatal care are responsible for developing programmatic actions for health promotion and education directly related to the health levels of the mother-child dyad and to the obstetric outcomes. Prenatal care is primarily provided in Primary Care settings, with approximately 90% of the Brazilian pregnant women receiving it in the basic health network<sup>14</sup>.

The most commonly used communication channels are visual, limiting access to and incorporation of meaningful information by visually impaired people. Thus, verbal communication should be the most used means by professionals during consultations and appointments<sup>15</sup>.

The verbal communication processes are important to ensure clarity and understanding

of the guidelines provided and are considered more than the mere emission and reception of messages; they involve the relationship between the actors involved in sharing specific content through verbal and non-verbal language. Women with visual impairment do not benefit from non-verbal language, and verbal communication is the primary source of interaction with the professionals<sup>5</sup>.

Prenatal care is a set of simultaneously preventive, health-promoting, diagnostic and curative actions, aiming at the good outcome of pregnancy for the mother-child dyad. Educational actions are a fundamental part of Nursing care, guaranteeing greater empowerment of women regarding their rights ensured in the gestational process and strengthening women's bond and safety in the health service, minimizing feelings of fear and anxiety at the time of childbirth<sup>16</sup>.

To facilitate consultations during prenatal care, technologies can be used as tools to assist in expanding the learning process, instruct on more complex subject matters, and encourage and ease the acceptance of a new life condition, especially when dealing with a visually impaired person. Consequently, the role of nurses and other professionals is fundamental in empowering these pregnant women. The production of technologies aimed at these women's needs not only expands care, but also provides knowledge construction<sup>17</sup>.

Educational technologies are a set of concepts and techniques that enable learners and educators to construct and reconstruct knowledge through the use of innovative techniques that enhance the educational process<sup>18</sup>.

The participatory development of technologies encourages interaction and knowledge exchange, valuing people's wisdom and experiences and considering their needs. In a participatory interface, co-creation of a technology product ensures a higher involvement degree in the individuals who are encouraged to reflect on their problems and propose solutions, becoming reality-transformative beings and achieving high-intensity participatory density<sup>8</sup>.

The limitations of this study refer to the small number of participants and its development in a single institution. The need to validate the technical content of this material by a panel of experts is also highlighted.

## FINAL CONSIDERATIONS

In their form and content, the "Simply mothers" educational technologies emerge from the experiences of visually impaired women in prenatal care. The innovation of these products consisted in incorporating women's voices regarding the care offered during prenatal period in a participatory manner, with the potential to stimulate reflections and the learning process of this target audience.

Participatively produced technologies highlight women's perspectives and specific needs regarding prenatal care and may serve as a basis for the actions of nurses and other professionals in consultations and support visually impaired women undergoing prenatal care.

The results of this research show that visually impaired women demand comprehensive and inclusive prenatal care. Therefore, care and attention proposals need to be devised in a way that considers their real needs according to the users' reality.

This study aims at contributing to Nursing assistance in prenatal care for blind women and in the production of educational materials providing guidelines on the gestational period, childbirth and postpartum for this target audience. It also provides support for the development of new strategies that can contribute to Nursing assistance by promoting accessibility and autonomy for these women during prenatal care and childbirth.

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#### Corresponding author:

Fernanda de Nazaré Almeida Costa Universidade Federal do Rio de Janeiro - Escola de Enfermagem Anna Nery Rua Afonso Cavalcanti, 275, Cidade Nova, Rio de Janeiro E-mail: fepedrinho@yahoo.com.br

#### Role of Authors:

Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work - Carvalho G de JF de, Tavares JS da C, Silva NCM da, Nascimento MHM, Teixeira E, Araújo STC de, Costa F de NA. Drafting the work or revising it critically for important intellectual content - Carvalho G de JF de, Tavares JS da C, Silva NCM da, Nascimento MHM, Teixeira E, Araújo STC de, Costa F de NA. Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved - Carvalho G de JF de, Tavares JS da C, Silva NCM da, Nascimento MHM, Teixeira E, Araújo STC de, Costa F de NA. All authors approved the final version of the text.

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