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Accessibility to Health Services and Support Networks Available to Blind Mothers

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Abstract

Objectives: The aim of this study was to assess blind mothers' perception and experience accessing health services. Methods: We conducted a qualitative, descriptive study including individual, in-depth interviews with blind mothers of children aged 0-10 years old, from March to July 2013. Interviews were held during home visits, in addition to direct observations of paths traveled by mothers when trying to access health services for their children. Data derived from interviews with mothers were analyzed using content analysis.

Results: The central categories that emerged from this study included influences on blind mothers' accessibility to health services, and the care provided to children. Study findings revealed the need to transform health services in order to facilitate the access and meet the needs of people with disabilities.

Conclusion: In addition, study findings show the need to comply with legal standards in order to ensure easier access to the blind mothers and their children by public health services.

Keywords: Access to health services; Blindness; Child health; Women's health

Significance: Government and the private sectors may use the results of this research in developing, implementating and evaluating health care strategies for the delivery of care to blind women and their children.

Introduction

Accessibility as a principle of the Unified Health System (SUS) in Brazil, guarantees to the population the provision of services, which must be qualified to meet and solve major problems by those requiring them.

Access is a complex concept ranging from authors, and changes according to the context. Some authors, such as Donabedian [1], employ the noun accessibility - character or quality of what is available [2], while others prefer the noun access - act of joining, inlet [2] - or both terms to indicate the degree of easiness with which people obtain health care [3].

In Brazil, accessibility is a concept closely linked to the rights of people with disabilities. These individuals receive this designation due to present a partial or total loss of functions or body structures, including psychological, which results in them facing specific and likely difficulties in limiting activities or restrict participation in social, economic and cultural [4].

In 1981, the NGO Disabled Peoples International drafted the Declaration of Principles, which defines "equalization of opportunities" as a process in which all human beings have equal opportunity to participate in all activities of life together and enjoy goods and services [5].

In Brazil, according to the Brazilian Association of Technical Standards (ABNT) accessibility refers to accessible space, including buildings, furniture, or any element that can be accessed, visited, and used by anyone, including those with any type of disability [6]. This standard uses the term "accessible" for both physical accessibility, as well as for communication and signaling, and defines accessibility as the possibility and range of conditions for use with security and autonomy of buildings, space, urban furniture, and equipment [6].

Accessibility is also defined as the presence or absence of financial, organizational, and / or structural to get basic health care [7].

The principle of accessibility goes beyond the understanding of the need of the existence of a health service near the reality experienced by the community. It becomes evident in the fact that the Family Health Strategy (FHS) seeks to provide, in their of care dynamics, greater access and resolution for all its users [8].

According to data from the IBGE, [9] it is estimated that there are about 140,000 blind people in Brazil, participants in society, without having more detailed information about the accessibility of primary health care [10].

Information obtained supporting the data produced by different health information systems are not an end in themselves, but they represent a way to support better decisions for policy, planning, management, monitoring and evaluation of health programs, and obviously, serve for epidemiological analysis and evaluation [11].

According to Brazil's current public health policy, there is a need for comprehensive health care to be accessible and affordable to

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people with disabilities and their families, allowing their inclusion as part of the community, and improving their quality of life, according to all possibilities [12].

Like any other woman, blind women, bear children are able to care for, and monitor their children's development. And, like any other woman, should count with the support of family and health care services to afford her successful caring for her children and herself [13].

Based on previous studies conducted in Ceara among blind people, there is still a need to gain a deeper understanding of the issues related to blind mothers' access to health care. Therefore, the purpose of this study are: 1) to understand blind mother's experience access and utilization of public health services, and 2) to identify barriers and facilitators to blind women's access to primary care services in Fortaleza, Ceara, Brazil.

Materials and Methods

We conducted a qualitative, descriptive study in the city of Fortaleza, capital of the state of Ceara during the period from March to July 2013 with blind mothers who had children aged 0-10 years old. The methodology included interviews and direct observation of the home and outside of the home environments of blind mothers and their children.

Participants were recruited from primary health care units. A research team member visited selected units to explain the study objectives and obtain the permission of services coordinator. After permission was obtained, research team member worked directly with community health workers responsible for home visitations in order to obtain the names of all blind mothers residing in their area.

Initially, to identify blind mothers living in Fortaleza, Northeastern of Brazil, community health workers were contacted by the Coordination of each of FHS Health Unit, to identify in their enrolled area, all mothers with visual disabilities who had child between the ages of 0 and 10 years old. The health worker has filed a registration form containing mother's name, number of children in this age group, full address. The community health worker and informed all blind women residing in their areas about the study objectives and obtained their written consent to have a researcher from the Federal University of Ceara contact them to further explain study objectives and what their participation in the research would entail, and to schedule an appointment with mothers who agreed to participate in the study. All written consent forms were sent to the coordinator of the Health Unit, for later collection by the research team. A follow up call was then made by a research member to schedule a initial home interview and further explain the objectives of the study and obtain final consent of participant enrollment in the study.

There were difficulties, however, to find blind mothers in the public system because there is no specific registration in the health system users with some kind disability. This record also does not classify the different types of disabilities, such as physical, visual, auditory and mental. Only two blind mothers were found through community health workers. Therefore, snowball technique to recruit additional blind mothers to participate in the study.

Participant's recruitment and enrollment into the study was done until the research team felt that data saturation was achieved to answer the study questions.

In the first stage of data collection, study participants completed of a detailed questionnaire including questions on participant's socio-demographic background, access and utilization of health services, social support networks, etc. In a second phase, an individual, in-depth interview, using a semi-structured guide with questions related to utilization of health services. The main guiding question was: "How do you access and use health services when you need to appointment or appointment your child?"

Interviews were conducted with blind mothers in their homes, using recording, previously allowed, for greater reliability of verbalized reports. All interviews were transcribed verbatim by a research team member. Data was analyzed using thematic content analysis to identify key concepts and themes [14-17]. Two research team members read all transcripts in full and coded the data. Discrepancies were discussed until agreement was achieved. Two main categories were identified: 1) Blind mothers' experiences in access and utilization of health services; and 2) blind mothers' experience with care provided to children.

The project was approved by the Ethics Committee of the Federal University of Ceara – UFC - COMEP, n° 237/07. The survey participants signed the informed consent form after reading done by the interviewer and the presence of a witness, reliable blind mother.

Results

A total of ten blind mothers participated in the study. Mothers' age ranged between 22 and 35. Most mothers had completed college, and some even higher graduate degrees, which probably confered the knowledge, values, and attitudes to health promotion and education of their children. All mothers owned their own housing with adequate sanitation. The average family income was above the minimum wage. Only one mother reported her child not utilizing services provided by the local health unit in her neighborhood. Names of mothers were removed from all data forms, and replaced with names of flowers. We chose flowers' names because of their graciousness, and because flowers leave scent in the hands of those who harvest them, which was what we experienced in our close interaction with blind women participating in our study. Moreover, the beauty, purity and fragility of the flowers were typical features also observed in the interviewed mothers.

Accessibility for blind mothers to health units

The easier access to health care is understood as an essential element for early diagnosis, in addition to establishing a satisfactory relationship between health professionals of the units and the clientele in general. In the case of a disabled woman, in addition to communication approach, it is essential to have a physical structure that provides an easy entry to the clinic with ramps and proper reception.

When I got to the clinic, the doctor was telling me that I couldn't meet there because I was at risk. Besides being very skinny, was inadequate and needed to be met in a hospital (Tulip).

Rarely has ramps, use stairs that also has no handrail and I've

never seen a differentiated floor (Lily).

Health professionals always are directed to my companion when they want to give information or ask a question, maybe they do not know that I can listen and talk (Rose).

The doctor said it was good I do a C-section and now connect the tubes because my pregnancy was at risk because I was disabled (Violet).

Always wondered if I was even alone with the child and spoke of the importance I go accompanied by a person who saw. I said I did not need, but they always insisted (Violet).

... soon the concierge staff did not want me to go with the boy. I had gone with someone I do not know right. The staff wanted me to get it to the boy because I was blind. ... I fought that was my son, who had to go was I, they thought because I'm blind could not keep up ... (Orchid).

Blind mothers' reports reveal a lack of essential guidelines and lack of communication between professionals and patients to provide information and/or clarification of doubts and anxieties.

I did not receive any information about breastfeeding and care to the child in prenatal (Tulip).

... I had no explanation. They didn't talk about breastfeeding. He spoke only about rest, for I have rest, not make art, these things as well, but beware of the baby. (Rose)

Blind mothers' experiences also captured the bond formed between the mothers and the health service, which enabled an effective delivery of health care. The following quotes are illustrative of blind mothers' experiences.

... when I go to his vaccine ... the nurse who was giving his vaccine, she explained to me how I could do. Then said I could do with him in case he got too sick with the thigh of the vaccine, she said I could put a little ice to not hurt too much. Then it was well explanatory even I liked. (Rose)

Treat well. They do everything to not separate the baby from me, take care that go along with me because the greatest fear I have is having to separate one from me... (Tulip).

Discussion

This qualitative study examined blind mothers' experience accessing and utilizing health services for themselves and their child. Mothers reported that they began prenatal care when they discovered the pregnancy, performing primarily at health facilities near their homes, with subsequent referral to hospitals and maternity wards, ease of tests such as ultrasound due to the completion of sterilization. Some of blind mothers describe that in the basic health unit professionals forwarded early to a secondary or tertiary level institution, because by being visually impaired, were regarded as "risk" for a premature birth or the possibility of some complications.

The lack of professional ability to meet the needs of disabled women was evident in mothers' descriptions of their experiences in the utilization of health services. This finding highlights a serious problem that needs to be minimized. Professional development and education of health professionals is needed for better delivery of health care to blind women attending the public health system.

It is important to note that some mothers reported not having access to health education, such as guidance on breastfeeding and care of the newborn. In addition, our findings revealed a lack of patient (blind woman)-health care provider communication about the psychosocial condition of the mother, showing the lack of a holistic and humanized care by health professionals, as has noted in the reports. This finding is of importance as it reflects the poor quality of prenatal care for blind women, which must not only address the physical health of the mother and fetus, but also must integrate actions related to aspects of psychosocial health, given that blind women's special needs including social support from health professionals, family members and the community in order to achieve a successful and effective childbirth and child care [18,19].

Health education practices should be directed to patient's particular circumstances, aiming to provide adequate and quality of care by health professionals in their everyday practices. In the case of the blind, patient-provider communication is a central component of care, as well as acknowledgment of the special needs of blind women, which may require integration of all senses, including smell, touch and hearing, so that blind women can fully experience an integrated and holistic delivery of care, which is often reliant on technology that uses health visual materials for education that are not appropriate for this special population group [13].

The birth of a child is accompanied by a series of emotions, feelings of uncertainty, which historically strengthens a condition of fear and anxiety to women throughout the gestation period [20].

Brazil has one of the highest prevalence of caesarean sections in the world [21]. Studies show that several factors influence a woman's decision to have a c-section including overall lack of knowledge about childbirth and natural birth, fear of pain, and time for the child's birth [22]. On the other hand, studies show that factors influencing health care professionals to perform caesarean section are less time spent with pregnant woman in child labor, financial benefit, and greater control over the procedure involved in childbirth [23].

Nevertheless, research shows that there is a greater acceptance by natural birth, when guidance is provided on the birthing procedures, technical training of the professionals involved to use non-pharmacological analgesic techniques, as well as the involvement of companion throughout the labor process. The nurse is the professional who most promotes the performance of this type of birth [24]. In some cases; however, surgical intervention is required in which to prioritize the safety of life of the mother and child [25]. In the case of special population groups, such as visually impaired women, the lack of sensitivity of some professionals in the childbirth room is considered an important element to increase the sense of loneliness and anguish experienced by these blind women during childbirth, as reported in the speeches with a description of their feelings of insecurity and fear because they are alone. A pregnant woman should be granted the right of partner's presence during childbirth, and there should be an adjustment of physical space and the team approach to receive properly a new member of the childbirth room. Tracking a family, fellow or friend during birth increases the

confidence of the woman to be a mother, reduces the use of drugs for analgesia, enhances women's autonomy in decisions about her body and increases the duration of breastfeeding. Sometime professionals may be able to participate in the support network of these women by offering them confidence and emotional comfort [26,27].

It is known that it is important to integrate a multidisciplinary team to provide proper care to the child, with consultations to assess the development and promote preventive health actions. Another important factor is the participation of parents in consultation, as these are the main source of information about the child, referring family history, community situation in which the child is located, and support network needed to develop it. The service should be personalized and holistic, and should be used only forms to guide the consultation, which are adapted to that situation. The information sent to parents should be strengthened with some information material for effective capture of this process [28]. In the case of blind parents, this information should be available in tactile and auditory material, and may even be willing electronically for the blind, with internet access. The use of technology should assist the healthcare professional in the transmission of knowledge related to health education for blind customers, allowing the accessibility of this information [29].

Users feel well attended, especially when they have respected their autonomy and participate in their healing process. The bond formed between health professional and user promotes adequate care, according to the principles of SUS. For the effectiveness of services, it is necessary to have a team committed to work in sufficient numbers and listen to the opinions user by modifying the service according to the needs of the clientele. Thus forms a service where there is co-participation between users and professionals in order to make access to comprehensive health services and effective [30].

With regard to children, mothers feel responsible for the health of their children and for their caregivers. Therefore, it is important to obey their right to accompany their children. The blind, regardless of their disability, are able to care for their children and, like other women, is the family caregiver, responsible for monitoring child health services.

Conclusion

It is considered that much needs to be transformed in the delivery of health care services to visually impaired mothers. The current legislation, which ensures unrestricted access to services by special population groups, such as the visually impaired, is not being followed by many health care services and professionals, who share responsibility in ensuring the exercise of citizenship of this population.

The importance of training health professionals on humanized ways to deliver health care to special population groups, such as blind mothers and their children is illustrated in the testimony of blind mothers participating in our study, who have faced several barriers to access and utilize health care service, including difficulties in communication with health care professionals during their attempts to utilize public health services in Fortaleza.

The bond formed between health professional and user promotes adequate care, according to the principles of SUS. For the effectiveness of services, it is necessary to have a team committed to work in sufficient numbers and listen to the opinions user by modifying the service according to the needs of the clientele. Thus forms a service where there is co-participation between users and professionals in order to make access to comprehensive health services and effective [30].

Government and the private sectors may use the results of this research in developing, implementating, and evaluating health care strategies for the delivery of care to blind women and their children. Furthermore, information derived from our study may be used to sensitize health professionals to comply with what is already assured by law, in ensuring the physical and social accessibility of all people at all environments in humanized manner.

Curricula of health profession courses should include health promotion and care of people with disability. This training should be a central part of training of health care professional in the delivery of care for blind women at any stage of the delivery and care of her child.

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