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Health care for deaf women in the pregnancy-puerperium cycle: a scoping review

Atenção à saúde da mulher surda no ciclo gravídico-puerperal: uma revisão de escopo

Atención a la salud de mujeres sordas en el ciclo embarazo-puerperal: una revisión del alcance

Abstract

Objective: to identify and summarize the evidence available in the national literature on health care for deaf women in the pregnancy-puerperal cycle. **Method:** Scope review studies according to theoretical and methodological precepts of the Joanna Briggs Institute. The research was performed via CAPES journals, in the bases LILACS; MEDLINE via PubMed®; SCIELO, WOS, and CINAHL electronic library. **Results:** A total of 1,831 studies were identified, and 12 made up the final sample. Difficulties in communication, and the lack of trained professionals in Libras, in addition to suffering, prejudice, and discrimination, are part of the experience of deaf women in the pregnancy-puerperal cycle. **Conclusion:** the production of knowledge at the national level about assistance to deaf women in the pregnancy-puerperal period is still leadoff, and encouraging studies and evidence-based practices to produce initiatives that dialogue about the autonomy and strengthening of the exercise of sexual and reproductive rights of deaf women in Brazil is necessary.
Descriptors: Women's Health; Deafness; Persons With Hearing Impairments; Pregnancy.

Resumo

Objetivo: identificar e sumarizar as evidências disponíveis na literatura nacional sobre a atenção à saúde da mulher surda no ciclo gravídico-puerperal. **Método:** Estudo de revisão de escopo, segundo preceitos teóricos metodológicos do *Joanna Briggs Institute*. A busca foi realizada via periódicos CAPES, nas bases LILACS, MEDLINE via PubMed®, Biblioteca eletrônica SCIELO, WOS e CINAHL. **Resultados:** Identificaram-se 1.831 estudos, dos quais 12 compuseram a amostra final. As dificuldades na comunicação e ausência de profissionais capacitados em Libras, além de sofrimento, preconceito e discriminação, fazem parte da vivência da mulher surda no ciclo gravídico-puerperal. **Conclusão:** a produção do conhecimento no âmbito nacional sobre a assistência à mulher surda no período gravídico-puerperal ainda é incipiente e faz-se necessário fomento de estudos e práticas baseadas em evidências para a produção de iniciativas que dialoguem sobre a autonomia e o fortalecimento do exercício dos direitos sexuais e reprodutivos da mulher surda no Brasil.
Descritores: Saúde da Mulher; Surdez; Pessoas com deficiência auditiva; Gravidez.

Resumen

Objetivo: identificar y resumir las evidencias disponibles en la literatura nacional sobre la atención a la salud de la mujer sorda en el ciclo embarazo-puerperio. **Método:** Estudio de revisión de alcance según preceptos teóricos y metodológicos del Instituto Joanna Briggs. La investigación se realizó en las revistas CAPES, en las bases LILACS; MEDLINE vía PubMed®; Biblioteca electrónica SciELO, WOS y CINAHL. **Resultados:** se identificaron 1.831 estudios, de los cuales 12 conformaron la muestra final. Las dificultades en la comunicación, la falta de profesionales capacitados en lengua de señas, además de sufrimiento, prejuicio y discriminación son frecuentes en la vivencia de las mujeres sordas en el ciclo puerperal del embarazo. **Conclusión:** la producción de conocimiento a nivel nacional sobre la atención a las mujeres sordas en el período embarazo-puerperio es aún incipiente, y es necesario incentivar estudios y prácticas basadas en evidencias para producir iniciativas que dialoguen sobre la autonomía y el fortalecimiento del ejercicio de los derechos sexuales y reproductivos de las mujeres sordas en Brasil.
Descriptores: Salud de la Mujer; Sordera; Personas con Discapacidad Auditiva; Embarazo.

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INTRODUCTION

Data from the National Health Survey (Pesquisa Nacional de Saúde - PNS) in 2019 show that 17.3 million people aged two or over (8.4% of the entire population) had some kind of disability - visual, hearing, or physical, representing 10.5 million females and 6.7 million males[1]. It also found that 2.3 million (1.1%) Brazilians have hearing impairment[1].

The survey also found that 31,000 children between 2 and 9 years old presented some level of hearing loss, the number increased as people got older, reaching 1.5 million for individuals at 60 or over (4.3% of the population)[1]. In 2021, the World Health Organization foresaw that 2.5 billion people will have to live with some degree of hearing disability by 2050[2].

According to the Ministry of Health, deafness is defined as the inability or impossibility of hearing[3], and it presents different levels: mild, medium, severe, profound, and cophosis, and varying causes, such as deafness in the family, premature birth, congenital infections, and low birth weight. Yet, deaf parents can give birth to a hearing child, and having familiar cases is not a rule.

All disabled people, except the deaf population, use the Portuguese language. Some deaf people speak it but still communicate using Brazilian Sign Language (Libras) - recognized as the deaf community's form of expression and communication. According to the National Health Survey, of the 1.7 million deaf people between 5 and 40 years old, only 9.2% (153,000) know Libras[1].

Libras is recognized by law as a means of communication, defined as a visuospatial language used for deaf communities in Brazil. It is a linguistic system that coexists with the Portuguese language[4], being independent of each other and possessing its proper grammar and structure, even with regional dialects, not making it a universal language since each country has a specific sign language.

It is noteworthy that, according to the Decree of the Presidency of the Republic of Brazil No. 5.626 of 2005, a deaf person is one who, due to hearing loss, understands and interacts with the world through visual experiences, manifesting their culture mainly through Libras[5], and who has bilateral hearing loss, partial or total, of forty-one decibels (dB) or more, measured by audiogram in the frequencies of 500Hz, 1,000Hz, 2,000Hz and 3,000Hz[5]. According to this decree, the state must guarantee these individuals' constitutional right to comprehensive education and health care that has to be provided by trained professionals in Libras' translation and interpretation[5]. However, the Brazilian Sign Language implementation, the regulation of translator and interpreter professionals, and accessibility to services and core activities of educational institutions and public offices are a distant reality in Brazilian public health services[6,7].

Attempting to reverse this situation, some Brazilian states, such as Pernambuco, Acre, Mato Grosso do Sul, and São Paulo, have enacted state laws reinforcing the deaf or hearing-impaired pregnant women's right to have a Brazilian Sign Language interpreter during prenatal care, labor, and delivery. As a result, public and private maternity hospitals and birthing centers must hire Libras translators and interpreters in these situations if requested by pregnant women.

In 2019, the Ministry of Health published the Health Guide to Women with Disabilities and Reduced Mobility, in which sexual and reproductive rights are described as fundamental for people with disabilities, which include access to actions and services to guarantee the free, safe, and informed experience of these rights[3]. The guide provides a simplified approach to promoting the maternal health of women with disabilities, with information on preconception care, prenatal care, abortion, prenatal care, puerperium, and breastfeeding, as well as

aspects that health professionals should be aware of in each of these topics[3].

Despite health being a constitutional right of all and a duty of the state, and despite the implementation of the National Policy for Comprehensive Women's Health Care and the National Policy for the Health of People with Disabilities, research carried out in the national context warns of the persistence of difficulties and neglect experienced by deaf women when they seek health services and do not find professionals trained to provide qualified care[7-10].

It should be noted that in both documents the proposals for concrete actions and governmental and professional responsibilities to guarantee the rights of deaf women in the field of sexual and reproductive health are still incipient. Therefore, despite the progress made in terms of policies and legislation, actions aimed at effectively strengthening comprehensive sexual and reproductive health care in practice have yet to be implemented[11].

Given the importance of obstetric care for improving the quality of labor and birth in the Brazilian context, the gaps cited above, besides failing to comply with the laws, neither ensure the inclusion of hearing-impaired people in the health service nor prevent discriminatory conduct, prejudice, and indifference on the part of professionals. As a result, deaf pregnant women remain unassisted from health services, making them more susceptible to problems during pregnancy, childbirth, and postpartum[3].

Given the invisibility of this issue in health discussions and the scarcity of practices aimed at these women in the context of maternal health, this paper aimed to identify and summarize the notes available in the national literature on health care for deaf women in the pregnancy-puerperal cycle.

METHOD

It is a scoping study or scoping review, whose theoretical precepts include six methodological steps established by the Joanna Briggs Institute (JBI), i.e., developing the research question; searching for relevant studies; screening the studies; extracting the data; separating, summarizing and reporting the results; and finally disseminating the results[12,13], which allows the identification of current knowledge in a given area, mapping concepts and productions, summarizing evidence, and indicating gaps to explore in future studies[12,13].

This review was guided by a previously planned protocol based on a Checklist and Explanation from the Preferred Reporting Items for Systematic Reviews and Extended Meta-Analyses for scoping reviews (PRISMA-ScR) to help researchers plan, organize, and carry out the review, registered in the Open Science Framework (doi:10.17605/OSF.IO/GPBTX). Thus, describing the entire process aids in ensuring consistent results and guaranteeing the scientific study's reproducibility.

The PICO mnemonic structure was used to define the study question, adapted for Population, Context, and Concept (PCC), as proposed by the JBI. The following study interest determinants were defined: Population (P) - deaf women; Concept - health care during pregnancy, childbirth, and the puerperium; and Context - publications of research carried out in Brazil. Based on this structure, the following research question was developed: What are the characteristics of health care for deaf women during pregnancy, childbirth, and the puerperium, according to national publications on the subject? Besides, a secondary question was developed: What are the challenges to implementing comprehensive health care for deaf women in the pregnancy-puerperium cycle according to the national scientific literature?

For each item in the PCC strategy, we selected a set of descriptors available in the Health Sciences Descriptors (DeCS): People with hearing impairments OR Deafness OR

Sign languages AND Pregnancy OR Prenatal OR Prenatal care OR Childbirth OR Postpartum period and in the Medical Subject Headings (MeSH): Prenatal Care OR Parturition OR Postpartum Period OR Pregnancy AND Persons with Hearing Impairments OR Deafness OR Sign Language.

The search strategy was devised by combining DeCS and MeSH terms based on the acronym PCC, considering the application of the Boolean operators AND/E and OR/OR, and the description crossings, adapted according to the language and particularities of the following database systems: Latin American and Caribbean Health Sciences Literature (LILACS), Medical Literature Analysis and Retrieval System (MEDLINE) via PubMed, SCIELO Electronic Library, Web of Science (WOS) and the Cumulative Index to Nursing and Allied Health (CINAHL).

After carrying out the advanced search, the retrieved references were sent to the Endnote Web bibliographic manager to exclude duplicates using the system. Subsequently, the exclusion was done manually, based on the inclusion criteria: research publications carried out in Brazil featuring deaf women as their population and addressing the issue of prenatal care, childbirth, and the puerperium; publications available in full, online and with free access; and publications in Portuguese, English, and Spanish. It is important to note that, due to the small number of publications, no time frame was applied.

The selection of studies happened in three stages. First, the title and abstract were analyzed. Then, the chosen studies were assessed for eligibility and read in full in the second stage. Afterward, the selected studies were distributed among three researchers, who proofread the eligible studies in full to analyze the whole text in the third and final stages; additionally, the references of the selected studies were evaluated to capture and include research not retrieved when searching the databases. The analyzed references, theses, dissertations, and course completion monographs related to the topic that were not retrieved from the databases were also included for analysis.

Editorials, letters to editors, opinion articles, or papers not fully available for reading were excluded. We also left out publications outside the scope, i.e., not dealing with prenatal care, pregnancy, childbirth, or the puerperium, not carried out in Brazil, or published in languages different from Portuguese, English, or Spanish. On the other hand, documents published in conference proceedings, as expanded or full abstracts, and consistent with the study theme were included, allowing the retrieval of a larger number of publications.

The variables extracted from the studies were inserted into a matrix built in Microsoft Excel for Windows® version 2021 by the three researchers independently, who dealt with questions and doubts about the extractions by consensus between them. Summarizing the results made it possible to see the current panorama of knowledge about deaf women's care in the pregnancy-puerperium cycle through all the information retrieved on the topic reviewed. The results were presented in the form of a summary table and descriptive format, according to the guidelines of the PRISMA protocol - extension for scoping review[12].

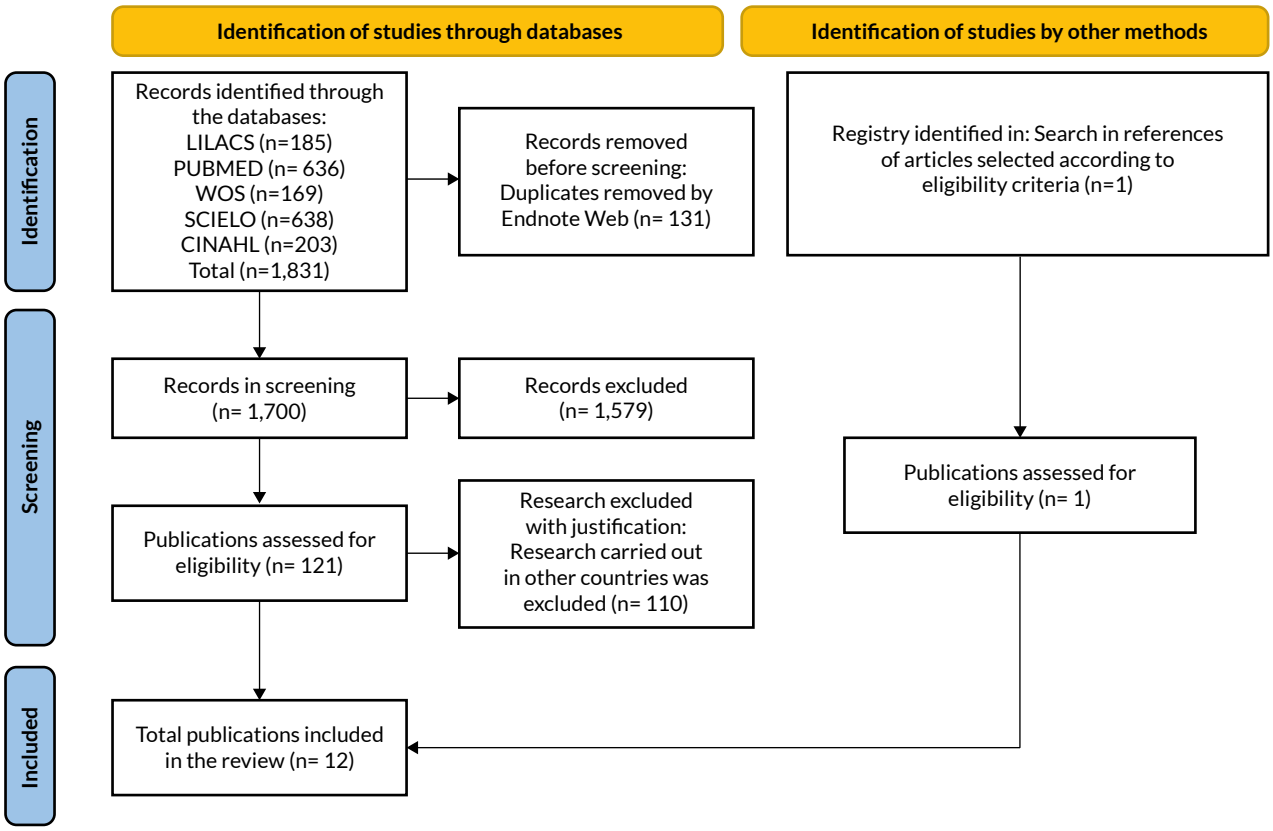
This review was based on secondary data, making it unnecessary to obtain approval from ethics committees for research involving human beings. Besides, this review's authors have no links with funding institutions that could characterize potential conflicts of interest.

RESULTS

The database search resulted in 1,831 documents, of which 131 were duplicates, leaving 1,700 documents to read the titles

and abstracts. After applying the PCC strategy, 1,579 records were excluded, leaving 121 studies for a thorough reading of the full text and peer selection, thus adding up to a final sample of 12 studies for this scoping review (Figure 1).

Figure 1 – Flowchart for selecting the studies identified according to the PRISMA-ScR recommendations.



Source: Research data.

The presentation of the results follows the Preferred Reporting Items for Systematic Reviews and Extensions of Meta-analyses for scoping review (PRISMA-ScR). The format for presenting the results was conducted in such a way as to provide an overview of the results. The results of the search and selection are described in the PRISMA-ScR flowchart[14].

Of the 12 studies included in this review, 10 were articles and two academic works (a dissertation defended in 2020 at the Graduate School of Dentistry of the Federal University of Minas Gerais and a course completion paper presented in 2021 to the Federal University of Santa Catarina, as a requirement to obtain the bachelor's degree in LIBRAS Literature). Regarding the year of publication, nine publications (75% of the citations) were between 2017 and 2021.

Most studies (58.3%) were published in health journals (Nursing and Public Health), with diversification of study types, being 07 qualitative, 02 quantitative, 02 reviews, and 01 thought-provoking study, and from the 07 qualitative ones, 06 conducted interviews or applied questionnaires to deaf women; five studies were carried out in the Northeast, three in the Southeast, and only one in the Midwest and South. The principal results of the studies analyzed in this review are described in Table 1.

Table 1 – Summary of the studies included in the review.

ARTICLE TITLE	PLACE OF STUDY	METHOD/ PARTICIPANTS	MAIN RESULTS
Deaf women's experience of pregnancy[15]	Bahia	Case study, with the participation of two deaf women.	Deaf women experience unplanned pregnancies, face communication difficulties with health professionals, and are more susceptible to having their reproductive rights violated by having an undesired cesarean section, for example. A study highlighting health care's weakness for deaf women, despite the law to support them.
Care for deaf pregnant women: communication barriers encountered by the health team[16]	Pernambuco	A quantitative, descriptive, and exploratory study carried out with 60 health professionals.	The lack of health professionals trained in Libras hinders understanding, which is the main obstacle to communication. The care provided is not suited to the needs of these women.
(Non-)systematic review on psychological care for deaf pregnant women[17]	Not applicable	Integrative literature review, analyzing nine studies.	The scarcity of studies concerning the subject of deaf pregnant women and the exclusion of this population from health services and scientific research contribute to prejudice and discrimination in different parts of society.
The nurse's challenge in attending deaf pregnant women: an experience report[18]	Mato Grosso	An experience report by health professionals.	Deafness, seen from the perspective of disability, keeps deaf people aloof from hearing people. There is a need to stimulate the training of human resources in health services and more discussion on the subject.
Welcoming and listening to silence: nursing care from the perspective of deaf women during pregnancy, childbirth and the puerperium[19]	Minas Gerais	A qualitative study in which 9 deaf women were interviewed.	Communication difficulties were one of the main barriers to nursing care for women. The absence of an interpreter and nurses' lack of training in caring for deaf women during pregnancy is a reality in health services.
Nurse communication in childbirth care: from the perspective of deaf women[20]	Bahia	A qualitative study in which 9 deaf women were interviewed.	The lack of an interpreter and the presence of untrained professionals in the hospital environment led to communication obstacles during childbirth. To communicate, nurses use gestures, the help of a companion, and writing in Portuguese, which compromises care.
Nursing care in the perception of deaf women during the prenatal and puerperal period[21]	Minas Gerais	Qualitative study, interviews with nine deaf women.	There is a lack of interpreters and professionals trained in Libras in health services. Deaf women reported little contact with the nursing team during pregnancy. Doctors carry out care with guidance restricted to prenatal care and breastfeeding.
Breastfeeding practice and sociodemographic factors that influence the behavior of deaf mothers compared to hearing mothers[22]	Minas Gerais	This was a cross-sectional, retrospective, and comparative epidemiological study involving 29 deaf mothers and 87 hearing mothers.	Deaf mothers are more likely to give birth prematurely, more anxious during breastfeeding, and more prone to bottle-feeding than hearing mothers. There is a lack of studies with actions to minimize this problem and enable deaf mothers to experience the benefits of breastfeeding.
The challenges of motherhood and the importance of being a mother for disabled women[23]	Ceará	A descriptive and exploratory study with a qualitative approach in which 12 disabled women took part.	The need for qualified prenatal care. Health professionals need to know more about this issue to propose improvements in care for these women during the pregnancy-puerperal period.

(continues)

ARTICLE TITLE	PLACE OF STUDY	METHOD/ PARTICIPANTS	MAIN RESULTS
The Challenges Faced by Libras/Portuguese Interpreters in Prenatal and Childbirth Care for Deaf Women[24]	Rio Grande do Sul	Multiple case study conducted with 27 Sign Language/ Portuguese translators and interpreters and five deaf women.	Health professionals dealing with prenatal care and childbirth do not always have specialized training courses for deaf women during pregnancy and childbirth periods. Furthermore, discrimination, frustration, and misinformation reveal contradictions between legislation and practice in services.
Reproductive autonomy: a case study on deafness[25]	Not applicable	Thought-provoking article.	There are still many institutional, cultural, and social barriers that need to be overcome to guarantee deaf women's autonomy and the exercise of their reproductive rights.
Accessibility in labor and birth for people with motor, visual or hearing disabilities: structure of SUS establishments linked to the Stork Network (Rede Cegonha)[26]	Maranhão	This is an ecological, descriptive study carried out in all 606 establishments from the Stork Network that performed births in 2015.	The structure of hospital/maternity facilities linked to the Stork Network in Brazil is still not adapted for people with motor, visual, or hearing disabilities, making it difficult for these women to access quality prenatal, birth, and postpartum care.

* Work presented to the Federal University of Santa Catarina as a completion requirement for the Bachelor's Degree in LIBRAS Literature.

DISCUSSION

Given the scarcity of publications, we found that all included studies highlighted limitations in deaf women's care during pregnancy and childbirth. The main ones, and the ones that most cause these women to withdraw from health services, are communication difficulties and the lack of interpreters and health professionals fluent in Brazilian Sign Language, both in maternity wards and in other health services, as well as prejudice and discrimination[27].

Effective and efficient communication is recognized when the understanding between the receiver and the sender is fulfilled. In this sense, some deaf people experience a challenge in communication because they don't know Libras or are not literate in Portuguese[18]. Communication, as one of the demeanors of comprehensive and humanized care in the pregnancy-puerperium period, involves not only elucidating the procedures and tests to be carried out and the institution's routines and rules but also helping to understand the needs of women and their families. Thus helping to reduce the insecurity and anxiety inherent in this period in a woman's life.

Difficulty communicating was one of the main limitations described in studies on care for deaf women during pregnancy and childbirth[19]. The lack of health professionals trained in Libras hinders the process of understanding on both sides and compromises the quality of care offered to these women[16]. This is a complex reality, impacting the provision of educational practices to promote the sexual and reproductive rights of deaf women and men in Primary Health Care. Deaf women often experience unplanned pregnancies and have limited access to other means of information about reproductive planning and sexual and reproductive rights[15].

Communication between deaf women and health professionals during prenatal care and childbirth also has an impact on the puerperium, meaning that effective communication can prevent postpartum depression in deaf pregnant women[17]. In this respect, the nurses' academic qualifications can enhance the interaction

between future professionals and pregnant and postpartum women, making them valuable allies in the therapeutic and care process[16].

Despite the importance of knowing Libras for health professionals and communication in caring for and strengthening health as a right for all, this topic is still not discussed in undergraduate courses[18]. In practice, health courses are still permeated by weaknesses regarding this, with only one optional subject on offer and poor student mobilization, as well as the invisibility of the deaf community's health in undergraduate theoretical and practical subjects, the absence of health teachers trained in Libras and no experience of caring for deaf people during internships and course practices[16,17,20].

It should be noted that not all deaf people use Libras, so providing resources that improve acoustic quality (such as magnetic rim or remote microphone and the FM System - Modulated Frequency System, when their understanding of some speech by using hearing technologies may be facilitated) can favor accessibility and inclusion for all groups of people with hearing impairment[1].

Ethics and professional secrecy are essential in health care, especially in women's care during prenatal and childbirth. The interpreter and health professional should receive counsel to conduct an empathetic and responsible dialog, strengthening the communication and autonomy of deaf women[20,27].

An interpreter does not guarantee the success of a deaf woman's communication; on the contrary, it can cause difficulties and take away the patient's privacy[27]. However, such professionals can aid communication between deaf women and health professionals, given that communication difficulties lead to dissatisfaction and frustration regarding the care offered, which increases barriers and keeps the patients aloof from health services[25, 26].

Deaf women reported little contact with the nursing team during pregnancy. According to them, doctors oriented them during prenatal care and breastfeeding[21,22]. In addition, it should be noted that the hospitals/maternities infrastructure is not fully adapted to ensure accessibility for people with motor, visual, or hearing disabilities[23,26].

The nursing team's role in assisting deaf women in the puerperal period goes beyond identifying complications in the puerperium since this professional must guide and strengthen women's autonomy over their bodies and health. Besides, they should orient self-care, newborn care, and breastfeeding through effective communication, solving doubts about childbirth and postpartum hardships[22]. These are some of the nursing attributions that can contribute to deaf women's health during and after pregnancy[19].

In addition to the social stigma imposed by gender inequality, deaf women's sexuality is disregarded because of their hearing loss[19]. Therefore, there is a shortage of health practices aimed at promoting sexual health and reproductive planning for these women. Besides, prejudice and discrimination can further limit their sexuality and make it impossible for them to exercise their sexual and reproductive rights[24].

Knowledge of one's own body for safe sexual health and the use of contraceptive and conceptual methods are some of the precepts of sexual and reproductive rights that can help women plan pregnancies and experience positively and uniquely the birth of a child[21].

The visibility of deaf women's sexual and reproductive rights can be stimulated through the promotion of educational groups and the production of informative materials such as booklets and subtitled videos on the subject, considering the uniqueness of this population section and their needs concerning sexual and reproductive health. Therefore, stenotypists and subtitlers can help strengthen

the engagement of this content in the deaf community.

It is known that some deaf people can read and write and benefit from autogenerated or recorded subtitles on videos and broadcasts on digital platforms. Using technology through artificial intelligence to capture and transcribe speech can favorably potentialize establishing effective communication with deaf people.

It was also noticed the invisibility of deaf women's reproductive rights, so thus the simple existence of laws and government regulations is not enough to ensure the rights of the deaf community. Deaf people, in general, already feel vulnerable and are more susceptible to discrimination because of their condition and the fact that their rights are constantly violated[28].

In this context, besides training health professionals to improve communication, there is a need to discuss the ethics and quality of care offered to that population because of the need to eliminate prejudice and stigmatizing practices given their physical, visual, or hearing limitations[24]. This is a pressing issue since the sociocultural and linguistic differences imposed by deafness cannot be characterized as a disability but as a diversity that must be respected and considered in healthcare practices.

FINAL CONSIDERATIONS

The scarcity of studies on this review's subject raises a crucial discussion about the uncertainties and gaps in sexual and reproductive health care for deaf women in Brazil. The articles analyzed in this study corroborate the communication difficulties faced by these women in women's health care services during pregnancy and childbirth, which lack accessibility and trained health professionals or interpreters.

To promote inclusion and accessibility in health services, two measures are needed: including a Libras course in the curriculum as a compulsory subject and training professionals who already work in the area, especially in women's health care and obstetrics. Compliance with laws regarding the availability of interpreters in maternity wards can also contribute to improving access and health care for deaf people nationwide.

Recently, these measures have become even more necessary due to the obligation of wearing masks to protect against COVID-19, which made lip-reading communication more difficult.

The option to only analyze open-access articles in a limited number of databases and not to include studies carried out in other countries can be considered limitations of this scoping review.

It was noted that most of the studies are recent, i.e., produced in the last five years. This demonstrates an upward movement in the number of researchers interested in the subject and signals the possibility of increasing the visibility of these women who have been hitherto forgotten and neglected by the health sector.

Nurses must understand the importance of their roles, not only because they work directly with obstetric care and the pregnancy-puerperal period, but because nursing care is necessary to promote those women's life quality and rights. These are fundamental aspects to valorize their needs and promote sexual and reproductive health autonomy.

The knowledge produced regarding the care for deaf women in the pregnancy-puerperal period is still incipient nationwide. It is hoped that this study's results encourage discussion of the subject in the academic and health spheres and contribute to the production of initiatives and future research that dialog about autonomy and strengthening the exercise of deaf women's sexual and reproductive rights in Brazil.

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