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Original Article

# Women with disabilities living in the rural context: situations of vulnerabilities and protection

Mulheres com deficiência vivendo em contexto rural: situações de vulnerabilidades e proteção

Mujeres con discapacidad que viven en el contexto rural: situaciones de vulnerabilidad y protección

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# Abstract

**Objective:** to analyze the situations of vulnerability and protection experienced by women with disabilities in the rural context. **Method:** qualitative, descriptive and exploratory study, carried out with ten women with disabilities living in rural areas of five municipalities in the north and northwest regions of Rio Grande do Sul, Brazil. The interviews took place in the households from January to June 2019. The empirical material was recorded, transcribed and subjected to thematic content analysis. **Results:** the revealed vulnerabilities were: restrictions on responsibility, education, work, income, autonomy and social benefit. As for the conditions improving the protection against vulnerabilities, strong links were observed with the Rural Family Health Strategy and the Association of Parents and Friends of Exceptional Children, besides the receipt of the Continuous Cash Benefit. **Conclusion:** actions of rural health teams articulated in the care network help to overcome the weaknesses of women with disabilities.

**Descriptors:** Disabled Persons; Health Vulnerability; Gender and Health; Rural Population; Women's Health

## Resumo

**Objetivo:** analisar as situações de vulnerabilidade e de proteção vivenciadas por mulheres com deficiência em contexto rural. **Método:** estudo qualitativo, descritivo e exploratório, realizado



com dez mulheres com deficiência residentes em áreas rurais de cinco municípios das regiões norte e noroeste do Rio Grande do Sul, Brasil. As entrevistas ocorreram nos domicílios nos meses de janeiro a junho de 2019. O material empírico foi gravado, transcrito e submetido à análise temática de conteúdo. **Resultados:** as vulnerabilidades desveladas foram: restrições de responsabilidade, educação, trabalho, renda, autonomia e benefício social. Quanto às condições potencializadoras de proteção às vulnerabilidades, observaram-se vínculos fortes com a Estratégia Saúde da Família Rural e a Associação de Pais e Amigos dos Excepcionais e recebimento do Benefício de Prestação Continuada. **Conclusão:** ações de equipes de saúde rural articuladas na rede de atenção auxiliam na superação de fragilidades de mulheres com deficiência.

**Descritores:** Pessoas com Deficiência; Vulnerabilidade em Saúde; Gênero e Saúde; População Rural; Saúde da Mulher

## Resumen

**Objetivo:** analizar las situaciones de vulnerabilidad y protección que viven las mujeres con discapacidad en el contexto rural. **Método:** estudio cualitativo, descriptivo y exploratorio, realizado con diez mujeres con discapacidad residentes en áreas rurales de cinco ayuntamientos de las regiones norte y noroeste de Rio Grande do Sul, Brasil. Las entrevistas tuvieron lugar en los hogares de enero a junio de 2019. El material empírico fue grabado, transcrito y sometido al análisis de contenido temático. **Resultados:** las vulnerabilidades reveladas fueron: restricciones de responsabilidad, educación, trabajo, ingreso, autonomía y beneficio social. En cuanto a las condiciones que potencian la protección contra las vulnerabilidades, se observaron fuertes vínculos con la Estrategia de Salud Familiar Rural y la Asociación de Padres y Amigos de los Excepcionales, además de la recepción del Beneficio de la Provisión Continua. **Conclusión:** las acciones de los equipos de salud rural articuladas en la red de atención ayudan a superar las debilidades de las mujeres con discapacidad.

**Descriptores:** Personas con Discapacidad; Vulnerabilidad en Salud; Género y Salud; Población Rural; Salud de la Mujer

## Introduction

Epidemiological data from the World Health Organization measure the existence of more than one billion people in the world living with some type of disability, and many deal with important obstacles in relation to daily life and health.<sup>1</sup> In Brazil, the Brazilian Institute of Geography and Statistics, based on the National Health Survey, estimated that, of the 200.6 million people living in permanent private households, 6.2% had at least one type of disability, whether visual, auditory, physical/motor or intellectual.<sup>2</sup>

Women with disabilities are described in the literature as a marginalized and vulnerable population, given the intersection between sex and disability.<sup>3-4</sup> This results in a unique experience of inequality and segregation, not experienced by other individuals,<sup>3</sup> even by men with disabilities.<sup>5</sup> Furthermore, it is considered that these women are more susceptible to experiencing abuse and poverty, have greater difficulties in achieving

financial independence, accessing services<sup>6</sup> and entering the labor market.<sup>7</sup>

When these women live in rural contexts, whose social organization is based on traditional family models, they can present multiple vulnerabilities, since, almost always, people with disabilities (PwD) depend on someone in the family or on the generosity of others to meet their needs related to daily life and health. In addition, with no incentive to claim their rights, they accept what official health, public education and social assistance agencies offer. Cases in which they engage in political struggles for better living conditions are rare.<sup>8</sup>

The knowledge about situations of social vulnerability of populations with disabilities, especially women, is essential for the implementation of public policies. The evidence that the adverse socioeconomic status of women with disabilities creates greater hindrance to the activities of daily living reinforces the importance of actions based on biopsychosocial care models.<sup>9</sup>

To analyze vulnerability, it is necessary to understand how people and groups of people experience health/illness situations. It can be observed based on three dimensions: the individual, which is related to biological, behavioral and affective aspects; the social, which interconnects the characteristics of the context in which the individual is inserted and the relationships that he/she establishes and accesses for his/her healthy development; and the programmatic, which refers to policies, programs, services, actions and the way in which they interfere in the situation experienced by the being.<sup>10</sup>

Considering the singularities of the life and health context of women with disabilities living in the rural setting, in this study, it was chosen to use the theoreticalmethodological framework of vulnerability based on the three dimensions mentioned above.<sup>10</sup> This study starts from the research question: How are situations of vulnerability and protection experienced by women with disabilities living in the rural context? In view of this, this research had the objective of analyzing the situations of vulnerability and protection experienced by women with disabilities in the rural context.

## Method

Qualitative, descriptive and exploratory research,<sup>11</sup> carried out in five municipalities in the north and northwest regions of Rio Grande do Sul, belonging to the 15<sup>th</sup> and 19<sup>th</sup> Regional Health Coordination Offices. These municipalities have more than

70% of the population living in the rural context and their economy is based on family farming, characterized by smallholdings.

The study was attended by women with disabilities living in the rural setting of these municipalities who complied with the following inclusion criteria: being over 18 years of age, living in the rural context for at least six months and presenting some type of disability (visual, auditory, intellectual, physical or multiple), congenital or acquired. As an exclusion criterion, the degree of intellectual commitment was considered, evaluated together with the main researcher and the health professional, based on the support received in the different areas of the subject's development, considering the following dimensions defined by the American Association of Intellectual and Developmental Disability (AAIDD): intellectual skills; difficulty in social interaction; social participation; adaptive behavior; health and context.<sup>12</sup>

To carry out the selection of the participants, the research team had the help of the Community Health Workers (CHW) of the Family Health services of each municipality. These professionals prepared a list of 113 women with disabilities living in the rural setting of the municipalities, possible participants in the study.

With the list organized from the five cities, the participants were selected by drawing lots. The interviews took place interspersed, respecting the order and the representativeness of the cities. Data production was interrupted when the internal logic of the object of study was understood.<sup>13</sup> Thus, ten women with disabilities participated in this study, two representatives from each city. It should be underlined that there were no refusals or withdrawals and the researchers did not have any type of link with the health services in which the participants' information was collected.

Data production was conducted using the semi-structured interview technique, with researchers who had experience. Prior to the interview, the researchers introduced themselves to the participants, citing their degree of training, link with the university and research trajectory. At that time, they also explained the objective of the investigation, its procedures, possible risks and benefits, by reading the Free and Informed Consent Form (FICF). The women who agreed to participate in the study signed the FICF in two copies, one of which remained with them and the other with the researchers.

During the interview, initially, variables were collected to characterize the

participants: age; color/race; marital status; number of children; education; sources of income; family composition; type of disability and whether congenital or acquired. The interview followed, guided by a semi-structured script with the following questions: How do you move to school, work, health and social activities? Do you use public and/or private transportation? When do you look for health services? Which? How do you feel when you are assisted by health professionals? How often do you consider the quality of the health service? Do you need medicines? If yes, how are they acquired? In terms of rehabilitation, what activities do you perform? And what technologies do you use or would you need? What are the difficulties encountered on a daily basis in your personal life? Do you receive any benefits? If yes, which? How was the path to obtaining it? What relationships do you have (friends, dating, family, neighbors and marriage)? How do you perceive the access to your rights?

The interviews were conducted between January and June 2019, at the participants' homes, based on prior scheduling via telephone or personal contact, carried out by the CHW of the micro-areas in which they lived. On the scheduled day, the researchers went to the health units, where they found the CHW, and from there they went to the homes accompanied by these professionals. It should be underlined that the first contact between the researchers and the participants was face-to-face and, from this, the interviews followed.

The interviews were conducted in safe and private environments. Therefore, upon arriving at the home of women with disabilities and identifying the presence of other people, data collection was rescheduled, and three reschedules were made. Furthermore, it is noteworthy that, at the time of the interview, only the participant and researchers remained. This procedure aimed to minimize the risk of bias and preserve ethical research principles. The interviews lasted an average of 30 minutes and were audio-recorded with the help of digital media devices, with the consent of the participants, thus seeking to ensure authentic material for analysis.

The recorded material was transcribed in full, with the help of the Microsoft Word text editor, and subjected to the thematic content analysis technique. Data processing was carried out in three stages. The first, called pre-analysis, corresponded to the pre-

exploration of the material, with floating readings to choose the analytical corpus and text clippings. The second stage, the exploration of the material, led to the definition of categories (coding system) with the identification of registration and context units, allowing the categorization. The third and final phase enabled the treatment of results and interpretations.<sup>14</sup> To that end, the categories were analyzed in the light of the theoretical framework of vulnerability<sup>10</sup> and relevant scientific literature.

To ensure the anonymity of the participants, the letter M was adopted for women, followed by the number of the interview according to the order in which it was carried out and the type of disability. The research complied with Resolution 466/2012 of the National Health Council.<sup>15</sup> The project was approved by the Research Ethics Committee of the Federal University of Santa Maria through the Certificate of Presentation for Ethical Appreciation n<sup>o</sup> 69973817.4.0000.5346, on August 9<sup>th</sup>, 2017.

## Results

Ten women aged between 38 and 84 years old participated in this study, with an average age of 52 years. All declared themselves white. Six were married and the rest were single. Seven had children. With regard to education, nine had incomplete elementary school and one had complete high school.

With regard to sources of income, four received the Continuous Cash Benefit (BPC, as per its Portuguese acronym); one received Family Grant; two received old-age pensions; and one received sick pay. Concerning the family composition, the participants reported living with husbands and children, in addition to daughter-in-law, grandchildren, nephews, siblings, brothers-in-law. One mentioned living alone.

Among the ten participants, six had a congenital disability and four had an acquired disability. Seven had physical disabilities; two had low-grade intellectual disability; and one had multiple disabilities. Regarding the use of medicines, four were using antidepressants and four were using antihypertensive drugs.

Two categories emerged from the thematic analysis: Situations of vulnerability of women with disabilities in the rural context: restrictions on responsibility, education, work, autonomy and rights; and Situations of protection to the vulnerabilities of women with disabilities in the rural context: access to health, education and social assistance services.

Situations of vulnerability of women with disabilities in the rural context: restrictions on responsibility, education, work, autonomy and rights.

During childhood, some participants took on the responsibility of caring for sick family members, even with limitations imposed by their disabilities. For one of them, the physical limitation prevented her from playing with her siblings.

> *I suffered a lot, because I took care of my father, I had to change my father's clothes with only one hand. Moreover, I could never play with my siblings; I didn't have the courage because I was sick.* (M4 – acquired multiple disabilities) *I took care of her [sister].* (M6 – congenital physical disability)

Participants mentioned different barriers faced in accessing school education. They recognized important gaps in the learning process due to difficulties imposed by disabilities and exacerbated by obstacles characteristic of rural areas, such as long distances, lack of transportation and little support for the poorer families.

*I have difficulties because old age is coming and we have no education, and we understand very little* [...] *I feel embarrassed by this, but we have to live like this* [...]. *I attended school, but I didn't learn.* (M1 – congenital intellectual disability, low grade)

[...] I have to spell it to read; and if there are too many letters, I can't [...] I ask her [sister] to read the sentences for me to understand [...] I attended [school] for nine months and stopped because the teacher moved, went to live far away. (M6 – congenital physical disability)

[...] *I only studied until the 5<sup>th</sup> grade because it was hard to go, there was no transportation and it was very difficult.* (M7 – congenital physical disability)

[...] to go to school was complicated, because the father did not have a car and he had to walk a kilometer with me on his back when it rained [...] and that was to take me to get transportation, because there was no transportation close by. (M5 - congenital physical disability)

The difficulties in terms of insertion and permanence of women with disabilities in the formal labor market were also revealed by some participants. Others carried out productive activities that contributed to the support of the family, but understood their income as secondary to the income of their husbands, who managed the budget and, sometimes, the work they developed.

*No, currently I don't work* [...] *but I used to work with a formal contract.* (M3 – congenital physical disability)

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When I worked, it was 200 reais [...] now it's the small changes we make, sometimes, and my husband's wage. (M1 – congenital intellectual disability, low grade) I have the store, it's my job, which is in my husband's name, but I'm the

one who deals with it, because he doesn't understand, it's been 7 years [...]. (M2 – acquired physical disability)

The limitation caused by the disability transforms the women's work routine in the domestic and public space, requiring adaptations to give continuity to their activities. There were expressive manifestations regarding the difficulties to establish autonomy in daily tasks.

*I can't* [work], *I barely have time to take a shower and sometimes I make food.* [...] *I used to be a street vendor on a motorcycle, I spent almost 10 years selling on a motorcycle. When he* [the husband] *retired, he made a CNPJ for me to have the store.* (M2 – acquired physical disability) *Yes, I work at home, but not much.* (M4 – acquired multiple disability) *I can do very little [at home], almost nothing.* (M9 – acquired physical disability) *I can't do anything [at home].* (M10 – acquired physical disability)

Although with limitations due to disability, other participants were able to handle

domestic services such as cleaning house, preparing meals and washing clothes.

*I work, do the laundry, make the food and take care of the house.* (M1 – congenital intellectual disability, low grade)

*I work, I can do anything.* (M3 – congenital physical disability) *It was as if it were normal, I do all the services inside the house, if I have wood and water, the fire, I take care of everything, I scrub the floor with a cloth, using wax, I even bake bread.* (M6 – congenital physical disability) *Inside the house, I can clean, but outside I can't, because I can't do heavy work* [...]. (M5 – congenital physical disability)

*Yes, I cook food, wash clothes* [...] (M7 – congenital physical disability).

Some women did not have access to the BPC program, as they were unable to prove their

need due to legal requirements. In addition, they did not receive support from the family to obtain

it, thus recognizing the importance that the assistance would have on their quality of life.

*I don't get anything* [benefit]. *I went after it, had x-rays, but they said I'd have to have at least one more disability.* (M3 – congenital physical disability)

*I don't get anything* [benefit], *and the guy* [brother] *says it's a lot of rush to go after* [...] *I had to have something to help to buy the medication, the clothes* [...] *I like to get dressed up, buy perfume, I needed some help.* (M4 – acquired multiple disability)

Another issue raised by the surveyed women refers to accessibility, as they reported not

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having adequate public transportation for their needs. In addition, there were several barriers

that made it difficult for them to move around in the environment in which they lived.

*Transportation doesn't provide accessibility and I don't have a wheelchair.* (M2 – acquired physical disability) *At the same time there is and there isn't* [transportation]. *You've to walk a lot in places that are difficult to access, roads with a lot of stones, stairs* [...] *Speaking of the bus, it's hard for me to get there* [...]. (M5 – congenital physical disability)

In the case of the participants who had their own car, none was purchased at a discount for people with disabilities, even though it is a right guaranteed by Brazilian law. One of them even mentioned that she was not aware of this benefit.

> The car was achieved through a (brique) land negotiation, so we didn't use the discount. (M3 – congenital physical disability) It's an old car from an inheritance, so we didn't get a discount. (M4 – acquired multiple disability) He [husband] bought it in installments, but I didn't know I was entitled to get this discount. (M7 – congenital physical disability)

The restrictions experienced by the women who took part in this study imposed on them living conditions in which there was greater individual, social and programmatic vulnerability when they did not access the rights guaranteed by law and public policies, which may be related to misinformation, lack of family support and of the health, education and social assistance services themselves.

Situations of protection to the vulnerabilities of women with disabilities in the rural context: access to health, education and social assistance services

The positive evaluation of the care received in the health services and the appreciation of this procedure were present in the testimonies.

*The quality* [of the health service] *is good, because we didn't have anything before, but now we have things* [...] *I feel good, they treat us well.* [...]. (M1 – congenital intellectual disability, low grade) *Look, there're people who complain, for us, for me, for my father, whenever I needed help, I had help.* (M3 – congenital physical disability) *Pretty well, they are very dear and they serve well.* (M7 – congenital physical disability)

Women with disabilities accessed health services that they did not have

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before, for gynecological and clinical consultations, as well as for requesting prescriptions for medicines for continuous use.

[...] *it's easier for us, who live here. Before I used to go, there were no forms, but now there are. I started to do things because there are, when we look for them.* (M1 – congenital intellectual disability, low grade) *Once a month, I make an appointment to get the medicine and tests when I'll have a surgery, then I do a heart and blood test. I haven't had a mammogram and preventive screening for about four years, because I depend on getting the request and then someone takes me [...]. (M2 – acquired physical disability)* 

In turn, at the Association of Parents and Friends of Exceptional Children (APAE, as per its Portuguese acronym), women with disabilities reported that they received physical therapy services. The surveyed women reported an excellent relationship with health service professionals and APAE.

*I started to take part in the little school [APAE], and then, there, I ride a horse, do physical therapy, play soccer.* (M4 – acquired multiple disability)

*I feel happy because, just yesterday, they found me and clapped their hands for me, because I sold all the calendars the teacher gave me.* (M4 – acquired multiple disability)

[...] they [the health unit professionals] are all friendly [...]. (M8 – congenital intellectual disability, low grade)

Although some participants reported difficulties in obtaining BPC, others reported an accessible process for achieving this right. This benefit is used for purposes that go beyond their private needs, complementing the family's income, thus helping to pay the household bills and the children's health expenses.

*I receive BPC, it was very easy, and there was no difficulty in getting it [...]. It is to buy my little things, food and well-being.* (M8 – congenital intellectual disability, low grade) *Yes, in a matter of 30 days I was receiving BPC; it was very quick* [...]. (M9 – acquired physical disability) *I buy medicines, pay the electricity, and help with the house bills.* (M2 – acquired physical disability) *As much as I can, I help with the house expenses, for medication, for my* 

*little girl, it's more for health or for some other need of mine.* (M5 – acquired physical disability)

*I use [the benefit] to buy what I need and I'm making savings* [...]. (M6 – congenital physical disability)

Access to health, education and social assistance services reveals programmatic actions

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of public policies in this context, which, associated with the individual and social potentialities of women with disabilities, guaranteed them greater protection and development potential.

## Discussion

The results of this study reveal that most participants had congenital disabilities, present since birth. Other women, in turn, had acquired disabilities, which came from a situation that occurred in childhood or youth. According to these women, both disabilities generated limitations of different degrees, including preventing them from playing. This data is also pointed out by another study that identified that the women who had disabilities since childhood did not have the opportunity to play with other children at this stage of their lives.<sup>3</sup>

Despite this, some participants in this study, still in childhood and even with physical restrictions, took on domestic responsibilities. In this condition, these women needed support to better develop. Support from family, friends and the community is essential for living new experiences and helping with the impacts that disability causes in everyday life. When the support network is not strong and presents weaknesses, this person will be vulnerable to conditions of access to transportation, health, education and other rights inherent to the citizen.<sup>16</sup>

In the rural context, care is related to gender and class relationships.<sup>17</sup> In this juncture, the woman since her childhood takes on the role of caregiver, providing physical, psychological and affective well-being to men, elderly and sick people who constitute her family nucleus.

The participants of this study had difficulties to attend school and, therefore, had low education. Women with disabilities face multiple challenges to enjoy civil rights and fundamental services such as education.<sup>5</sup> One of these challenges is the absence of public and private transportation and their lack of accessibility for PwD,<sup>3-5</sup> in addition to long distances and unsuitable roads.<sup>3</sup> On the other hand, despite the fact that women living in the rural context deal with hindrance to accessing education, there is evidence that they have more years of studies when compared to men.<sup>18</sup>

Research that investigated the factors that influence the employment status of women with disabilities in South Korea indicated that the educational level increased the employment rates of these women.<sup>4</sup> Accordingly, policies that provide this population with

access to education, and that it is inclusive and devoid of prejudice, are considered essential.

Most of the participants in this study did not have a paid job and those that did were for a short time and earned low wages. In this sense, research finds that most women with disabilities do not have work and fixed income, which negatively impacts their economic situation and creates difficulties to meet their basic needs. When there are job opportunities, they are subordinated, with significantly lower pay, poor working conditions and fixed deadlines.<sup>3</sup>

The urban region is identified as the main locus of paid work for women with disabilities or chronic diseases living in the rural context of Hungary, being considered fundamental, since most of them have unfavorable socioeconomic conditions and the income from this work tends to contribute substantially to their lives.<sup>7</sup> In this context, disability is one of the major sources of disadvantage for rural women to enter and remain in the labor market, considering that their health condition tends to affect their work performance or even their opportunities to move around.<sup>8</sup>

Despite the restrictions, some participants kept on developing certain domestic activities that they were able to carry out. It is pointed out that women with disabilities, even with limitations, try to take on responsibilities at home, cooking, washing and ironing clothes, among others.<sup>3</sup>

The work for rural women who live off family farming is based on sexual and social relational division and their responsibilities are directed toward caring for the home, the children, the husband and the household. Such activities tend to require less physical strength, while men are responsible for making decisions on administrative, financial and general family matters, in addition to performing the work considered "heavy". This setting reveals the inequalities between men and women in the social hierarchy, with regard to the distribution of work and professional position.<sup>17</sup>

The domestic service performed by women is sometimes made invisible. However, when it is not developed, it causes family tensions. In the rural context, the work of women with disabilities could be performed by a professional and paid with the help of BPC, considering that the support network is almost always limited.

At times when rural women need help with domestic service, they ask for help from their daughters. Because they have no choice, these women see domestic work as their only function and do not allow themselves to be free from this idea. They learn from childhood, with their mothers, grandmothers and aunts, who will develop these activities, and pass them on to their daughters. Thus, domestic work is reaffirmed as feminine.<sup>17</sup>

When men help with domestic activities, this practice does not represent gender equity in the division of tasks. Moreover, they participate in domestic activities, almost always, in the absence of women. In this case, the principle of segregation of work is reiterated, distinguishing what belongs to the feminine and the masculine.<sup>17</sup>

Rural women develop activities often considered masculine, but not recognized as work, such as growing food and caring for animals beyond subsistence. This is due to a socio-historical construction based on gender, from which activities aimed at subsistence and which do not generate income are considered feminine. This idea that there are services to be done by men and others to be done by women, in the rural environment, is also defined by the need for strength required to carry out certain activities.<sup>18</sup>

Working does not just mean earning income to survive, it goes beyond that, since it qualifies people as independent and gives them a social function that makes them valued in their setting. The PwD who enters the formal labor market becomes another person, giving rise to an independent, freed person, more self-assured and living in the social environment.<sup>19</sup>

In this study, some women with disabilities did not have access to BPC, due to the difficulty in proving the disability and forwarding the documentation. Furthermore, they did not have enough information and family support to achieve this right. The BPC program serves 2,527,257 people with disabilities; however, to confirm this need, PwD have a long way to go, facing numerous bureaucracies and proofs that must be carried out and make access difficult.<sup>20</sup>

As for receiving BPC, women are in second place, and there has been a decrease in requests granted due to the criteria that evaluate the person's limitations and restrictions, whose intensity of dependence varied from mild to moderate.<sup>19</sup> The granting of this benefit is approved by the National Institute of Social Security (INSS, as per its Portuguese acronym), involves the evaluation of a social worker, medical examinations and other requirements that reveal a subjective nature, because each professional can have his/her own view of disability, influencing the judgment of the necessity of receiving the BPC money by the woman.<sup>21</sup> Another factor that also hinders the achievement of this right is the amount of per capita income that the family must have, considering that people with disabilities have high expenses with medicines, rehabilitation activities and other intercurrences. Sometimes, even if the per capita income is greater than ¼ per family member, it still does not cover all needs, and receiving more than this wage would be of paramount importance for the PwD and his/her family.<sup>20</sup>

It is important to mention that families of PwD who live in the rural setting suffer a process of intensified impoverishment, with the risk of collapse of the economy and the well-being of the family nucleus. This process is a direct or indirect result of their family member's disability, represented by health care costs, loss or reduction of the workforce and income. It is also the result of the structural barriers potentiated by the rural context, such as difficulties in accessing social protection and restricted subsistence choices, with limited possibilities for paid work, among others.<sup>22</sup>

The lack of access to public transportation was present in the participants' lives, a situation also reported in other studies developed with women with disabilities.<sup>3-5</sup> One of them pointed out that 60% of the women could not use buses, since they were not accessible for people using wheelchairs and crutches, for example.<sup>5</sup> PwD living in rural areas become invisible, since they are geographically distant from bodies representing rights, which could reinforce the achievement of accessibility to transportation and assistive equipment and technologies.<sup>8</sup>

Some participants in this study pointed to access to health, education and social protection services, as well as the support of some professionals from these services to live in their contexts. These resources helped to overcome obstacles in life and health, becoming a form of protection against vulnerabilities. Here, it is denoted the relevance of the dimension of individual vulnerability combined with the social and programmatic ones to obtain greater protection. To that end, it is considered that there is a structure of opportunities in the public sphere and the participation of people.<sup>10</sup>

The possibility of rehabilitation plays a fundamental role in the life of a PwD. It is important to offer spaces in which professionals are prepared for specialized care. Nevertheless, the implementation of public health policies that support this group is still incipient for the reestablishment of more complex conditions.<sup>23</sup>

The women in this study accessed health services and considered the relationship with professionals to be very positive. They portrayed that their basic general health needs were met. PwD wait for help in discovering new activities; and, in this sense, the support network made up of health professionals from Primary Care offers these conditions, thus cooperating with their insertion in society and enabling experiences that generate physical and psychological independence.<sup>16</sup>

The bond between the disabled women and the health team members is shown to be a positive factor, increasing the power of speech and allowing the expression of feelings and anxieties of these rural populations in relation to their needs. The team professional, when listening to them, can guide and build possibilities and alternatives to meet their health demands, considering the peculiarities of rural families and their needs.<sup>24</sup> Strong bonds and people's internal and subjective capacities to deal with difficulties and conditions present in their life contexts can reduce vulnerabilities marked by social and economic inequalities.<sup>10</sup> The economic fragility of PwD can be alleviated by obtaining BPC, and their lives improved by being articulated to services, projects and benefits from Social Assistance, as well as the effectiveness of the work with the beneficiaries and their families.<sup>22</sup>

The women with disabilities in this study who received BPC obtained the benefit easily and, therefore, in addition to subsidizing their treatments and those of their children, they helped with household expenses. It is perceived that BPC is an important financial resource, being considered one of the main sources of care for people with disabilities living in rural contexts and of access to rights.<sup>8</sup>

Finally, in light of these considerations, it is highlighted the potential of nursing in the care of women with disabilities who live in rural areas. The understanding of how to care for these people must take into account the set of experiences related to their living and health conditions. Nurses can play an emancipatory role with PwD, being co-participants in their process of strengthening autonomy.<sup>25</sup> Therefore, the practice of care focused on health and its determinants must be strengthened, especially in those that generate vulnerabilities.

The recognition of the Health Care Service by women with disabilities in the study setting as a support point can be the basis for strengthening the Health Care Policy for the Rural Population, while the Rural Family Health Strategy (ESFR, as per it is

Portuguese acronym) is gateway to the Brazilian Unified Health System (SUS) in this context. Moreover, ESFR can become the locus that integrates women with disabilities into all essential services for their rehabilitation and social inclusion, aiming at comprehensive care and the mitigation of individual and social weaknesses. However, there is still progress to be made regarding the health care model applied by ESFR. This is because the actions in terms of health promotion and prevention of diseases and evils constitute challenges for professionals.<sup>26</sup>

Within the scope of ESFR, in addition to individual consultations focused on the disease, groups can be developed with women with disabilities living in the rural setting, aiming to promote the health of these women. In this perspective, a study indicates that groups of women can constitute an important source of empowerment, social support and information for women with disabilities.<sup>27</sup>

From the analysis of the situations of vulnerability and protection of these women, there are subsidies to (re)think, especially, the access to intersectoral care services. As for health education, addressing the context of life and health of women with disabilities in the rural context is essential to support professional practices, considering the singularities of this group. In the research, it is necessary that further investigations be carried out with this population, thus seeking to understand their biopsychosocial needs.

This study has as a limitation the small sample group of a specific context, which should be considered for the generalization of the results. Nevertheless, it makes unique contributions by giving voice to women with disabilities living in rural settings, a marginalized social group, vulnerable in multiple dimensions and whose recruitment is extremely challenging.

# Conclusion

The study shows that the vulnerabilities experienced by women with disabilities living in rural contexts include restriction, lack of access to education, work and income, rights, welfare benefits and public transportation, in addition to environmental and architectural barriers. It is also found that some women experience situations that protect them from the vulnerabilities present in the rural context when they have access to health and education services and positive relationships with the professionals of these services.

The vulnerabilities of women with disabilities living in rural contexts, in part,

derive from the absence of public policies on health, education, work, income and leisure. These policies are interconnected and can be carried out in intersectoral actions with qualified professionals. In addition, they are supported by the PwD law since 2015.

Efforts are needed to, in fact, offer these women the opportunity for human development in the social dimensions and to foster social inclusion in family farming with greater autonomy for activities that go beyond the so-called domestic, in the female field, despite the disability. The protective aspects identified in the study can be better explored, bearing in mind that some of these women, even without a support network and access to all essential services for their rehabilitation and development, have a positive outlook on life.

# References

1. World Health Organization (WHO). World report on disability [Internet]. Genebra: WHO; 2011 [cited 2021 mar 07]. Available from: <u>http://www.who.int/disabilities/world\_report/2011/report.pdf</u>

2. Instituto Brasileiro de Geografia e Estatística (IBGE). Pesquisa Nacional de Saúde: 2013: ciclos de vida: Brasil e grandes regiões [Internet]. Rio de Janeiro (RJ): IBGE; 2015 [acesso em 2021 jan 27]. Disponível em: <u>https://biblioteca.ibge.gov.br/visualizacao/livros/liv94522.pdf</u>

3. Daoud S, Elmagboul N, Miso MH. Vulnerability and discrimination of young displaced women living with disabilities: a case of Mandela South Khartoum/Sudan. Ahfad J [Internet]. 2018 [cited 2021 mar 30];35(2):45-54. Available from: <u>https://search.proquest.com/openview/314ec134071c53d1693474fefff5ed19/1?pq-</u> <u>origsite=gscholar&cbl=5287</u>

4. Kim JY. Factors for employment of women with disabilities in South Korea. J Evid Based Soc Work. 2020;17(6):749-60. doi: 10.1080/26408066.2020.1798320

5. Akter A, Rahman MM. Women with disabilities in Bangladesh: accessibility in the built environment. Figshare (PROSHIKHYAN J Train Dev). 2018;26(2):1-12. doi: 10.6084/m9.figshare.13181315.v1

6. Stuntzner S, MacDonald A, Dalton JA. Exploration of a resilience intervention among women with disabilities: an examination of two case studies. Int Phys Med Rehabil J. 2020;5(4):183-91. doi: 10.15406/ipmrj.2020.05.00255

7. Fabula Sz, Timár J. Violations of the right to the city for women with disabilities in peripheral rural communities in Hungary. Cities. 2018;76(1):52-7. doi: 10.1016/j.cities.2017.12.005

8. Tonini H, Lopes MJM. Desenvolvimento, cuidado e vulnerabilidade: pessoas com deficiência em áreas rurais do RS. Rev Interdiscip [Internet]. 2017 [acesso em 2021 mar 14];10(3):110-24. Disponível em: <u>https://dialnet.unirioja.es/servlet/articulo?codigo=6771925</u>

9. Boccolini PMM, Duarte CMR, Marcelino MA, Boccolini CS. Social inequalities in limitations caused by chronic diseases and disabilities in Brazil: the 2013 National Health Survey. Ciênc Saúde Colet. 2017;22(11):3537-46. doi: 10.1590/1413-812320172211.22552017

10. Ayres JRCM, Calazans GJ, Saletti Filho HC, Franca Junior I. Risco, vulnerabilidade e práticas de prevenção e promoção da saúde. In: Campos GWS, Minayo MCS, Akerman M, Drumond Júnior M,

Rev. Enferm. UFSM, v.12, e14, p.1-19, 2022

Carvalho YM, organizadores. Tratado de Saúde Coletiva. São Paulo: Hucitec; Rio de Janeiro: Fiocruz; 2006. p. 375-418.

11. Minayo MCS, organizadora. Pesquisa social: teoria, método e criatividade. Rio de Janeiro: Vozes; 2016.

12. Alles EP, Castro SF, Menezes ECP, Dickel CAG. (Re)Signification in the assessment process of young and adult subjects with intellectual disability. Rev Bras Educ Espec. 2019;25(3):373-88. doi: 10.1590/s1413-65382519000300002

13. Falqueto JMZ, Hoffmann VE, Farias JS. Saturação teórica em pesquisas qualitativas: relato de uma experiência de aplicação em estudo na área de Administração. Rev Ciênc Adm (Florianópolis). 2018;20(52):40-53. doi: 10.5007/2175-8077.2018V20n52p40

14. Bardin L. Análise de Conteúdo. São Paulo: Edições 70; 2016.

15. BRASIL. Ministério da Saúde. Resolução nº 466, de 12 de dezembro de 2012. Diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos. Brasília, DF: Ministério da Saúde, 2013. Disponível em: http://bvsms.saude.gov.br/bvs/saudelegis/cns/2013/res0466\_12\_12\_2012.html. Acesso em: 26 out. 2020.

16. Brignol P, Schoeller SD, Silva DMGV, Boell JEW, Lopes SGR, Souza SS. Support network for persons with physical disabilities. Rev Enferm UERJ. 2017;25(1):175-14. doi: 10.12957/reuerj.2017.18758

17. Hirata H. Gênero, patriarcado, trabalho e classe. Rev Trabalho Necessário. 2018;16(29):14-27. doi: 10.22409/tn.16i29.p4552

18. Lopes MJM, Langbecker TB. Inclusão produtiva, pecuária familiar e situação das mulheres rurais do Programa Brasil sem Miséria em um município do RS - contexto de uma realidade pouco conhecida. Redes (St Cruz Sul) [Internet]. 2018 [acesso em 2021 mar 09];23(1):31-52. Disponível em: <u>https://dialnet.unirioja.es/servlet/articulo?codigo=6354647</u>

19. Duarte FMO, Corrêa MH, Bueno RC. O desafio de incluir pessoas com deficiência (PCDs) no<br/>trabalho: um estudo para mais recursos humanos. Rev Cient Doctum Multidiscip [Internet]. 2018<br/>[acesso em 2021 mar 09];1(1):1-17. Disponível em:<br/>http://revista.doctum.edu.br/index.php/multi/article/view/180

20. Stopa R. O direito constitucional ao Benefício de Prestação Continuada (BPC): o penoso caminho para o acesso. Serv Soc Soc. 2019;135:231-48. doi: 10.1590/0101-6628.176

21. Vaitsman J, Lobato LVC. Continuous Cash Benefit (BCP) for disabled individuals: access barriers and intersectoral gaps. Ciênc Saúde Colet. 2017;22(11):3527-36. doi: 10.1590/1413-812320172211.20042017

22. Shaun G. Disabled families: the impacts of disability and care on family labour and poverty in rural Guatemala. Societies. 2019;9(4):1-16. doi: 10.3390/soc9040076

23. Amorim EG, Liberali R, Medeiros Neta OM. Avanços e desafios na atenção à saúde de pessoascom deficiência na atenção primária no Brasil: uma revisão integrativa. Holos (Natal). 2018;1:224-36.doi:10.15628/holos.2018.5775

24. Oliveira AR, Sousa YG, Silva DM, Alves JP, Diniz IVA, Medeiros SM, et al. Primary Health Care in the rural context: the nurses' view. Rev Gaúcha Enferm. 2020;41:e20190328. doi: 10.1590/1983-1447.2020.20190328

25. Schoeller SD, Lima DKS, Martins MM, Ramos FRS, Zuchetto MA, Bampi LNS, et al. Protocol for

a scoping review on nursing care and the autonomy of disabled persons. BMJ Open. 2018;8(10):e022106. doi: 10.1136/bmjopen-2018-022106

26. Morrison J, Colbourn T, Budhathoki B, Sen A, Adhikari D, Bamjan J, et al. Disabled women's attendance at community women's groups in rural Nepal. Health Promot Int. 2017;32(3):464-74. doi: 10.1093/heapro/dav099

27. Costa LA, Carneiro FF, Almeida MM, Machado MFAS, Dias AP, Menezes FWP, et al. Estratégia Saúde da Família rural: uma análise a partir da visão dos movimentos populares do Ceará. Saúde Debate. 2019;43(N Esp 8):36-49. doi: 10.1590/0103-11042019S803

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