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Accessibility to health services by persons with disabilities

ABSTRACT

OBJECTIVE: To analyze the difficulties in accessibility to health services experienced by persons with disabilities.

METHODOLOGICAL PROCEDURES: A qualitative study was performed with individuals who reported having a certain type of disability (paralysis or amputation of limbs; low vision, unilateral or total blindness; low hearing, unilateral or total deafness). A total of 25 individuals (14 women) were interviewed in the city of São Paulo, Southeastern Brazil, between June and August 2007, responding to questions about transportation and accessibility to health services. Collective Subject Discourse was the methodology used to analyze results and analyses were performed with the Qualiquantisoft software.

ANALYSIS OF RESULTS: The analysis of discourses on transportation to health services revealed a diversity in terms of the user going to the service alone or accompanied; using a private car, public transportation or ambulance or walking; and requiring different times to arrive at the service. With regard to the difficulties in accessibility to health services, there were reports of delayed service, problems with parking, and lack of ramps, elevators, wheelchairs, doctors and adapted toilets.

CONCLUSIONS: Individuals with a certain type of disability used various means of transportation, requiring someone to accompany them in some cases. Problems with accessibility to health services were reported by persons with disabilities, contradicting the principle of equity, a precept of the Brazilian Unified Health System.

DESCRIPTORS: Disabled Persons. Mobility Limitation. Health Services Accessibility. Disabled Health. Qualitative Research.

INTRODUCTION

Persons with disabilities are more exposed to comorbidities associated with their disability,[11,19] resulting in greater need for health service use to maintain their physical and mental integrity.

However, between the need for services and their satisfaction, there is the question of accessibility to services, which, if not adequately dealt with, may cause persons with disabilities to face obstacles that prevent their access to health services. Accessibility is defined by Frenk[9] (1985) as the product of the relationship between effective availability of health services and access to these services by individuals. Effective availability occurs when the availability of health services is analyzed along with the resistance that the environment creates against it.[9] This resistance has an important role when accessibility of persons with disabilities to health services is studied. It can be understood as the difficulty found to obtain health services and it is a determinant for the health

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of persons with disabilities. Due to the general picture of disability and comorbidities resulting from it, more difficulties arise between persons with disabilities and health services, thus increasing resistance.[26]

As the occurrence of disabilities is directly associated with the increase in population longevity and with the rise in the number of occurrences by external causes,[5] the percentage of persons with disabilities in the community tends to increase with time. Thus, the investigation of the difficulties found by persons with disabilities when accessing health services could aid health planning, structuring and improving services, so that they adequately meet the needs of this population group.

The present study aimed to analyze the difficulties in accessibility to health services experienced by persons with disabilities.

METHODOLOGICAL PROCEDURES

A qualitative exploratory study was conducted, including an intentional sample of 25 individuals with a certain type of disability (visual, hearing or physical). The identification of persons to be interviewed was obtained from a longer list, with 414 persons with disabilities, originated from the total number of persons interviewed by the City of São Paulo Health and Life Conditions Survey (ISA-Capital) – 2003.[a]

This study was included in the initial phase of the Project of Accessibility to Health Services (AceSS), conducted with 333 individuals with a certain type of disability in the capital city of São Paulo and in the greater São Paulo (Embu, Taboão da Serra and Itapecerica da Serra), Southeastern Brazil, in 2007. Interviews were conducted from June to August 2007, with a semi-structured questionnaire about the difficulties in accessibility to health services faced by persons with a certain type of disability. The following questions were analyzed: those about the transportation of persons with disabilities to health services, such as "How do you go to the health service?" and "Could you tell me more about this?", and those about problems associated with accessibility to health services, such as "Many health services hinder the access of persons with disabilities, because they lack ramps, parking lots, signs etc. How about your experience, how has it been?".

Data were collected using household interviews, which were fully recorded and transcribed. A database was created with the information obtained from the transcribed speech, that was analyzed with the QualiQuantiSoft software.[13] This program aimed to facilitate the performance of studies that use Collective Subject Discourse (CSD) as their methodology. QualiQuantiSoft enables thoughts, beliefs, values and representations to be associated with objective characteristics of individuals who have these representations, such as sex, age, level of education and income.

Based on the database, the main ideas were extracted from the responses of each individual and the CSD were subsequently constructed, aiming to empirically express the thoughts of participants as a group, rather than as individual beings,[13] thus creating a collective thinking entity, with a voice and responses to the questions made.

The qualitative research methodology evaluates the perception of persons, originating from the product of discourses/verbalizations of social participants directly involved with the theme.[18] The qualitative approach to the way of thinking about the questions studied enables the individual perceptions of participants to be obtained, transforming it into a more coherent and consistent discourse. Thus, the social representations of the themes that this group of persons dealt with can be achieved. The qualitative methodology is used in the field of studies on disabilities.[6,12,22]

According to Nagai et al[18] (2007), the CSD could have more than one main idea in an individual's response, or the same main idea could emerge in the discourse of many different individuals. There is also the possibility of parts of their speech having their own identity and not reflecting the response of other persons. In addition, Lèfreve et al[14] (2006) clarifies that, in this way, responses can deal with the same problem in different manners, complementing one another and/or explaining one another.

The main ideas of each question were described in items and a CSD was constructed for each of them.

Of all 25 persons with disabilities interviewed, three of them were aged between 11 and 20 years (three women); three, between 31 and 40 years (two women); 12, between 55 and 69 years (four women); and seven, between 70 and 90 years (five women).

Among the interviewees, eight persons reported having a certain type of physical disability (paralysis or amputation of limbs); nine persons, a hearing disability (low hearing or unilateral deafness) and eight persons, a visual disability (low vision or unilateral blindness). Participants were users of both Unified Health System (SUS) services and private health plan services.

The present study was approved by the Research Ethics Committee of the Faculdade de Saúde Pública da Universidade de São Paulo (Protocol 1653/2007). All participants signed an informed consent form.

[a] Cesar CLG, Carandina L, Alves MCGP, Barros MBA, Goldbaum M. Saúde e condição de vida em São Paulo: inquérito multicêntrico de saúde no Estado de São Paulo. São Paulo: Faculdade de Saúde Pública da USP; 2005.

ANALYSIS OF RESULTS AND DISCUSSION

Transportation to the health service

The main ideas of the CSD about transportation to go to health services (Question 1 – How do you do go to the health service? Could you tell me more about it?) were as follows:

Main idea 1.1: Goes alone, uses public transportation and arrives at the health service quickly.

[CSD 1.1] *I use public transportation; I usually don't need anyone to accompany me and it doesn't take me long because I live close by.*

Main idea 1.2: Goes accompanied by someone, uses a private car and arrives at the health service after a long time.

[CSD 1.2] *Someone goes with me, I use a private car and it take me long to arrive.*

Main idea 1.3: Goes accompanied by someone, uses public transportation and arrives at the health service after a long time.

[CSD 1.3] *Someone goes with me, I use public transportation and it takes me long to get to the health service.*

Main idea 1.4: Goes accompanied by someone and takes an ambulance to go to the health service.

[CSD 1.4] *I have to go by ambulance because I can't sit down and need to have someone with me; it's difficult for doctors to come to my home.*

Main idea 1.5: Goes accompanied by someone, uses public transportation and arrives quickly at the health service.

[CSD 1.5] *I go by bus or subway, I need someone with me and the health service is close to my home.*

Main idea 1.6: Goes alone, uses public transportation and arrives at the health service after a long time.

[CSD 1.6] *I go alone to the health service, I only bring someone if I need it; I use public transportation and it takes me a long time to get to the health service.*

Main Idea 1.7: Goes alone, uses a private car and arrives at the health service after a long time.

[CSD 1.7] *I go by car, I can go alone and it takes me a long time to get to the health service because it's not close to my home.*

Main idea 1.8: Goes accompanied by someone, goes on foot and arrives at the health service quickly.

[CSD 1.8] *I go on foot because it is close, it doesn't take me long to get there; and someone usually goes with me.*

Main Idea 1.9: Goes accompanied by someone, uses a private car and arrives at the health service after a long time.

[CSD 1.9] *I always have to be with someone else, I go by car and it takes me a long time to get there, because of the distance or traffic.*

The discourses reported showed a diversity of opinions among participants, with variations in terms of time of transportation, means of transportation used and need for someone to accompany them. When the time spent is analyzed, it is observed that approximately one third of respondents pointed out this difficulty in transportation to arrive at the health service. Travassos & Martins[24] (2004) affirmed that geographic accessibility is an important factor for the effective use of health services, which could reduce or increase the difficulties in access. In the present article,[24] the authors suggest that the correct spatial distribution of health services and patients must be coherent for adequate use.

According to the discourses, approximately half of the persons with disabilities reported having the need for someone to accompany them. Caldas[2] (2003) discusses the elderly persons' dependence on their family and emphasizes the association between dependence and fragility, showing the close relationship between the support provided to the elderly and the performance of daily tasks. This example can be applied to persons with disabilities, who, in a way, also have characteristics of fragility due to the disabling process.[10] According to Othero & Dalmaso[21] (2009), the family or caregiver has an important role in the health of the persons with disabilities, in terms of the contact that this caregiver/family has with health professionals, receiving information that complement the treatment of this individual. In a study conducted in the city of São Paulo, Southeastern Brazil, the disability combined to the dependence has been frequent, with the increase in longevity and the occurrence of disabilities.[3]

With regard to the means of transportation used by persons with disabilities, the discourses show varied patterns. Approximately half of participants used public means of transportation. Araújo et al[1] (2006) observed the importance of the transportation factor for the family structure, in terms of spending on and quality of health, implying financial expenses and difficulties in health service use.

In addition, the need to use an ambulance to arrive at a health service was mentioned. This represents an obstacle, once the patient depends on the availability of such means of transportation to arrive at this

service, considering the fact that certain persons with disabilities need this because their body functions are compromised, preventing them from using other means of transportation.

Accessibility to health services

The main ideas of the CSD about accessibility to health services (Question 2 – Many health services hinder the access of persons with disabilities, because they lack ramps, parking lots, signs etc. How about your experience, how has it been?) were as follows:

Main idea 2.1: Without problems

[CSD 2.1] *I've always been well cared for, there's parking, a ramp, handrail, elevator, signs, adapted toilet and a waiting room.*

Main idea 2.2: Delayed service

[CSD 2.2] *It takes some time to get medical attention, because there's always a waiting line. If the appointment is set for 10 o'clock, you have to arrive at 6; you have to arrive early.*

Main Idea 2.3: Parking problems

[CSD 2.3] *There's no parking, so you have to park on the streets.*

Main idea 2.4: Lack of ramps

[CSD 2.4] *There's no ramp in the health service. They've already called me three times, but I can't go, because there's no ramp to get in; and when there is a ramp, there's no handrail.*

Main idea 2.5: Health service facilities

[CSD 2.5] *There's not enough space for everyone to wait, so sometimes people wait sitting on the floor. And, in some rooms, there's no way for a person with disability to get in.*

Main idea 2.6: The health service lacks wheelchairs

[CSD 2.6] *There aren't enough wheelchairs in the health service, you have to compete for a wheelchair and, at times, a person with disability has to be carried in someone's arms.*

Main idea 2.7: There are not sufficient adapted toilets for persons with disabilities

[CSD 2.7] *I've never seen toilets for people with disabilities in the health service. And when there is, it's dirty and out of work (clogged).*

Main idea 2.8: There is a lack of doctors

[CSD 2.8] *There are only nurses in the health clinic I got to. It's like this now, there are no doctors.*

Main idea 2.9: There is a lack of elevators

[CSD 2.9] *There's no elevator in the health service, you have to use the stairs.*

Main Idea 2.10: Problems with signs

[CSD 2.10] *There are not enough signs, so I keep asking for information.*

Waiting time was one of the factors reported as an obstacle to health service use and this is frequently mentioned as a problem in outpatient[8] and hospital care.[20] This waiting period can be an important factor for patients with a certain type of disability, because they may have special diet, hygiene or rest needs. Federal Law 10,048 of November 8th, 2000,[b] guarantees priority health care in governmental institutions to persons with disabilities, elderly individuals aged 60 years or more, pregnant and breast-feeding women, and those with small children. However, in a hospital environment or health service, this prioritization based on the presence of a disability may be questioned due to ethical reasons, because a person with a disability may not be the patient who most needs health care at a certain moment.

Another factor that was found to be an obstacle to the good use of health services by persons with disabilities were the parking problems. Decree 3,298/99 regulates Law 7,893/89,[c] which consolidates norms of protection for persons with disabilities, provides for the compulsory presence of parking spaces for vehicles owned by persons with disabilities or those transporting such persons to public buildings. Thus, this decree also guarantees specific vacancies reserved for persons with disabilities in health services that are used by the public. However, Mendonça & Guerra[16] (2007) reported that the presence of facilitating factors such as parking and health service location may not have so much influence on satisfaction with the service.

Approximately one tenth of participants mentioned the absence of ramps as a factor that hindered health service use. The same Decree 3,298/99 requires the installation of ramps or electromechanical devices for vertical transportation, where there is a difference in level between rooms, in certain establishments. In addition, the lack of elevators and signs for persons with disabilities, aspects that are provided for by Law 3,298/99, were also reported.

[b] Brazil. Law 10,048 of November 8th, 2000, grants priority service for individuals thus specified, in addition to other provisions. *Diario Oficial Uniao*. 09 nov 2000[cited 2009 Sep 08];Seção1:1. Available from: http://www.soleis.com.br/L10048.htm

[c] Brazil. Decree 3,298 of December 20th, 1999, regulates Law 7,853 of October 24th, 1989, provides for the *Política Nacional para a Integração da Pessoa Portadora de Deficiência* (Brazilian Policy on the Integration of Persons with Disabilities) and consolidates forms of protection, in addition to other provisions. *Diario Oficial Uniao*. 21 dez 1999[cited 2010 May 24];Seção1:10. Available from: http://www.planalto.gov.br/ccivil/decreto/d3298.htm

Certain inadequate aspects of health services were mentioned by participants, such as waiting rooms with insufficient places and rooms where persons with disabilities had no access through physical obstacles. One of the reports shows that health establishments whose obstacles prevented the entry of persons with disabilities went against their right to come and go, provided for by law in the Constitution.

One discourse revealed the need for wheelchairs for persons with disabilities, because, at certain moments, they had to be carried in someone's arms to be cared for. This may hinder health service use, because those accompanying patients may not always have conditions to transport the persons with disabilities in their arms, thus causing them to be dependent on health service professionals.

The absence or inadequacy of adapted toilets was reported by participants. Law 10,098/2000[d] guarantees the construction of such toilets for persons with disabilities in governmental institutions and their adequate maintenance.

The lack of doctors in health services was also reported by participants, who mentioned that the service was provided by nurses. Thus, there was no medical care, only nursing care.

In addition, the main idea "I never had problems" was present, reflecting the adequacy of the health service sought for the accessibility needs of persons with disabilities. Machado & Nogueira[15] (2008) also reported the absence of problems to use services in a group of users of a physiotherapy clinic. This information could indicate that persons with disabilities do not always encounter problems of accessibility in health services, which leads to the assumption that some of them have all their needs of accessibility to health services met.

CONCLUSIONS

The discussion about such aspects goes beyond the simple approach of presence/absence of obstacles to health service use, touching on a broader theme which is more relevant to public health: health equity. Equity is one of the SUS pillars, which, according to Travassos[23] (1997), is a principle of social justice. This concept could be translated as, "to treat those who are unequal unequally".[7]

Thus, this would differ from equality, understood as equality of opportunities. For a person with disability, it is not enough to have the same opportunities, when there are no conditions to take advantage of them, compared to someone who has no disabilities. As a consequence, the principle of equity would be away to benefit persons with disabilities, so that they have equal opportunities. Carneiro Junior et al[4] (2006) characterize equity as "positive discrimination", once it is aimed at socially disadvantaged population groups, with planning and policies of health care that seek to eliminate such inequities.

Thus, the problems reported by participants would act in a way that negatively puts pressure on persons with disabilities in terms of their use of health services. This situation is contrary to the SUS principle of equity, based on the idea that all individuals of a society must have equal opportunities to develop their health potential. Such system, which is founded on equity, is responsible for the reduction in avoidable or unfair differences among individuals, thus functioning against obstacles.[25]

The relationship between inequality (the aspect opposite to equity) and disability is described in the literature[17] and points to several obstacles that work against the correct use of health services, causing this population group to have disadvantages, in terms of health service use.

In conclusion, the discourses express that persons with disabilities use certain means of transportation, with varied periods of time to arrive at the health service and requiring someone to accompany them in certain cases. Problems of accessibility to health services were reported by persons with disabilities, violating the principle of equity, a precept of the SUS. The elimination of these obstacles could have a significant value for the use of health services by this population, providing equal opportunities, when compared to persons without disabilities.

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[d] Brazil. Law 10,098 of December 19th, 2000, establishes general norms and basic criteria to promote accessibility of persons with disabilities or those with reduced mobility, in addition to other provisions. *Diario Oficial Uniao*. 20 dez 2000[cited 2009 Sep 08];Seção1:2. Available from: http://www.planalto.gov.br/ccivil/LEIS/L10098.htm

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