

Welcome and listen to the silence: nursing care from the perspective of deaf woman during pregnancy, childbirth and postpartum

Acolher e escutar o silêncio: o cuidado de enfermagem sob a ótica da mulher surda durante a gestação, parto e puerpério

Recibir y escuchar el silencio: el cuidado de enfermería desde la perspectiva de la mujer sorda durante el embarazo, parto y puerperio

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How to quote this article:

Costa AA, Vogt SE, Ruas EFG, et al. Welcome and listen to the silence: nursing care from the perspective of deaf woman during pregnancy, childbirth and postpartum. Rev Fund Care Online. 2018 jan./mar.; 10(1):123-129. DOI: <http://dx.doi.org/10.9789/2175-5361.2018.v10i1.123-129>

ABSTRACT

Objective: to identify the perception of the deaf woman regarding nursing care during pregnancy, childbirth and postpartum. **Method:** this is a exploratory-descriptive study with a qualitative approach, carried out with nine deaf women of a northern city of Minas Gerais. It used a semi-structured interview in which the processing of data was through the Content Analysis. **Results:** deaf women faced difficulties in receiving assistance from the nursing staff during the perinatal period due to factors such as lack of preparation of professionals in the use of sign language; lack of interpreters in service; speakers who talk too fast; and the use of masks by professionals, making it difficult to read lips. **Conclusion:** the communication barrier is observed in the interaction between deaf women and health professionals, making it essential that both find ways to interact to ensure improved quality of care.

Descriptors: Deafness, Pregnancy, Nursing Care, Sign Language, Communication.

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RESUMO

Objetivo: identificar a percepção da mulher surda quanto aos cuidados de enfermagem durante a gestação, o parto e o puerpério. **Método:** trata-se de um estudo descritivo, exploratório, com abordagem qualitativa, realizada com nove mulheres surdas de uma cidade do norte de Minas Gerais. Utilizou-se uma entrevista semiestruturada na qual o tratamento dos dados se deu por meio da Análise de Conteúdo. **Resultados:** as mulheres surdas enfrentaram dificuldades na assistência prestada pela equipe de enfermagem durante o período perinatal devido à fatores como: despreparo dos profissionais quanto ao uso da linguagem de sinais; ausência de intérpretes nos serviços; interlocutores que falam rápido demais; e uso de máscaras pelos profissionais, dificultando a leitura labial. **Conclusão:** a barreira de comunicação é verificada na interação entre surdas e profissionais de saúde, tornando-se indispensável que ambos encontrem formas de interagir para garantir uma assistência de melhor qualidade.

Descritores: Surdez, Gravidez, Cuidados de Enfermagem, Linguagem De Sinais, Comunicação.

RESUMEN

Objetivo: identificar la percepción de la mujer sorda y la atención de enfermería durante el embarazo, parto y puerperio. **Método:** se trata de un estudio descriptivo, exploratorio, con un enfoque cualitativo, realizado con nueve mujeres sordas de una ciudad del norte de Minas Gerais. Se utilizó una entrevista semiestructurada en la cual el tratamiento de los datos fue a través del análisis de contenido. **Resultados:** las mujeres sordas enfrentan dificultades para asistir al personal de enfermería durante el período perinatal debido a factores como la falta de preparación de los profesionales en el uso del lenguaje de signos; falta de intérpretes en servicio; oradores que hablan demasiado rápido; y el uso de máscaras por los profesionales, por lo que es difícil de leer los labios. **Conclusión:** la barrera de comunicación se verifica en la interacción entre sordos y profesionales de la salud, por lo que es esencial que tanto encontrar maneras de interactuar para garantizar una mejor calidad de la atención.

Descriptores: Sordera, Embarazo, Atención de Enfermería, Lenguaje de Signos, Comunicación.

INTRODUCTION

The issue of the inclusion of disabled people in all spheres of society, is still very incipient in Brazil. Thousands of people with some form of disability are being discriminated against in the communities in which they live or are excluded from the labor market.¹ In other cases, the disabled are self-excluded because they feel inferior or isolate themselves from normal people and seek to coexist with those who have a similar disability.²

Each deficiency ends up causing a type of behavior and provoking different forms of reactions, prejudices and worries on the part of the people who live with those who have similar deficiency. Physical impairments, such as paralysis, lack of vision or limbs, cause immediate apprehension because they have greater visibility. On the other hand, the mental and auditory deficiencies are little

perceived initially by the people, but cause more stress as one becomes aware of their reality.

Prejudice regarding “different” people has been thoroughly criticized by sectors of society.³ In this way, the slogan is “inclusion”, because society has realized that benefits must be added to those who, for some reason, have not been able to achieve better results in the face of the challenges of modernity.

According to the Brazilian Institute of Geography and Statistics (IBGE), in Brazil, 23.9% of the general population has some deficiency, corresponding to 45.6 million people. Of these, 9.7 million have some hearing impairment, and 347,481 have declared themselves deaf. As for women, 4% of those aged between 15 and 64 years have some degree of hearing impairment.⁴

Hearing impairment can be conceptualized as: “Total or partial loss, congenital or acquired, of the ability to understand speech through the ear. It is manifested as mild or moderate deafness, which is the loss of up to 70 decibels and severe or profound deafness, which is hearing loss above 70 decibels.”^{5:166}

In view of the difficulty in communicating the deaf, the Brazilian Language of Signals (LIBRAS) was established, regulated by Law 10.436 of April 24, 2002, in order to standardize the gestures issued by the deaf at the time of communication.⁶ LIBRAS can be understood as a systematization of the signs used by the hearing impaired, although under the influence of culture and regionalism in Brazil and in other countries.

Among the laws that guarantee the rights of the hearing impaired, Portaria nº 2.073/2004, in its first paragraph, resolves “to promote the wide coverage in the service to hearing impaired patients in Brazil, guaranteeing universality of access, equity, Comprehensiveness and social control of hearing health”.⁷ However, in assisting the hearing impaired, there are no specific actions or professionals in the health units.

It can be seen that health care for deaf people does not resemble what the current laws guarantee, such as: the right to participate in decision-making about their health; The right to up-to-date, relevant and comprehensible information about their diagnosis, treatment and prognosis, and to know the identity of the doctors, nurses and others involved in their care, including students, residents or others trained; Besides the right to have an interpreter when their language is not understood.⁸

The deaf woman, because she is considered incapacitated and therefore carrying an asexual body, has the exercise of her sexuality questioned, and in the eyes of society, the woman’s body is only the bearer of biological functions. The hearing impaired, in addition to being discriminated against for being a woman, still suffers from prejudices and unequal treatment for her disability, which adds even more urgency to studies on the deaf woman in our society.⁹

Motherhood is currently becoming a conscious choice for the listener or deaf woman. In an inclusion approach, it is clear that deafness alone does not prevent a woman from choosing to be a mother.

The care provided during pregnancy, childbirth and postpartum should be redoubled and able to help the deaf woman overcome the obstacles imposed by the limitation of listening, speech and pregnancy itself. Good care and effective communication assume an even greater proportion than normal, since this mother faces the difficulty of not being understood by health professionals, who are generally not prepared to establish an adequate communication process.¹⁰

Therefore, the objective was to identify the perception of the deaf woman about the care received by the nursing team in prenatal, childbirth and puerperium, under a social inclusion approach.

METHODS

“Nursing Care and Nursing Care from the perspective of pregnant and deaf parturient” presented to the Multiprofessional Residency Committee - COREMU, University Hospital Clemente de Faria/State University Of Montes Claros (HUCF/UNIMONTES). Montes Claros - MG, Brazil, 2014.

This is a descriptive, exploratory, qualitative study carried out with nine deaf women aged between 27 and 43 years, enrolled in the Association of Disabled Persons of Montes Claros - ADEMOC, residents of the urban area of Montes Claros/MG, who presented a historical Gestation and who knew how to communicate through LIBRAS. In this way, the women who, although enrolled in ADEMOC, did not present the other characteristics for inclusion were excluded from the study.

The sample was closed by saturation of the data. This type of sampling considers the number of subjects sufficient when the data obtained present in the evaluation of the researcher some redundancy or repetition, and it is not considered relevant to persist in the data collection.¹¹

The use of the qualitative approach is justified by allowing the search for the universe of meanings, motives, aspirations, beliefs, values and attitudes, which corresponds to a deeper space of relationships.¹¹

The data collection was done from a semi-structured interview composed of five questions that dealt with the subject and was previously scheduled according to the availability of the interviewees, and the women's approach was mediated by an interpreter with a LIBRAS domain.

After previous contact for scheduling the date and time, the interviews were conducted in the period from August to October 2014, in the participants' homes and filmed. At the end of the collection, the data were transcribed, organized into categories and later analyzed according to the thematic content analysis technique,

which consists of discovering the sense nuclei that make up a communication whose presence or frequency is significant for the analytical objective.¹²

In order to guarantee the anonymity, privacy and confidentiality of the participants' identity, their names were replaced by the letter “M” followed by the number representing the order of the interviews (M1, M2, M3, M4, M5, M6, M7, M8 and M9).

The study obeyed the ethical precepts established by Resolution 466/2012 of the National Health Council, which regulates the conduct of research involving human beings. The project was appreciated and approved by the Research Ethics Committee of the State University of Montes Claros (CEP UNIMONTES), with Opinion No. 625.966/2014, Presentation Certificate for Ethical Assessment (CAAE) nº 26538414.2.0000.5146. The women who agreed to participate in the study signed the Informed Consent Form (TCLE) in two ways.

RESULTS E DISCUSSION

Nine deaf women enrolled in ADEMOC participated in the study, who declared that they had already undergone parturition. The interviewees were between 27 and 43 years old, being five single women, three married and one in stable union. Regarding the level of schooling, most of them have completed secondary education (six women), one has a full course, one is studying higher education and only one woman has a primary education. Of the participants, six alleged to carry out some formal work activity and three affirmed to dedicate themselves exclusively to the activities of the home.

The number of deaf people who said they were single mothers led them to reflect on the inefficiency of family planning strategies. The Family Planning Policy exists for all women, but the deaf do not seek the services because they are unaware of them or, when they seek, they are not fully served by difficulties related to communication.¹³

The number of live children among the interviewees ranged from one to two children, including a woman who had twins. None of the children had been diagnosed with deafness so far. Among the women interviewed, three had two pregnancies, and six women had one gestation, one of whom was pregnant with the second child at the time of the research. Two women reported a stillbirth story each. Regarding the type of delivery, six women had vaginal delivery, one of them with the help of forceps, and three underwent cesarean delivery.

Studies describe that the most frequent reasons for seeking the health service by people with severe or profound deafness are: headache, stomach pain, reasons related to gestation, earache and cough.¹⁴ Therefore, discussing issues related to the assistance provided to the deaf woman in the perinatal period is relevant so that the health professional is prepared to deal with the particularities of the deaf.

There are health professionals who associate hearing impairment with other disabilities and eventually consider the deaf woman civilly incapable of fathering a child. These women are sometimes subjected to sterilization treatments without their free and informed consent, as they are limited due to a lack of effective communication with family members and health professionals.¹³ This fact is inconsistent, since the interviewees take care of their children independently and prevent a deaf woman from deciding whether or not to raise children should be considered disrespect for human rights.

It is known that the choice of the woman in relation to the type of delivery, as well as her satisfaction with the whole process, is related to the fact of having information and control over the event, the degree of relaxation and the positive opinions about the team that Provided care, in a caring and affectionate manner, in addition to the presence of a chaperone. Regarding the type of delivery, the number of women in the sample who underwent cesarean section reflects the high rate of cesarean deliveries throughout Brazil, reaching 52% of births in general, when the recommended by the World Health Organization (WHO) is at most 15%.¹⁵

The assistance provided by health professionals to the gestation, delivery and birth of deaf women is characterized by an impersonal relationship, in which the professionals are distanced. The relationships are asymmetric, based on poor communication, and the use of technical terminologies that make it difficult for women to understand.¹³

The data were analyzed and gave rise to two categories: nursing team performance in the care process; Barriers in the communication with the nursing team.

Nursing team performance in the care process

It was unanimous the report of the participants about the little contact with the nursing team during the gestation. The prenatal care of deaf women was performed by the physician, although only one woman interviewed had a high-risk pregnancy due to hypertension. One interviewee reported having undergone pre-cancer cervical cancer screening with the Family Health Strategy nurse.

“My prenatal visit was with the doctor by agreement. I have never had contact with the ESF nurse” (M2).

“The doctor took care of me. The nurse did my prevention. When I got there she just took my identity and filled out a paper, gave me a nightgown and showed the bed. I lay down and she took the exam. I was afraid because she did not explain to me what I was going to do.” (M7).

“The health worker came home to make the appointment. I did not consult the nurse because I had high blood pressure and only the doctor could take care of it” (M1).

During childbirth and puerperium, women also reported restricted contact with the nursing staff. Some interviewees did not know if they were attended by any component of the nursing team throughout their stay in the hospital and others said they received few guidelines that were more directed to preterm delivery and breastfeeding.

“Nursing staff went to the room only sometimes and asked how it was. I was very thirsty but could not explain” (M6).

“In childbirth I cannot remember if I had a nurse. I do not think so!” (M7).

Breastfeeding is an educational and assistance item to be worked from prenatal and extended to childbirth and puerperium, as it helps and clarifies to women the importance and the right to enjoy the practice of early contact and breastfeeding. However, through the speech of one of the interviewees, it is understood that the few attempts to assist in breastfeeding were ineffective due to the difficulty of communication.¹⁶

“The nurse came into the room and mimed trying to explain how I was going to nurse. He put the baby’s mouth in his chest and stayed there until he got it, but when he got home I did not know how to do it and my chest hurt” (M9).

Through the report of one of the women it is inferred that there were divergences among nursing professionals when carrying out guidelines.

“They guided the walk at the time of delivery, but it was difficult because one nurse said she could and the other told me to lie down” (M4).

Gestation is one of the moments in life in which the woman experiences a range of feelings. She feels joy when the gestation has been desired and, if not expected, may present surprise, sadness and even denial. Anxiety and doubts about the changes that will occur, about how the child is developing, fear of childbirth, not being able to breastfeed, among others, are also common feelings present among women.¹⁷ In non-verbal pregnant women, these feelings, both good and bad, are intensified by the difficulty of establishing dialogue to express doubts and apprehensions and to receive the proper guidelines.

An appropriate prenatal obstetric care prepares the woman for motherhood as a whole. During this period the woman receives guidelines on nutritional habits, hygiene, exercises, corporal modifications, prevention of gestational diseases, among others.¹⁸ All these guidelines can be carried out through the nursing consultation, which is an independent activity, carried out privately by the nurse, and aims to provide

conditions for the health promotion of pregnant women, whether deaf or hearing.

According to the Ministry of Health and as guaranteed by the Professional Exercise Law, regulated by Decree No. 94,406 / 87, the nurse practitioner can fully follow low-risk prenatal care in the basic health care network.^{18,19} The total number of consultations should be at least six, with follow-up between doctor and nurse, and situations considered as risk should necessarily be referred to a referral service, and the basic health unit should remain responsible for the follow-up of the pregnant woman in primary care.¹⁵ It is emphasized that deafness at any level is not considered a gestational risk factor. Therefore, the fact that pregnant women, including those who reported hypertension, was not accompanied by medical professionals alone.

Throughout labor, nursing professionals should partner with women to clarify procedures and conduct their participation to minimize fears of childbirth and provide security.²⁰ However, what is perceived in the reports of deaf women is the relation of power exercised by the professional, when it addresses the woman with neglect, restricting her freedom of expression, without giving the parturient the space to express their feelings.

“At the time of delivery, the nurse who had already gone in the room before, pushed my belly, but I did not even complain because I thought it was normal to do this” (M5).

After birth, doubts arise that can be cured with prenatal guidelines, however, new doubts naturally tend to appear.²¹ The role of the nursing team in assisting deaf women in the puerperal period is very important for the identification of puerperal complications, as well as for providing subsidies that allow women to obtain autonomy in their health through self-care and security in the care of the newborn. However, what was found was a gap in this care process, leading the deaf woman to face a series of doubts and difficulties to play the maternal role.

Barriers in communication with the nursing team

Most of the interviewees stated that they did not find any facility in the communication with the nursing team in the perinatal period. Of the three women who reported some ease, the communication was related to personal factors and even the contribution of roommates in the hospital, not the attitudes of the professionals who attended them.

“The facility was having my mother-in-law with me and knowing how to do lip reading” (M6).

“Everything just was not more difficult because I wrote some words and she understood more or less” (M4).

“It was easier because the woman in the bed next to me in the room knew how to mime and taught me some things” (M5).

As for the barriers in communication with the team, the women pointed out the lack of interpreter of pounds in the services, the dependency of a familiar during the attendances, the lack of knowledge of the professionals on notions of LIBRAS, the speed with which the professionals were orally expressed and the masks by professionals.

“Nurses do not know pounds and have no patience. At the hospital, my mother-in-law said that one of them complained that I was making a lot of noise at the time of delivery and was nervous” (M6).

“It’s hard to have to take my mother everywhere I go. Professionals should know the LIBRAS” (M5).

“Sometimes I was not even going to see the doctor. I wanted an interpreter available because the people I know have other commitments” (M8).

“It was difficult to breastfeed. My son only suckled two months, my milk dried up and I did not understand the girl’s explanations” (M3).

“I know how to read lipstick, but with the mask and how quickly they spoke I could not” (M2).

Among the barriers, those interviewed who had the experience of having stillborn children or with a health problem reported the difficulty to understand what had happened to the children.

“When my daughter died I only knew the day after because no one could explain it to me. I did not even see her” (M3).

“I only learned that my son had died when the nursing woman came to talk to my sister in the room and I did lip-reading. I was sad and curious to know what had happened” (M7).

“I heard about the cleft lip still in the gestation and I searched the internet, but no one in the hospital came to explain me better. My grandmother told me not to be sad because just as I was deaf and I was able to win, my baby would also be well” (M4).

Communication is indicative of quality of life, so when professionals know how to communicate with the deaf, they promote humanized health care focused on the context of an inclusive society.²²

The legislation establishes that public institutions and concessionaires of public health care services must provide adequate care and treatment to deaf people, but it is perceived that the absence of the professional interpreter in LIBRAS in the health services transfers to the relatives and friends of women the responsibility of accompanying them in clinical consultations. Although it may be an aid, the companion can become a problem when he does not allow the deaf to actively participate in the conversation, since it is he who explains to the professional the difficulty presented by the woman and receives the guidelines, limiting the individuality necessary and minimizing the opportunities of customer to state their doubts.^{23,24}

In order to have a satisfactory nursing care, it is necessary to know the importance of the communication between the staff and the client as support and systematization of the development of the nursing process in all its phases, independent of the specialties of the health area, allowing the personalization of the assistance and, At the same time, the provision of necessary, competent and humanized care.

It is noticed that it is not only the deaf that finds barriers when looking for the health service, but the hearing women and the nursing professional who attends to it as well. A study carried out with 78 women in a maternity hospital in Ceará shows that the puerpers note as reasons for dissatisfaction the delay in care and the difficulties or neglect in the communication, since, besides the professionals use a language of difficult understanding, they are a lot of information and Content mismatch.²⁵ When there is no effective communication, there is no way to help women solve their problems and minimize conflicts.

In general, the feelings of nurses and other professionals in dealing with the deaf are frustrations, impotence and impatience, because they can not maintain communication, either through sign language or lip reading, thus tending to transfer responsibility family members, often going unnoticed by the anguish and difficulties that the users suffer.²⁶ In relation to the use of writing for communication, sign language has grammar and vocabulary different from written Portuguese and, in this way, a person who was born deaf in Brazil may be fluent in LIBRAS and not master written Portuguese, being of great It is important that health professionals be trained in sign language with continuing education to improve the quality of nursing care provided.^{27,28}

Since some deaf people do lip-reading, which helps a lot in the process of professional-deaf communication, nursing team professionals should look directly at the woman while speaking slowly and should still avoid hiding their face and lips with hands, hair, objects and surgical masks.²⁸

During the interviews, spontaneously, the women gave suggestions to facilitate communication and improve the care received in the health services.

“Having an interpreter is interesting, but it would be best if all the professionals knew how to talk to us without mediators.” (M3).

“It would be good if at least one team professional knew how to talk to us. Doctors spend little time with us. Nurses stay longer, so they should be trained” (M2).

“Having a professional interpreter is better because if we take someone we are afraid of gossip, of telling our intimacy to the deaf community” (M8).

The presence of the Libras interpreter in the health services is already foreseen in the Law, although, apparently, it is not being fulfilled. Law No. 10.098, of December 19, 2000, known as the Accessibility Act, in its Chapter VII (Accessibility in communication and signaling systems), article 18 states that: “The Public Power will program the training of professional writers In braille, sign language and guide-interpreters, to facilitate any type of direct communication to the person with sensory deficiency and with communication difficulties “.²⁹

The Unified Health Service (SUS) must provide communication accessibility for the deaf in any health care unit, since it is the universal right to health, it is necessary that federal entities comply with accessibility standards in health services, Measures to be taken to provide better.²²

The deaf value the presence of the interpreter to improve communication, but with some reservations such as distrust, embarrassment to expose oneself to the interpreter, a feeling of pity and difficulty in finding interpreters available.²²

An interesting suggestion is the continued education in LIBRAS, that is, the professionals would have the opportunity to learn sign language, would be continuously updated and monitored regarding the performance in the exchange of information with the deaf through LIBRAS.²⁴

CONCLUSION

Communication is one of the main instruments in assisting the deaf woman during pregnancy, childbirth and the puerperium, and it is also the greatest difficulty of the nursing team with this clientele. Having the capacity to interpret and understand how the human relations that produce the engagement are built will certainly allow us to provide assistance that meets the woman's expectations and gives her the perception of belonging, reciprocity and respect. Through the reports of deaf women we can see the lack of contact with the nursing team during the perinatal period, and the clients faced difficulties in the care provided by the professionals due to factors such as: unprepared professionals regarding the use of LIBRAS, Absence of interpreters in

services, speakers who speak too fast and use of masks by professionals, making lip reading difficult.

The dissatisfaction of the deaf with the services provided is not general, since some professionals have tried to program ways of relating effectively in order to provide well-being and transmit greater confidence, either through mime or written communication. The communication barrier is verified in the interaction between deaf-health professionals, making it essential that both find ways to interact to ensure better quality care. Verbal or non-verbal communication is part of human existence, and it is up to the nursing team to use it to provide satisfactory care for pregnant women, parturients, and puerperal women. The changes are difficult and slow, but some proposals can be put into practice immediately, such as bringing the discussion about non-verbal communication to the spaces of health practice.

In the scientific field, studies are still incipient, involving the analysis of the use of health actions and services by deaf women in the perinatal period, which indicates the need for further research in this line of study in order to produce knowledge and subsidies for political actions.

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Received on: 09/06/2016

Reviews required: 05/05/2017

Approved on: 01/04/2017

Published on: 01/08/2018

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