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Disabled persons in the rural setting: conception of Community Health Workers

Pessoas com deficiência no cenário rural: concepção dos Agentes Comunitários de Saúde

Personas con discapacidad en el entorno rural: concepción de Agentes Comunitarios de Salud

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Abstract: Objective: to describe the conceptions of Community Health Workers about disabled persons who live in rural contexts. **Method:** descriptive-exploratory research, with a qualitative approach, performed in four municipalities in the northwest region of Rio Grande do Sul, Brazil. It had the participation of thirteen Community Health Workers. Data collection took place between January and February 2018 through semi-structured interviews, analyzed by thematic modality. **Results:** the conceptions of these professionals are especially anchored in the words "difficulty", "attention", "care", "contempt" and "access". Moreover, they reveal the poor knowledge about disabled persons living in the rural setting, by ignoring the different types of disabilities or pointing out conditions that do not fit their conception. **Conclusion:** we should highlight the urgent need for instrumentalization of these health professionals on the theme, in order to provide health care based on integrality and equity.
Descriptors: Disabled persons; Rural areas; Primary health care; Community health workers; Rural health

Resumo: Objetivo: descrever as concepções dos Agentes Comunitários de Saúde sobre as pessoas com deficiência que vivem em contexto rural. **Método:** pesquisa descritivo-exploratória de abordagem qualitativa, realizada em quatro municípios da região noroeste do Rio Grande do Sul, Brasil. Participaram treze Agentes Comunitários de Saúde. A coleta de dados ocorreu entre janeiro e fevereiro de 2018 por meio de entrevistas semiestruturadas, analisadas pela modalidade temática. **Resultados:** as concepções dos profissionais estão ancoradas especialmente nas palavras "dificuldade", "atenção", "cuidado", "desprezo" e "acesso". Ademais, desvelam o conhecimento insuficiente acerca

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das pessoas com deficiência residentes no cenário rural, ao desconhecerem os diferentes tipos de deficiências existentes ou apontarem condições que não se enquadram em sua conceituação. **Conclusão:** evidenciou-se a necessidade premente de instrumentalização destes profissionais de saúde sobre o tema, a fim de proporcionar uma atenção à saúde com base na integralidade e equidade.
Descritores: Pessoas com deficiência; Zona rural; Atenção primária à saúde; Agentes comunitários de saúde; Saúde da população rural

Resumen: **Objetivo:** describir las concepciones de Agentes Comunitarios de Salud sobre las personas con discapacidad que viven en un contexto rural. **Método:** investigación descriptiva-exploratoria, con enfoque cualitativo, realizada en cuatro ayuntamientos de la región noroeste de Rio Grande do Sul, Brasil. Participaron trece Agentes Comunitarios de Salud. La recolección de datos tuvo lugar entre enero y febrero de 2018 mediante entrevistas semiestructuradas, analizadas por modalidad temática. **Resultados:** las concepciones de los profesionales están ancladas especialmente en las palabras "dificultad", "atención", "cuidado", "desprecio" y "acceso". Además, revelan el conocimiento insuficiente sobre las personas con discapacidad que viven en el entorno rural, al ignorar los diferentes tipos de discapacidad que existen o al señalar condiciones que no se ajustan a su concepción. **Conclusión:** se evidenció la necesidad urgente de instrumentalizar a estos profesionales de la salud sobre el tema, con miras a brindar una atención médica basada en la integralidad y la equidad.
Descriptores: Personas con discapacidad; Medio rural; Atención primaria de salud; Agentes comunitarios de salud; Salud rural

Introduction

Historically, in Brazil, many movements have sought integral care for disabled persons, which converges with the principles of the Brazilian Unified Health System (SUS).[1] The concept related to disability has evolved worldwide, especially after the 1960s, when it began to be conceived as a reflection of the close relationship among the limitations experienced by people with disabilities, the structure of the environment and the attitudes of the community.[2]

According to the 2010 Census, 45.6 million people, that is, 23.9% of the total Brazilian population, have some type of disability, whether it be visual, auditory, motor, mental or intellectual. Of this population, 7,132,347 people live in rural areas. Among all Brazilian states, Rio Grande do Sul has one of the highest rates of disabled persons in the country, corresponding to 22.5% of the local population.[3]

Worldwide, it is recognized that these people face widespread difficulties in accessing health, education and social assistance services, including housing and transportation. Such

difficulties make them more vulnerable to health problems compared to people without disabilities. In addition, higher rates of poverty, unemployment and social exclusion are reported among people with disabilities.[4]

Although in the urban space such difficulties in accessing services and exclusion are present, they are aggravated when considering the rural setting.[5] The difficulties of access of this population, specifically in relation to health services, are shown by international and national studies.[6-10] In this perspective, geographical barriers are described, such as the distance to health services, the conditions of land and roads, as well as transportation barriers, such as the lack of public transportation and high-cost private transportation.[7-8,10] We should also cite the organizational barriers, such as the lack of resources and the delay in serving people with disabilities; barriers related to the behavior of professionals, such as stigma[7,9-10] and communication difficulties.[10] Such limitations presented by the rural setting, when added to the physical and/or intellectual characteristics of people with disabilities, end up giving them invisibility,[5] thereby limiting their possibilities.

In this sense, in order to overcome these difficulties and promote articulation between the disabled persons living in the rural setting and the local health services, we can cite the Primary Health Care (PHC). This is a set of actions that include the promotion, prevention, protection, diagnosis, treatment and rehabilitation of health, developed by a multiprofessional team in a defined territory and focused on individuals, families and communities.[11]

Within PHC, among the professionals who develop their actions in the rural setting, we should highlight the Community Health Worker (CHW), who is part of the Family Health Strategy (FHS) team. CHW acts as a link between health actions and the population, especially in areas of difficult access and with marginalized groups,[12] such as, for example, people with disabilities. Accordingly, the role of CHW becomes even more relevant in the rural setting, considering its peculiarities. Among other duties, this professional performs the registration of

families in their micro-area of coverage, guides families on health services and develops interventions aimed at health promotion and disease prevention through home visits, such as checking the vaccination situation.[13-14]

In view of the exposed problem, which highlights the complexity that involves access to health for people with disabilities who live in rural settings, there is a need to qualify the implemented actions, considering the vulnerabilities experienced by this population.[6] Accordingly, this study seeks support for the elaboration of public policies and qualification of health care practices, with a view to promoting care for people with disabilities living in the rural context, based on the perspective of CHW. To that end, the objective is to describe the conceptions of CHW about people with disabilities living in the rural context.

Method

Descriptive-exploratory research with a qualitative approach, performed in four municipalities belonging to the 15th Regional Health Coordination (CRS, as per its Portuguese acronym), located in the northwest region of the State of Rio Grande do Sul. The 15th CRS is composed of 26 municipalities, with a population of 166,764 inhabitants.[15]

In order to organize the study setting, we sought the regional municipalities that had more than 70% of their residents in rural areas and that were assisted by CHW. Were listed four with such characteristics. It is pointed out that they did not have information on the exact number of people with disabilities in their rural population, only that they existed, which reveals their invisibility. Moreover, there was no FHS unit located in the rural setting of these municipalities. Accordingly, CHW were the main professionals who developed actions with the population in this setting, through home visits. These visits were held by other professionals only when there were specific demands and there was no possibility for the user to travel to the FHS unit.

After approval by the FHS managers, the researchers contacted the 15 CHW who were developing their activities in the rural areas of the study setting to invite them to participate. This invitation was verbally made by the responsible researcher and an assistant research during meetings scheduled with the CHW of each municipality. We used as an inclusion criterion to be working in the service for more than six months; and as an exclusion criterion to be on leave or vacation. Of these CHW, two were on vacation and the others agreed to participate in the study. Accordingly, 13 CHW participated in this study, each responsible for a micro-area in their municipality. Of the total number of participants per municipality, three CHW participated in three and four participated in another.

In order to generate data, we used semi-structured and individual interviews, using a script with open questions related to the sociodemographic and training data of CHW, their conceptions about people with disabilities living in rural settings and their daily work in assisting them. When starting the interview, each CHW was asked to cite words that would refer them to disabled persons in rural areas. The evocation by the participants at the beginning of the interview was intended to support the construction of a word cloud, which groups and organizes them according to their frequency. In this cloud, the words are randomly arranged, and the most cited are more representative. This means that each word has its size governed by the relevance in a given text *corpus*.[16] This cloud was designed from a free online access program. After this first moment, the other questions were accomplished. Data collection ended when the internal logic of the study object was understood, based on the recurrence and complementarity of information.[17]

In order to preserve the privacy of the participants, the interviews were previously scheduled and carried out at the time chosen by each CHW, in a reserved room in the FHS units of each municipality. They were saved on a digital recorder (audio), with an average duration of 30 minutes. Data generation took place in the months of January and February 2018.

After the interviews were conducted, they were literally transcribed in a text editor program. Subsequently, the transcribed empirical material was subjected to thematic content analysis, consisting of three stages: pre-analysis, exploration of the material, and treatment of the obtained results and interpretation.[18] In the pre-analysis, we held the floating reading and the constitution of the *corpus* in line with the proposed objective. In the exploration of the material, coding was performed using similar words or phrases in the speeches, thereby elaborating the categories. In the treatment of the results and interpretation, it was possible to group the speeches, visualize the obtained information and relate them to the scientific evidence concerning the study object.[18] From this analysis, two thematic categories were raised: Conceptions of CHW about disabled persons through the representativeness of words; and Invisibility of multiple disabilities in the rural context in the voice of CHW.

The study followed the recommendations expressed through Resolution nº 466, dated from December 12th, 2012, of the National Health Council.[19] The same was approved on August 9th, 2017, by the Research Ethics Committee of the Federal University of Santa Maria, with Opinion nº 2.208.566. CHW were informed about the objectives and method by reading and explaining the Free and Informed Consent Form and those who agreed to participate signed it in two copies, one for the participant and the other for the researcher. In order to preserve their anonymity, the testimonials will be identified by the acronym CHW followed by the number corresponding to the order of the interview (e.g.: CHW 1, CHW 2 ... CHW13).

Results

Of the total study participants, 10 were female and three were male. The average age was 36.9 years. As for education, nine had completed High School; three had completed Higher Education; and one had completed Elementary School. The time of operation as CHW ranged from six months to 16 years, with an average of 6.6 years.

Conceptions of CHW about disabled persons through the representativeness of words

The word cloud based on the analysis of the evocations of CHW that referred to disabled persons in rural settings is shown below (Figure 1). In total, 65 words were evoked. The most cited during the interviews and similar in terms of their meaning were: difficulty and/or difficulties (12.3%); attention and care (9.2%); contempt, pity, needy and affection (7.7%); and access (4.6%).

Figure 1 - "Word cloud" representation through query by means of word frequency. Palmeira das Missões/RS, Brazil, 2019

The testimonials allow us to illustrate the words that were most frequently cited and that constituted the cloud.

> *Disability* [...] *I think it's a person who needs more care, more attention.* (CHW 1)

> *I associate the disability with the difficulty to come to the health center, in case* [...] *if one day he needs to come here to get a vaccine, it's difficult.* (CHW 5)

> *I think that disability means, mainly, a person who needs more affection and more attention* [...] *because today, in society, she is being despised* [...]. (CHW 7)

> *He [referring to a young man with a physical disability] is a person who wants to reach something better* [...] *he has already looked for a lot of Jobs, but it didn't work yet* [...] *access to the field of work isn't easy* [...] *it's a difficulty task for people with disabilities.* (CHW 8)

> *Disability means a special person* [...] *who has to have a special care.* (CHW 10)

> *A person with difficulty* [...] *who sometimes is not accepted by other people, leaving them more excluded.* (CHW 12)

In this category, it was possible to highlight that the participants represented disabled persons from the words: difficulty, attention, care, contempt, pity, needy and affection. They refer to the daily lives of these people, permeated by demands, difficulties in accessing services and spaces in the labor market, as well as by social exclusion.

Invisibility of multiple disabilities in the rural context in the voice of CHW

In the testimonials below, CHW cited only a few types of disabilities, thereby ignoring the totality of existing disabilities. In addition, they pointed out conditions that do not fit the concept of disability.

> *For me, disability in my area* [...] *there are visual, intellectual, auditory, physical.* (CHW 3)

> *Disability, for me, means any type of loss or abnormality limiting physical or mental function.* (CHW 4)

> *Many people with depressive problems* [...] *I think that depression is a disability.* (CHW 5)
>
> *There is the physical disability* [...] *the cognitive disability.* (CHW 6)
>
> *In my area, I have a physical disability.* (CHW 10)
>
> *The disabled person has difficulty in moving around* [...] *a visual problem.* (CHW 12)

The following testimonials reveal the lack of knowledge on the part of CHW in relation to the universe of disabled persons.

> *I don't have much knowledge.* (CHW 4)
>
> *We have little information about them* [referring to disabled persons]. (CHW 5)
>
> *We had to have a better qualification to work with these people* [...] *we don't have information about what it is* [...] *or training.* (CHW 13)

This category allows us to identify the invisibility and the poor knowledge about disabled persons living in the rural setting on the part of CHW, thereby highlighting the low qualification that they had to assist this population.

Discussion

Regarding the first thematic category, the words most mentioned by CHW during the interviews were associated with the difficulties faced by people with disabilities living in rural settings. Other conceptions were revealed from the evocation of "attention" and "care", followed by "contempt", "pity", "needy" and "affection". CHW also had their conceptions imbued by the aspects related to the access of people with disabilities living in rural settings to health services and the world of work.

The conceptions represented by the word “difficulty” are related to the difficulties faced in the daily life of this population, present in the family context, in public spaces and in access to services. Disabled persons have limited or no social relationships and are generally restricted to the family sphere.[20] Based on these conceptions of difficulty, the imminent need to expand access to public policies based on the particularities of the lives of people with disabilities in rural settings is unveiled.[6]

The representation of the words “attention” and “care” carry conceptions about the need to promote care based on integrality, considering the peculiar and complex needs of disabled persons. In this regard, the pertinent literature highlights that the health care of people with disabilities who live in the rural setting by PHC health professionals is still focused on the biomedical model, disregarding the sociocultural aspects of users and being guided by the model based on the biological-bodily characteristics, thereby directly influencing the solvability of the service.[6]

Another conception of CHW is revealed from the words “contempt”, “pity”, “needy” and “affection”, referring to the awareness of these professionals with regard to the life situations of these people. Although this awareness is positive, a study pointed out that they do not feel comfortable having their condition associated with charity and mercy, thereby wishing to be seen as capable persons.[21]

The contempt that one of CHW reported represents the stigmatization experienced by disabled persons, a frequent situation in their daily lives. The pertinent literature points out that stigma is an important barrier to these people, especially for those who live in the rural setting. The fright and fear of suffering prejudice when leaving their homes acts as an unfavorable factor to their access to health services,[7] thereby causing many to stop seeking such services. In this setting of daily stigmatization, individuals with disabilities remain marginalized by society,

unable to fully exercise their rights,[22] one of which is the right to health, ensured by the Brazilian Federal Constitution.

Another word expressed by the participants was "affection", which allows us to understand a certain awareness of these professionals regarding the realities where disabled persons who live in the rural setting are inserted. However, in addition to being aware of this reality, it is necessary to transform it into effective care practices that take into account these individuals not only in their biological dimension. Such practices may involve the social inclusion and the promotion of their autonomy and quality of life through community groups in association with other services of the Care Network for Disabled Persons.

The word "access" was also evoked by CHW, being related to the difficulties of going to the PHC service and achieving a place in the labor market. With regard to services and health care, this was one of the main concerns when it came to the rural population, especially when they had some type of disability. In this regard, it is relevant to consider that the concept of access is closely related to that of accessibility. Accessibility refers to the possibility that the user has or not to reach the health service. Access, in turn, is linked to the provision of this service, thereby allowing its timely use to achieve the best possible health results.[23]

In this perspective, a study developed in a rural community in South Africa revealed that people with disabilities face significantly greater barriers to access to health care compared to those without disabilities, increasing according to their type and degree.[24] The barriers faced are especially related to geographical distance in relation to urban centers, lack of transportation and lack of money to pay for this transportation, thereby leading people with disabilities and their families to experience restrictions on the right to health and collective resources of social care protection and assistance.[7,24] The described context is in line with one of the assumptions of the International Convention on the Rights of Disabled Persons and its Optional Protocol in

Brazil, which states that they are entitled to the highest possible health standard,[25] which will only be viable from their access to health services.

With regard to the access to the labor market, historically, these individuals have been pleading for spaces for social participation, particularly through access to education and work.[20] Although the Brazilian Law for the Inclusion of Disabled Persons (Law nº 13.146, dated from July 6th, 2015) seeks to ensure their right to professional qualification, access and permanence at work, as well as to encourage entrepreneurship and autonomous work,[26] there are physical and attitudinal barriers to be overcome for this law to take effect.[20] This is made clear from the results of a Brazilian study that revealed that the main challenges for the inclusion of disabled persons in the labor market include, among others, their low qualification, lack of accessibility, prejudice and the unpreparedness of companies.[27]

The second thematic category addresses the invisibility of different types of disabilities by most CHW, which limit them to the physical and mental spheres, disregarding the others, namely, motor, auditory and visual. Moreover, one of the participants cited depression as a type of disability. However, it is a mental illness/disorder. Such restricted and sometimes mistaken conceptions are based on the poor knowledge of these professionals in relation to the theme, which is also revealed when they cited scarce information and training on disabilities.

The difficulties of the surveyed CHW may be related to the few experiences and/or contacts and, mainly, to the precarious training and qualifications. It is known that many trainings are carried out in a generic way, thereby disregarding singularities related to the territorial settings and populations. In order to provide successful trainings, we should start from the analysis of the needs of CHW and articulate them in line with the objectives and contexts of each health system, as envisaged in the international guideline.[28]

The poor knowledge of CHW directly influences the solvability of the health needs of these individuals. Such situation is also pointed out by a study developed with health

professionals in a rural area of southern Malawi, according to which most of them conceived the disability as a disease, based on the medical model of disability, resulting in a fragmented care for the health needs of these people.[29]

A study intended to assess the reliability of information about disabled persons collected by CHW in PHC services in two Brazilian cities also identified difficulties related to their knowledge. This is because the data on the prevalence of people with disabilities recorded by these professionals revealed an underreporting of approximately 50%, compared to the data collected by the researchers.[30]

It is reiterated that, without an adequate understanding of what the disability is and what its types are, it will be difficult for CHW to identify the demands of disabled persons and develop actions to meet them. In the rural setting, this becomes even more serious, since these professionals are the basis of communication between the disabled persons and the health service, specifically within PHC.

Conclusion

The conceptions of CHW are especially anchored in the words “difficulty”, “attention”, “care”, “contempt” and “access”. Moreover, their conceptions reveal the invisibility and the poor knowledge about disabled persons living in the rural setting, by ignoring the different types of recognized disabilities or pointing out conditions that do not fit their conception.

Through the results, it was possible to highlight and reinforce the invisibility setting of people with disabilities who live in rural contexts. This ends up influencing the health care actions targeted for this population, since CHW constitute the communication between this audience and the PHC sphere.

The study in question has shown some limitations related to the scarcity of scientific productions covering the theme of disabled persons and the rural environment, as well as the

small sample of a specific context. Accordingly, this last aspect should be considered for the generalization of the results.

Despite these limitations, it introduces contributions when addressing the conceptions of CHW about disabled persons in the rural setting. From these conceptions, we should highlight the urgent need for instrumentalization of these health professionals in relation to the theme, in order to provide health care based on integrality and equity, SUS principles. To that end, in view of the complexity of the theme, the role of Nursing is essential in the supervision and training of CHW, together with the multiprofessional team.

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