

## Understanding The Experience Of Deaf Women Regarding Care In Gynecological Consultations

A Compreensão Do Vivido Pela Mulher Surda Sobre O Atendimento Na Consulta Ginecológica

Comprensión De La Mujer Sorda Sobre La Experiencia Sobre La Atención En La Consulta Ginecológica

### RESUMO

Objetivo: Desvelar os sentidos do movimento existencial de ser mulher surda universitária e seu vivido na consulta ginecológica para o rastreamento do câncer de colo de útero. Método: Trata-se de um estudo qualitativo, utilizando como alicerce teórico, metodológico e filosófico a abordagem fenomenológica heideggeriana. A coleta de dados foi realizada por meio de entrevista aberta. Resultado: Em todo o processo de atendimento há presença da barreira de comunicação, resultando na falha da promoção do cuidado, pois a mulher necessita de uma terceira pessoa como interlocutora devido à falta de profissionais intérpretes nas instituições de saúde. Conclusão: A falta de acessibilidade para as mulheres surdas durante o atendimento nos serviços de saúde propicia uma posição de fragilidade, tornando-as ainda mais vulneráveis por não receberem o cuidado integral pelos profissionais de saúde.

**DESCRIPTORES:** Serviços de Saúde da Mulher; Exame ginecológico; Surdez; Barreiras ao acesso aos cuidados de saúde; Cuidados de Enfermagem.

### ABSTRACT

Objective: To reveal the meanings of the existential movement of being a deaf university student and her experience in the gynecological consultation for cervical cancer screening. Method: This is a qualitative study, using the Heideggerian phenomenological approach as a theoretical, methodological and philosophical foundation. Data collection was carried out through open interviews. Result: Throughout the care process, there is a communication barrier, resulting in the failure of care promotion, as the woman needs a third person as an interlocutor due to the lack of interpreters in health institutions. Conclusion: The lack of accessibility for deaf women during health care services creates a fragile position, making them even more vulnerable due to not receiving comprehensive care from health professionals.

**DESCRIPTORS:** Women's Health Services; Gynecological Examination; Deafness; Barriers to Access to Health Care; Nursing Care.

### RESUMEN

Objetivo: Inicialmente, las embarazadas no pertenecían al grupo de riesgo de Covid-19, pero los estudios han demostrado resultados maternos y neonatales desfavorables en las formas moderada y grave. Analizar y comparar los resultados maternos de las embarazadas afectadas por Covid-19 durante su hospitalización en un hospital terciario de maternidad. Se trata de un estudio descriptivo, transversal, documental, retrospectivo y con un enfoque cuantitativo que pretende correlacionar los acontecimientos y los posibles factores asociados al tema principal. La muestra consistió en todas las mujeres que interrumpieron su embarazo mientras tenían una infección activa por coronavirus desde enero de 2020 hasta julio de 2021 en una maternidad de Fortaleza. Se identificó un perfil joven, menor de 30 años, la mayoría con edad gestacional en el tercer trimestre y sin comorbilidades, pero las principales condiciones crónicas fueron hipertensión, asma y obesidad, que se asoció con progresión a síndrome respiratorio agudo grave. Covid-19 se asoció a tasas más elevadas de cesáreas y partos prematuros. Repercusiones fetales: prematuridad, bajo peso al nacer, sufrimiento y restricción del crecimiento fetal.

**DESCRIPTORES:** COVID-19; Embarazo; Mortalidad materna.

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**ID** **Grace Kelly Silva de Freitas**  
Nurse - Master in Nursing  
ORCID: <https://orcid.org/0000-0002-7287-4896>

**ID** **Guilherme Sacheto Oliveira**  
Nurse - Master in Nursing - Professor at the School of Nursing of FUPAC - Leopoldina  
ORCID: <https://orcid.org/0000-0003-2642-7320>

**ID** **Anna Maria de Oliveira Salimena**  
Nurse - Doctor in Nursing - Affiliation: Federal University of Juiz de Fora  
ORCID: <https://orcid.org/0000-0001-7799-665X>

**ID** **Natália Maria Vieira Pereira Caldeira**  
Doctor in Sciences. Adjunct Professor at the School of Nursing of the Federal University of Juiz de Fora.  
ORCID: <https://orcid.org/0000-0002-4231-7116>

**ID** **Monalisa Claudia Maria da Silva**  
PhD in Health. Assistant Professor at the School of Nursing of the Federal University of Juiz de Fora.  
ORCID: <https://orcid.org/0000-0002-6185-5171>

**ID** **Luciano Chaves Dutra da Rocha**  
Nurse  
ORCID: <https://orcid.org/0009-0005-1481-8377>

**ID** **Adriana Maximiano**  
Supervisor of Primary Health Care  
ORCID: <https://orcid.org/0009-0008-6963-0592>

**ID** **Zuleyce Maria Lessa Pacheco**  
DPhD in Nursing. Professor at the Faculty of Nursing at the Federal University of Juiz de Fora  
ORCID: <https://orcid.org/0000-0002-9409-8971>

## INTRODUCTION

The 1988 Federal Constitution guarantees access to health for all, free from prejudice related to race, color, origin, gender, social condition or disability, as established by the principles of the Unified Health System (SUS).<sup>(1-3)</sup>

Globally, there are around 500 million deaf people and by 2050 this number is expected to reach one billion, with one in four people living with some degree of deafness.<sup>(4)</sup> In Brazil, 4% of women between 15 and 64 years old have some degree of deafness.<sup>(5)</sup>

Deaf people often face challenges in accessing health services due to the lack of professionals trained in Brazilian Sign Language (Libras), which compromises the quality of care and the understanding of diagnoses and treatments. Even with the National Health Policy for People with Disabilities (PNSPD - Política Nacional de

Saúde da Pessoa com Deficiência), it is still necessary to adapt health services to ensure an equitable approach.<sup>(6-8)</sup>

Cervical cancer (CC) is the third most common cancer among women, with 17,010 new cases estimated for 2023 in Brazil. Early detection is crucial for a cure, but deaf women have less access to information about screening and risk factors due to the lack of educational materials in Libras and the difficulty of communicating with health professionals.<sup>(8-10)</sup>

This study aims to reveal the meanings of the existential movement of being a deaf university woman and her experience in the gynecological consultation for CC screening.

## METHODS

This is a qualitative study guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ) tool.<sup>(11)</sup> The Heideggerian phenomenological approach

<sup>(12)</sup> was used as a theoretical and methodological basis to explore the experience of being a deaf university woman, addressing the phenomenon of Dasein and its implications in the gynecological consultation for CC screening.<sup>(12-13)</sup>

The participants were deaf women enrolled in the Faculty of Letters, a Bachelor's Degree in Libras, at a federal public institution in the Southeast region of Brazil. Data collection took place between September and October 2019, including women over 18 years of age, deaf, sexually active, enrolled and who had at least one consultation for CC screening. Women with mental health problems were excluded.

Before contacting the participants, the lead researcher, with the help of a fellow, produced a video translated into Libras of the Informed Consent Form and the data collection instrument. An explanatory text about the research was sent to the course coordinator, who created a presentation video and

# Qualitative Article

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provided the contact details of the potential participants. The researcher then recorded and sent an adapted educational video via WhatsApp.

A pilot test was carried out with two deaf women to adjust the interview script. The selection of participants followed the non-probabilistic theoretical sampling method, known as snowball sampling<sup>(14)</sup>, which involved four steps:

**1. Identification of key informants (seeds):** the course coordinator indicated the first seed, who received the explanatory video and, after accepting, helped to identify other participants.

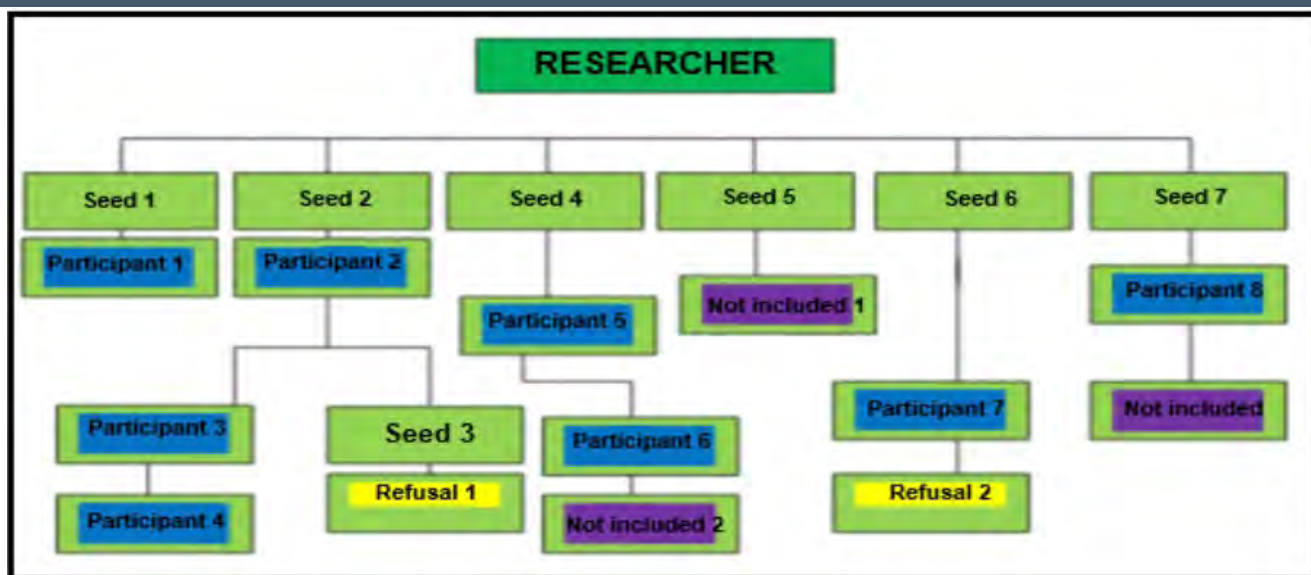
**2. Conducting the interviews:** the open interviews took place in a room at the Faculty of Arts, lasting an average of 20 minutes, in a location that guaranteed comfort and privacy. All interviews were re-

corded.

**3. Translation and transcription:** the course coordinator indicated the first seed, who received the explanatory video and, after accepting, helped to identify other participants.

**4. Data collection:** interviews continued until no new meanings emerged, ending the information collection phase.

FIGURE 1- CONTACT NETWORK ACTIVATED



Source: the authors (2024)

The testimonies were analyzed in two methodological moments as proposed by Heidegger.<sup>(12)</sup> The first stage consisted of Vague and Median Understanding, which involved transcribing the participants' testimonies to understand the phenomenon in question and the deponents' way of being. The second stage, called hermeneutic analytical movement, focused on revealing the meanings of the existential movement of being a deaf university student and the experience of the gynecological consultation for CC screening.

The analysis of the statements resulted in two units of meaning (UM): UM1 - the insecurity caused by the lack of understanding and the absence of an interpreter in health services, which generates dependence on a

companion; UM2 - the obstacles in communication, which cause dissatisfaction, nervousness, pain, fear, strangeness and embarrassment. Based on these UM and using the intuitive method, we sought to understand the meaning of the experience lived by the individual, with the aim of revealing the multiple facets of the phenomenon investigated.

To ensure the confidentiality of the participants, they were identified by the letter W (Woman), followed by ordinal numbers (from W1 to W8). This study complied with the recommendations of Resolution No. 466/2012 of the National Health Council and was approved by the Research Ethics Committee under No. CAAE 3,558,942.

## RESULTS

Eight deaf women, aged between 20 and 34, participated in this study. Of the participants, 62.5% self-identified as white and 37.5% as brown. Regarding monthly income, 62.5% reported receiving between one and four minimum wages, while 37.5% reported having no income of their own. All were single and nulliparous. Two thematic categories emerged from the analysis.

The results demonstrated that the existential meanings of being a deaf university student and the experience of the gynecological consultation for cervical cancer screening permeate factors that interfere with their care.

**UM 1- The insecurity of not being understood and the absence of an interpreter in health services generate dependence on a companion**

*I feel insecure, at the reception they don't ask if the patients are disabled, so that they can prioritize the doctor quickly and pay more attention [...]. In my opinion, in general in the health area, they (health professionals) always see patients, but they don't care and don't ask if they are disabled [...]. There is a difference between seeing regular patients and patients with disabilities. (W1)*

*They need to have interpreters for us (deaf people), having a sign language interpreter is essential. (W2)*

*It's hard to go to the appointment alone, the deaf community always depends on their mother or an interpreter. (W4)*

*During the exam, the gynecologist asks me a few questions before telling me to get changed. But it seems like those questions aren't being asked to me, you know? They're being asked to my mother. Because he doesn't look at me. I think it's just a lack of habit [...]. It would also be good for them (health professionals) to know sign language, so they don't have to depend on others. Having to take someone with me makes me feel ashamed. Sometimes I'd rather not go. (W5)*

## **UM 2 - Communication barriers generate dissatisfaction, nervousness, pain, fear, strangeness and embarrassment.**

*There is a lack of access, even care, in the interaction with the doctor, in the treatment and in the evaluation of our body [...]. I didn't understand very well how the procedure was performed (Pap smear collection), because I went alone and the professional didn't understand my doubts. (W1)*

*I was nervous because it was a professional (gynecologist) that I hadn't met yet, because the other one I knew was on vacation. So I had to explain my situation to him (that I'm deaf) and he had a little trouble understanding me. I decided to go to a private office with an interpreter who is a friend of mine. (W2)*

*It's strange because I don't really understand*

*how the exam works, what the doctor or nurse puts inside (the vagina). Sometimes it's uncomfortable, scary, I don't know if it's normal. I don't really like doing it, it's strange and you can't really know what's going on. (W5)*

## **DISCUSSION**

When providing care to deaf women, communication is often a significant challenge. However, nursing has the potential to overcome these barriers by providing clear and accurate information about the CC screening test. The goal is to empower women by promoting knowledge and autonomy regarding health care. However, in the narratives of the participants in this study, nurses are mentioned only in a generic way, as "health professionals", evidencing a common perception that considers the gynecologist as the only person responsible for the CC screening procedure. This view is contrary to COFEN Resolution No. 381/2011. <sup>(15-17)</sup>,

The deaf woman deals with things, being-in-the-world based on the significance of things and people that belong to her environment, through her significant references (the mother, the doctor, the health professional) and understanding her limitations in making herself understood by others who, unlike her, do not know sign language. This deprives her of her potential to be herself, and with this, the lack of effective communication can generate feelings of insecurity and distrust, resulting in the woman distancing herself from health professionals and compromising the bond with them and with the service. <sup>(18-19)</sup> In this sense, it is valid to question how these barriers contribute to the absence of the nurse in the participants' statements.

According to Heidegger, being-there (Dasein) is the form of existence that allows being to project itself into its possibilities. While other beings simply are, Dasein has the capacity to throw itself out of itself. <sup>(12)</sup> The deaf woman, when experiencing this existential condition, faces a deprivation of the potentiality of Dasein. It needs to be analyzed ontologically as a deprivation and ontically as a deaf-being. When comparing herself to others, the deaf woman perceives herself as more restricted in her ability to

respond to the demands of everyday life, evidenced by the limitations of communication and the feeling of helplessness, which could be alleviated with competence in Libras on the part of health professionals.

Participants highlighted the lack of interpreters and the lack of knowledge of Libras among health professionals, forcing them to be accompanied by family members, usually the mother. This scenario creates dependency and feelings of shame during the CC screening exam. In addition, many deaf women face the challenge of neglecting their own health needs, resulting in an inadequate understanding of the services offered and the importance of CC screening. <sup>(20)</sup>

Deaf women often have questions about gynecological procedures, such as the sensations expected during insertion of the speculum and collection of cytological material. They may also have difficulty communicating their discomfort, pain and feelings appropriately. <sup>(18-20)</sup>

Heidegger describes everyday discourse as a form of communication that seeks to maintain the possibility of understanding. Man, as an entity that has a unique relationship with his being, is the only one capable of accessing and extracting the meaning of being. <sup>(12)</sup> Thus, communication noise between health professionals and deaf women can impact these women's access to being-there.

Everyday life, according to Heidegger, is the way of being immersed in daily concerns, where choices are limited. For the deaf woman undergoing cytological collection, the experience occurs in profound silence, revealing a state of inauthenticity and impersonality. Fear can lead the deaf woman to not attribute meaning to the real need for screening, allowing others and circumstances to do so, resulting in an alienation from herself and a state of non-action. <sup>(12)</sup>

Fear, according to Heidegger, can be understood in three dimensions: what is feared, the fearing and what is feared for. For deaf women, the fear of not being understood and of feeling pain during the examination is an expected fear, but the unknown can transform it into horror. <sup>(12)</sup>

For those who do not experience deafness, it can be difficult to understand the



exclusion and ambiguity caused by lack of communication. However, it is crucial to recognize that communication goes beyond the transmission of information; it includes the sharing of the sensory experience of the world, shaped by our auditory, visual, tactile, olfactory and gustatory capacities. Therefore, reflection on the challenge of communication with deaf women must go beyond the technical and instrumental aspect. Language is an essential dimension of our existence, which allows us to reveal the meaning of the world and of ourselves.<sup>(20)</sup>

By remaining silent or delegating to an interpreter, the deaf woman does not reveal her anxieties, complaints and lack of knowledge, feeling enveloped by shame, apprehension, restlessness, pain and fear. She experiences a state of passivity, imposed by the lack of understanding of her world and its meanings.<sup>(18)</sup>

The world is more than a geographical space; it is the context of relationships established between beings, immersed in everyday life and predictable and unforeseen situations.<sup>(12)</sup> Deaf women feel insecure in their therapeutic journey due to the care they receive, from the reception. They strive to be understood and are held responsible for bringing an interpreter, despite this being a right guaranteed by law. This situation goes against the Federal Constitution and the principle of equity guaranteed by the SUS.<sup>(1-2;20)</sup>

Communication barriers interfere in the daily lives of deaf women, undermining their individuality and resulting in impersonal care that minimizes their self-identity. This causes discomfort and distress, affecting adherence to cancer screening recommendations.<sup>(20-21)</sup>

Language is essential to being, as it allows revelation through discourse. Therefore, it is necessary to reflect on the co-belonging between being and language, rescuing the revelatory capacity of the word.<sup>(12)</sup>

Feeling insecure when receiving health services shows that deaf women do not feel included in a public space, as if it did not belong to them, which goes against the principle of equity. Neglecting deaf women as part of society results in inadequate access

to health services and low adherence to cancer screening.<sup>(21)</sup>

The limited ability of health professionals to communicate with deaf people compromises prevention, health promotion and inclusion in services. The lack of knowledge of sign language makes it difficult to identify and meet the needs of these people.<sup>(18)</sup> Although the inclusion of Libras in the undergraduate curriculum is important, a single subject may not be enough to overcome the communication barrier.<sup>(21-22)</sup>

Studies show that the absence of interpreters results in a 63% dropout rate in consultations and that 61% of respondents say that health professionals are unable to understand them when they are unaccompanied.<sup>(21)</sup> This shows that the lack of interpreters or professionals qualified in Libras generates inefficiency in service.<sup>(22)</sup>

The lack of professionals fluent in Libras is a significant barrier, resulting in difficulties in providing adequate care. Even with interpreters, patients' autonomy may be compromised, as their experiences and needs may not be fully valued.<sup>(6-7;9;15-16;18-24)</sup> Decree No. 5,626/2005 guarantees the right to interpreters, but it is crucial that these professionals allow deaf women to actively participate in the care process.<sup>(23)</sup> To overcome these barriers, it is essential to recognize and value the particularities of deaf women, promoting practices that improve access and inclusion in health services.

While the study provides valuable insights into the experience of deaf women in CC screening, it has limitations due to the sample size, which may not represent the full diversity of women and the analysis of transcripts that may not capture all the nuances of nonverbal communication. The lack of comparison with hearing women also limits the understanding of communication barriers.

However, the study highlights the need to understand the specific needs of deaf women and to better prepare health professionals. The research emphasizes the importance of developing communication skills, such as the use of visual aids and the availability of sign language interpreters, to improve the effectiveness of care.

## CONCLUSION

When understanding the meanings of the existential movement of being a deaf university woman and the experience of the gynecological consultation for cervical cancer screening, it is clear that these women, when interacting with health professionals, face the barrier of a lack of mastery of sign language, which makes effective communication difficult, as professional-client interaction is not achieved.

The study participants revealed fear of not being understood, of feeling pain during the examination, shame, fear, and anxiety. Sometimes, when a third party is present during the consultation, they also feel invisible, in a state of passivity, as they delegate the answers to the health professional's questions to someone else.

During the gynecological exam, the patient is not the protagonist, nor is she at the center of the action, but rather, she perceives her body as an object of intervention, given over to technicality, and she perceives that her desires, feelings and questions are not valued. She experiences impersonal gynecological care, minimizing her identity, generating discomfort and anguish, perpetuating prejudiced attitudes that are culturally and historically rooted.

It is therefore necessary to include educational measures to support these women, from the moment they graduate, with the aim of promoting effective care, including understanding and autonomy, and guaranteeing health rights. And for a deeper understanding of the needs and challenges faced by deaf women in health contexts, future research could benefit from larger samples and methodologies that integrate different approaches. In addition, a more in-depth analysis of the training of health professionals in Libras could offer a more detailed view of how to improve communication and care.

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