

Access to health services by blind mothers: from coping to learning

Acesso aos serviços de saúde por mães cegas: dos enfrentamentos aos ensinamentos

Acceso a los servicios de salud por madres ciegas: del enfrentamiento a la enseñanza

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Abstract

Objective: To know according to the perception and experiences of blind mothers how access to primary health care services occurs in the city of Fortaleza, Ceará.

Methods: This is a qualitative study conducted in the city of Fortaleza, Ceará, with twenty blind mothers who had children from zero to ten years old. Data collection took place in the first half of 2017 through semi-structured interviews. Symbolic Interactionism was used as a theoretical framework and thematic content analysis, according to Bardin, as a method of analysis.

Results: Data analysis allowed us to understand how the experience of accessibility of blind mothers in health units takes place. The categories learned in the study were: "Accessibility of blind mothers to health units" and "Children care in health units". The professionals' lack of ability to care for people with disabilities was evidenced, pointing out a serious problem that needs to be minimized, with the preparation of these professionals from public health network since their academic training.

Conclusion: It is also considered that much needs to be transformed in health services in search of accessibility for people with disabilities. The need to comply with legal standards in search of easier access for these blind mothers and their children to public services is evident.

Resumo

Objetivo: Conhecer na percepção e vivências de mães cegas como ocorre o acesso aos serviços de atenção básica de saúde em Fortaleza, Ceará.

Métodos: Trata-se de um estudo de abordagem qualitativa realizado na cidade de Fortaleza-Ceará, com vinte mães cegas que tinham filhos de zero a dez anos de idade. A coleta de dados ocorreu no primeiro semestre de 2017 por meio de entrevista semiestruturada. Utilizou-se o interacionismo simbólico como referencial teórico e a análise de conteúdo temática, segundo Bardin, como método de análise.

Resultados: A análise dos dados permitiu compreender como se dá a experiência de acessibilidade das mães cegas nas unidades de saúde, sendo que as categorias apreendidas no estudo foram: acessibilidade das mães cegas às unidades de saúde e o cuidado prestado às crianças nas unidades de saúde. A falta de habilidade dos profissionais para atender as pessoas com deficiência foi evidenciada, apontando um sério problema que necessita ser minimizado, com a preparação destes profissionais que atendem na rede pública de saúde, desde a sua formação acadêmica.

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Conclusão: Considera-se, ainda, que muito necessita ser transformado nos serviços de saúde em busca da acessibilidade da pessoa com deficiência. Evidencia-se a necessidade de cumprir os padrões legais em busca do acesso facilitado a essas mães cegas e seus filhos aos serviços públicos.

Resumen

Objetivo: Conocer cómo es el acceso a los servicios de atención básica en salud según la percepción y vivencias de madres ciegas, en Fortaleza, estado de Ceará.

Métodos: Se trata de un estudio de enfoque cualitativo realizado en la ciudad de Fortaleza, estado de Ceará, con 20 madres ciegas que tenían hijos de 0 a 10 años de edad. La recolección de datos se llevó a cabo el primer semestre de 2017 mediante entrevista semiestructurada. Se utilizó el interaccionismo simbólico como referencia teórica y el análisis de contenido temático, según Bardin, como método de análisis.

Resultados: El análisis de los datos permitió comprender cómo es la experiencia de accesibilidad de las madres ciegas en las unidades de salud, y las categorías captadas en el estudio fueron: la accesibilidad de las madres ciegas en las unidades de salud y los cuidados que reciben los niños en las unidades de salud. La falta de habilidad de los profesionales para atender a personas con discapacidad es evidente, lo que deja ver un serio problema que debe ser mitigado con la preparación de estos profesionales que atienden en el sistema de salud pública, desde su formación académica.

Conclusión: Se considera que aún hay mucho para cambiar en los servicios de salud para lograr la accesibilidad de la persona con discapacidad. Queda en evidencia la necesidad de cumplir los estándares legales para facilitar el acceso de estas madres ciegas y sus hijos a los servicios públicos.

Introduction

Accessibility as a principle of the Brazilian Unified Health System (SUS - *Sistema Único de Saúde*) guarantees the offer of services, which must be qualified to meet and solve the main problems to those who demand them.

Accessibility is a concept closely linked to the rights of people with disabilities. These individuals receive this name due to having a partial or total loss of body functions or structures, including psychological ones, which results in them facing specific and susceptible difficulties in limiting activities or restricting participation in social, economic and cultural life.⁽¹⁾

According to the Brazilian Association of Technical Standards (ABNT, equivalent to ANSI from the United States), space, building, furniture or element that can be reached, visited and used by anyone, including those with any kind of disability, are accessible.⁽²⁾ This standard uses the concept “accessible” for both physical accessibility and communication and signaling, defining accessibility as the possibility and condition of outreach for use, with security and autonomy, of buildings, space, furniture and urban equipment.⁽²⁾

The principle of accessibility transcends the understanding of the need for a health service close to its reality experienced by the community. It is evident that the Family Health Strategy (FHS) seeks to offer, in its assistance dynamics, greater access and resolvability for users.⁽³⁾

Based on the current health policy in Brazil, there is a need for comprehensive care to people

with disabilities and their families, enabling their inclusion in the community and improving their quality of life, according to their possibilities.⁽⁴⁾

According to IBGE (*Instituto Brasileiro de Geografia e Estatística* - Brazilian Institute of Geography and Statistics) data⁽⁵⁾ it is estimated that there are about 140 thousand blind people, members of society. However, there is no more detailed information about their accessibility to primary care services.⁽⁶⁾

Blind women, as part of normal human development, can generate children at some point in their life, being able to care for and monitor their development, even if they need family and health support.

Studies carried out in Fortaleza found the complexity of situations experienced by blind parents when they breastfeed, feed, bathe and administer medications. Visually-impaired parents develop creative strategies in caring for their children with smell and touch use, the support of family members and neighbors. They reinforce that health professionals, especially nurses, should be closer to these people and produce knowledge for this group so little contemplated in our society.^(7,8)

Based on these studies that have been developed by researchers in the state of Ceará, with blind people, some questions have arisen to deepen this theme, namely: How are blind mothers being welcomed into the public health service? What are the facilities and difficulties to obtain easy access to primary care services in Fortaleza?

Thus, as a contribution to the more in-depth debate with the academic society and the commu-

nity in general on this topic, this research aimed to know access to health services according to the perception and experiences of blind mothers from Fortaleza in primary health care services.

Methods

This is a qualitative study carried out in Fortaleza, CE, from March to July 2017, with blind mothers and who had children aged 0 to 10 years old (covering first, second and third childhoods), phases in which children are more susceptible to diseases or health problems and have more needs for care and search for health services.

The population consisted of twenty mothers, obtained intentionally, using the snowball technique, in which a subject indicates an acquaintance, with the characteristics defined for searching the community.⁽⁹⁾

To define the number of participants, we adopted the data saturation technique, which occurs when the information analyzed becomes repetitive, that is, new ideas or concepts do not appear during the interviews.⁽⁹⁾

Identification of blind mothers registered in the municipal health system of Fortaleza was also used. There were difficulties, however, to find blind mothers in the public network, as there is no specific record in the health system, of users with some type of disability. This record also does not classify the different types of disabilities, such as physical, visual, auditory, and mental. Contacts were obtained based on the indication of visually impaired people, as well as calling by radio and TV stations in Fortaleza, who reported the objectives of the research and asked those who knew a blind mother to call the research support phone.

The blind mothers interviewed were between 21 and 42 years old; four had incomplete elementary school, four had completed elementary school, eight had completed high school, two had graduate degrees and two did not answer the question; 16 of them lived in a stable union and 4 were married, all had their own home, with adequate sanitary conditions and had a family income above the minimum

wage; 17 had had their children by c-section and 03 had normal labor.

In the first stage of data collection, a multiple-choice form was read and completed by the interviewer, according to the answers given by the blind mother interviewed. The form privileged aspects of identification (age, education, type of visual impairment, marital status, occupation, type of housing, sanitary conditions of the home, family income, age of the child, and type of delivery).

In the second moment, the interviewer conducted an individual interview with blind mothers, using a script with semi-structured questions in relation to access to health services, with the following guiding question: How do you use health services when you need a doctor's appointment or another health professional? They were carried out in the mothers' homes, using recording, previously allowed, to obtain greater reliability of the verbalized reports. The duration of each interview ranged between 55 and 122 minutes.

To understand the data obtained in the interviews, Symbolic Interactionism was used as a theoretical framework. Symbolic Interactionism is based on three premises: human beings act in relation to things, based on the meaning they have for them; these meanings are the result of social and individual interpretation established with other people; and these meanings are modified based on the interpretive process used by the person when dealing with experienced situations and found objects.⁽¹⁰⁾ In the perspective of Symbolic Interactionism and in the scope of the research, meaning emerges from the process of interaction between blind mothers and health professionals in the services they seek when caring for their children.

Transcripts of the speeches and repeated readings of the collected narratives were carried out. They were submitted to the Thematic Content Analysis technique.⁽¹¹⁾ After an in-depth analysis of the statements, two categories were identified: *Accessibility of blind mothers to health facilities*; and *Children care in health units*.

The Research Ethics Committee of the *Universidade Federal do Ceará* approved the project. The research participants signed the Informed

Consent Term, after reading by the interviewer and with the presence of a witness, trusted by the blind mother.

It should be noted that this study followed all the criteria established in the instrument Consolidated Criteria for Reporting Qualitative Research (COREQ) as a support tool in relation to the standard for qualitative study reports.

Results

Data analysis allowed us to understand how the experience of accessibility of blind mothers in health units takes place. The aforementioned categories will be described below, illustrated with data extracted from the mothers' speeches.

Accessibility of blind mothers to health facilities

Mothers reported that they started prenatal care as soon as they discovered pregnancy. Some of them said that, in the Basic Health Unit, professionals referred them from an early age to a secondary or tertiary level institution, because since they are visually impaired, they were considered to be "at risk" for a premature birth or the possibility of some complication. Those who had the opportunity to pay for a private plan mentioned the difference in service, especially in the more pronounced number of complementary tests that doctors requested, as they describe:

I immediately tried to carry out prenatal care, take care of everything correctly, for me, it was the same way. From the other daughter I was assisted more because in the last consultations I had two prenatal visits, because the other daughter I had in Caucaia (municipality located in the metropolitan region of the city of Fortaleza), which was where I was sterilized (I6).

... here at the clinic, when I went, they said they would not be able to stay with me... it was a doctor who said she would not stay with me because I was that way (blind), I was very narrow, I was disabled and everything, so she thought I would not

be able to have a child and if I had the child, the child would be born six months later (I1).

Look, at the time of my last pregnancy I had a health plan, then in relation to health plan you know how it is, one test after another (I4).

The interviewed mothers also reported that, in most cases, prenatal care was limited to routine physical examinations, such as measuring waist circumference, assessing the weight and auscultation of the baby, without guidance on maternal and child care:

Then the doctor would put on (measuring tape) and measure the belly and listen to the baby's heart and see if everything was okay with him (I12).

It was just the weight, checking the pressure and measuring the belly and that's it, nothing else (I8).

It is important to note that some mothers revealed that they did not have access to health education, such as guidance on breastfeeding and newborn care. There were also no moments of dialog between mothers and health professionals about the mother's psychosocial conditions, showing the lack of holistic and humanized care by health professionals, as can be seen:

Normal. Prenatal care. When I got there, I attended the prenatal consultation and I left. I didn't talk, I didn't talk about breastfeeding and baby care, no (I16).

... during pregnancy I had no explanation... I didn't talk about breastfeeding. He talked only about rest, for me to have rest, not to do anything, things like that, but not with the baby (I7).

The interviewed mothers also described their moments when they arrived at the maternity hospitals, pointing out the lack of clarification about labor and the decision made by doctors to opt for c-section, as a way to "relieve suffering", as they describe:

Then I went, I spent the whole night, there was no anesthesiologist at the time. I arrived on Sunday, there was no anesthesiologist so I waited, when it was six in the morning, the doctor touched... then she said, "boy" you could wait, but it is more suffering. It is better to have it soon because it is so much suffering for you as for the baby. Everything was normal, but it didn't break. Then she said, "I'll do it soon". She immediately called the anesthesiologist to arrive early, ahead of time, then he did it. It was only fifteen minutes; it was really fast (I20).

At the time, we are insecure, but soon after, we start to have greater security, because then, when you are on the side of the professional who is treating you well, we start to trust (I2).

Mothers also reported that companions were not allowed into the delivery room, describing their feelings of insecurity and fear, as they were alone. The lack of sensitivity of some professionals in the delivery room is pointed out as an important element to increase the feeling of loneliness and anguish, experienced by these blind women, during delivery, as they report:

Then I was just in a room, alone, I didn't even have another woman to moan with me... there was no companion. Only had a companion at night when I had the baby already... then I found it sad, very cold, you feel abandoned, the person arrives just to stare at you, because you start to moan due to nervousness, it's not even because of the pain. It's nervousness, you see everyone having a baby and you don't. Because it was just me, because I started to suffer... (I18)

No, no one came in, (the husband) was left out and came home and that's it (I3).

Children care in health units

The choice of care is based on trust and empathy between health professionals and users. Mothers consider that the consultation with their children is not satisfactory, as there was no interest from professionals in carrying out a more in-depth consulta-

tion, in which a longer time was used, sufficient to carry out an adequate clinical examination. With attention to these statements, it is reflected on the quality of child care, the daughter of blind mothers.

At first, at his first appointment I didn't like it very much. That was all he did, he asked if the child was eating well and everything, but he did not examine the child at all (I5).

Ah, I think so, it leaves a lot to be desired... it is quite closed. They don't have a lot of time for the child, they don't examine him/her, because they really don't even have space, the space is very small, so there's no way to monitor the child right there (I17).

Mothers also claim the right to accompany their children and demand to be recognized as competent to take care of them and accompany them to the health unit:

Quite difficult, because they do not even understand most of the time that we can go to that health center with their child, they think we have an obligation to take someone who can see (I2).

... right after the entrance, the staff didn't want me to enter with the boy. I had gone with a person that I don't know well. People wanted me to let her in with the boy because I was blind... I fought because the son was mine, I had to come in, they thought that because I was blind, I couldn't keep up... (I9).

However, users feel well cared for, especially when their autonomy is respected and they participate in their healing process. In the following statements, it is clear how the bond formed between blind mothers and the service allowed effective health care:

...when I am going to apply his vaccine... the nurse who was applying his vaccine explained to me how she could do it. Then he said what I could do with him if he happened to be very sick with the thigh vaccine, he said that I could apply ice so it wouldn't

hurt too much. So, it was very explanatory even I liked it (I11).

They treat well. Nurses do everything to not separate the baby from me, to be careful to go with me because the biggest fear I have is of having to separate one of them from me... (I13).

Discussion

Facilitated access to a pregnant and puerperal woman is understood as an essential element for early diagnosis, in addition to the establishment of a dialogical relationship between the health professionals of the units and the clientele.⁽¹²⁾ In the case of a woman with a disability, in addition to the communicational approach, it is essential to have a physical structure that provides an easy entrance to the health unit, with ramps and appropriate reception.⁽¹³⁾

The professionals' lack of ability to care for people with disabilities was evidenced, pointing out a serious problem that needs to be minimized, with the preparation of these professionals from public health network since their academic training.

It is noticed that there is a preference of professionals for more sophisticated exams, leading to an early reference to services, where the technological capacity is greater and that access to these procedures becomes easier in private health plans. Sterilization use demonstrates the failure in reproductive planning, which should be added to prenatal care, offering women autonomy over their bodies, without undergoing surgical procedures.⁽¹⁴⁾

According to reports, prenatal care was limited to routine physical examinations. These procedures allow an early detection of risk factors in pregnancy, such as hypertension and diabetes, which can lead to a complication, frequent causes of maternal and perinatal death during childbirth. Generally, prenatal care is carried out to monitor fetal growth, supported by the length of the pregnant abdomen. Blood pressure and weight values, procedures for monitoring the pregnant woman's health are checked to see if there are any risk conditions.⁽¹⁵⁾

However, there was no guidance on maternal and child care, which leads to reflection on the quality of prenatal care, in which the physical health of the pregnant woman and the fetus must be addressed. Actions must also be integrated to aspects of psychosocial health, given that this woman needs this support, both from the community and the family, as well as from professionals, to be successful in childbirth and childcare.⁽¹⁶⁾

The lack of access to health education, including essential guidelines related to breastfeeding and care for the newborn, was evidenced. Although breastfeeding is a natural practice, it is not entirely instinctive, and support is needed, especially in the case of a visually impaired mother.⁽¹⁷⁾

Health education practices must be geared to the client's specificities, aiming at an adequate understanding of this knowledge to make it daily practices. In the case of the blind, the communication necessary to guide the remaining senses, such as smell, touch and hearing, must be reinforced, thus surpassing what is traditional, since the main technology used for health education is visual materials.

In the researched universe, the fragility of the mothers' reception at the time of admission to maternity and the lack of clarification about labor were present. The birth of a child is followed by a series of emotions, feelings of uncertainty, which historically reinforces a condition of fear and anxiety for women throughout the gestation period. In Brazil, there was a change in the natural practices of childbirth, with a high prevalence of c-section.⁽¹⁸⁾

Authors describe that there is greater acceptance for natural childbirth, when guidance on childbirth procedures is provided, the technical training of the professionals involved in using non-medicated analgesic techniques, as well as the companion's involvement during the entire labor. Nurses are the professionals who most encourage this type of delivery.⁽¹⁹⁾ In some cases, however, surgical intervention is necessary, in which the safety of life of the mother-child binomial must be prioritized.⁽²⁰⁾

Another aggravating factor was the fact that companions were not allowed into the delivery room. The right to the companion's presence is guaranteed at the time of delivery, and there must be an adjust-

ment of the physical space and the team's approach to adequately receive a new member of the delivery room. The monitoring of a family member, partner or friend during childbirth increases the woman's confidence in being a mother, decreases analgesic medication use, reinforces the woman's autonomy in decisions about her body and increases breastfeeding time. At some point, professionals may be able to participate in the support network of these women, offering them confidence and emotional comfort.^(21,22)

It is known that it is important to integrate a multidisciplinary team to provide adequate care to the child, with consultations that assess the development and promote disease prevention actions. Another important factor is the participation of parents in the consultation, as they are the main source of information about the child, referring to family history, the situation of the community in which the child is inserted, the support network necessary for the child's development. Service must be personalized and holistic, using forms only to guide the consultation, which are adapted to that situation. The information transmitted to the parents must be reinforced with some informative material for its effective collection.⁽²³⁾

In the case of blind parents, this information must be available in tactile and auditory material, and may even be available electronically for the blind, with internet access. Technology use should assist the health professional in transmitting knowledge related to health education to the blind clientele, allowing the accessibility of this information.⁽²⁴⁾

The bond formed between health professionals and users promotes adequate care, in accordance with SUS (Brazilian health system) principles. For the services to be effective, it is necessary to have a team committed to the work, in sufficient numbers and who listen to the user's opinions, modifying the service according to the needs of the clientele. Thus, a service is formed in which there is participation between users and professionals to make access to health services comprehensive and effective.

Regarding children, mothers feel responsible for their children's health and as their caregivers. Therefore, it is important to respect their right to

accompany them to the health unit. Regardless of her disability, the blind mother is able to take care of her children and, like other women, she is usually the family caregiver, thus being responsible for accompanying the child to health services.

Mothers are able to adapt to stressors in caring for their children, some with the help of others, and others with determination and creativity, that is, they think, reformulate ideas, recreate strategies and methods to properly implement all care autonomously.

Conclusion

It is believed that this work can contribute to the knowledge of how motherhood is experienced in the context of visual impairment, considering that amid the results obtained with the theory of symbolic interactionism, health professionals have been able to identify and recognize the elements that compose it and thus be able to clarify them to the blind patient. Symbolic Interactionism's theory showed importance during the collection and analysis of data, as the phases of the theory were well interconnected with the actions of blind mothers, making it possible to perceive the desire they have to overcome themselves in society in caring for their child. Observing this aspect, it was asked during the contact with the data and its analysis, about the reflexes of the maternal visual deficiency in children, not only with regard to child behavior, learning performance and care received. It is considered that there are a large number of works that present the child only from the perspective of the mentioned aspects (behavior, learning and forms of care), with a gap in works that engage in the perceptions and filial feelings towards the blind parent. It is considered as a limitation of this study the fact that the perception of the son of a blind mother in relation to care was also not addressed. In view of what this study allowed to know about the specificities of mothers, blind women, it is possible to count on other resources for the better adequacy of health services for user care, which does not necessarily require

the formation of new services, but the inclusion of new knowledge, looks and attitudes towards those who seek care. As a means of adapting health care to these mothers, the training of health professionals and the formation of information groups are suggested, in which children care is addressed, as well as opening up so that mothers can expose their conceptions and experiences. Such an initiative can be a relatively simple resource to implement. Another suggestion for acting with blind mothers is not only the support that comes from formal services, but also being able to count on the informal support of the family, as well as being able to count on other mothers who are already more emotionally strengthened to serve as multipliers among their peers. Finally, it is important to consider the contribution of this work to the insertion of the health professional in the context of the treatment of these mothers. Health professionals require greater ability to establish a more humanized contact of care, with the possibility of carrying out an approach to the blind mother to have a privileged listening to the demands, devoid of the recognition of their needs. This attitude must be coupled with the proposal to form a multidisciplinary team to work in health. The knowledge of each area must be construed as proposals for care and attention, without losing its specificities in care, but capable of an integrative look at the needs of the service user. Mothers reported a desire for overcoming before society and the family when they decided to have their children and this desire was achieved, because even with their limitations they showed to be able to take care of their children.

Collaborations

Bezerra CP and Machado MMT participated in the conception and design, analysis and interpretation of the data. Nicolau AIO, Bezerra GPP and Pagliuca LMF participated in the writing of the article and relevant critical review of the intellectual content. All authors participated in the final approval of the version to be published.

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