






HOME-BASED CAREGIVERS OF PEOPLE WITH INTELLECTUAL DISABILITIES IN RURAL SETTINGS AND THEIR CHALLENGES

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ABSTRACT

Objective: to analyze the challenges, characteristics, and feelings of home caregivers of people with intellectual disabilities in the rural context. Method: this is a quanti-qualitative study with 124 caregivers of people with intellectual disabilities living in rural settings in eight municipalities in southern Brazil. Data were collected from September/2018 to June/2019, through a questionnaire with social, demographic, and daily variables of care. The analysis was analytical and descriptive type, through frequency and frequency comparison. Results: the home caregivers are women, mothers, sisters, of advanced age, with little education, but who, in the face of challenges such as accumulation of functions, work overload, low education, fatigue, social and professional isolation, develop their attributions with love. Conclusion: the study contributed to the identification of the characteristics and challenges of caregivers of people with intellectual disabilities in rural areas, revealing issues for the advancement of public health practices.

DESCRIPTORS: Caregivers; Intellectual Disability; Nursing; Rural Population; Social Support.

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INTRODUCTION

The caregiver is understood as the one responsible for taking care of someone who is sick and/or dependent, assisting in the performance of activities of daily living, such as feeding, hygiene, leisure, medications, and monitoring in health services⁽¹⁾. In addition, the caregiver is considered the bridge or the link between those who are cared for and the services, especially regarding health issues⁽²⁻³⁾.

The home caregiver or informal caregiver is the one who learned with practice, without training to perform such tasks, usually a family member. In this sense, it is noticed that home caregivers go through difficult situations, due to the lack of scientific knowledge, developing a more instinctive and experience-based care. Caring for people with disabilities at home is a challenging assignment, which involves love, respect, care, dedication, and presence, and can cause stress depending on the conditions and characteristics of each person with disabilities and family^(1,4).

Intellectual disability is defined by the American Association on Developmental Disabilities (AAIDD) as the coexistence of considerable limitations in intellectual functioning and deficits in adaptive actions in at least three areas, expressed in conceptual, social, and practical abilities, which involve daily activities of the subject and their adaptation to the demands of society⁽⁵⁻⁶⁾. The intellectual disability sometimes establishes a limited condition for the subject to express his/her will or make decisions, even though they are adult people. Such limitation makes these people more dependent, whether on the home caregiver, the family, or the health team. The intellectual disability affects about 2.6 million people in Brazil; of these, more than 445 thousand reside in the rural environment⁽⁷⁻⁸⁾.

The home caregiver of People with Intellectual Disabilities (PCDI) usually experiences an accumulation of functions inherent to the process of being at home, and usually has no one to share the care activities with and ends up performing multiple functions at home, such as the responsibility for meals, home organization, childcare, and professional activity. This context generates overload, exhaustion, affective and social isolation. Besides, the fact that it is routine can cause or aggravate diseases in the caregiver⁽⁹⁻¹⁰⁾. Added to this, there are other factors that contribute to the overload, such as age, socioeconomic conditions, and the environment, as well as social determinants (basic sanitation, leisure, culture, food, and others)⁽¹¹⁾. The characteristics of the rural areas end up depriving the population of these resources, which may hinder the process of universalization of rights and implying in the quality of life of families⁽¹²⁻¹³⁾.

The health indicators and social determinants of the rural population, in general, are lower than those of the urban population, besides the coverage of preventive actions, also less frequent in rural areas. The difficulties related to health services occur because of obstacles such as the insertion and maintenance of professionals in these areas, worker turnover, and unequal distribution, which also leads to work overload for professionals⁽¹³⁻¹⁴⁾.

The intellectual disability itself already causes great difficulties and limitations for those who live in rural areas, because people who live in the countryside and have no disabilities report having fewer difficulties when compared to those who live in the countryside and have disabilities, showing that the disability is an aggravating factor for limitations and difficulties faced daily by this population⁽¹⁵⁾.

There are few studies focused on the caregiver of People with Intellectual Disabilities (PCDI) in the rural setting. It is considered an important step in this scenario to break the invisibility, recognize their specificities and approach this context^(11,15-16). Therefore, identifying and understanding the challenges experienced by the home caregivers of People with Intellectual Disability (PCDI) can contribute to improvements in the process of care at home, especially in the rural setting. The aim of this study was to analyze the challenges, characteristics, and feelings of home caregivers of people with intellectual

disabilities in the rural setting.

METHOD

This study is characterized as a cut of the database of the matrix project "Social determinants of health in people with disabilities, families and support network in a rural setting: multiple vulnerabilities". The matrix project interviewed 275 people with disabilities and their caregivers, in eight municipalities, with rural characteristics, in the northwest region of the state of Rio Grande do Sul, Brazil. The present manuscript cut out the caregivers of People with Intellectual Disabilities (PCDI), totaling 124 participants.

This is a quanti-qualitative study carried out with home caregivers of people with intellectual disabilities (PCDI). The criterion used for the selection of the municipalities in the study was to have at least 70% of the population living in rural areas, totaling eight municipalities.

The selection criteria were home caregivers of People with Intellectual Disabilities (PCDI) who were over 18 years of age and who did not have mental or intellectual disabilities. The participants were selected and contacted through the records available in the Municipal Health Services, through the researchers' previous contact with the nurses of the municipalities' health units.

The field work consisted of, first, selecting the People with Intellectual Disabilities (PCDI) who lived in rural areas and, later, the definition of the main caregivers of this population. The community health agent (CHA) was the professional responsible for the researchers' interaction with the study population (caregivers). After the initial contact with the health services of the participating municipalities, the interviews were scheduled according to the availability of the CHAs and caregivers, according to the collection dates made available by the researchers.

The information was collected through a questionnaire with the following open-ended questions: What feelings does the role of caregiver awaken in you? What are the main difficulties you feel in caring for the person with disability? A closed instrument was also used to characterize the caregivers in terms of age, gender, color, and other socioeconomic variables. The instrument was applied by the researchers at the homes of the people with intellectual disabilities. The collection took place in the period from September 2018 to June 2019. 124 home caregivers of People with Intellectual Disabilities (PCDI) participated in the study.

Quantitative data were entered into Excel spreadsheets, and later analyzed under descriptive and analytical analysis (frequency comparison, Chi-square, and Fisher's exact test), using the Statistical Product and Service Solutions (SPSS) statistical program, version 18.0. A significance level of p-value less than or equal to 5% was used. For qualitative data analysis, we used the Word Cloud application, which organizes/presents the words with greater repetition (simple frequency analysis) to build the results, by means of highlighting figures. The words were typed according to the absolute frequency of answers in the interviews, and the most repeated ones are highlighted in size (largest presentation font) in the representation of the "word cloud". This is a qualitative analysis by repetition of the key words listed in the statements.

The study was approved by the Research Ethics Committee of the Federal University of Santa Maria, under opinion number 2208566.

RESULTS

The results are presented in tables and word clouds, seeking to characterize the caregivers of People with Intellectual Disabilities (PCDI) and their daily challenges. In Table 1, the characterization of these caregivers is described.

Table 1 - Characterization of Caregivers of People with Intellectual Disabilities. Palmeira das Missões, RS, Brazil, 2019 (continues)

Variable	n	%
Degree of relationship		
Father	8	6,5
Mother	55	44,4
Brother	29	23,4
Uncle or Aunt	3	2,4
Others	29	23,4
Gender		
Male	25	20,2
Female	99	79,8
Age		
18-42 years old	30	24,2
43-52 years old	33	26,6
53-63 years old	30	24,2
> 63 years old	31	25
Color		
White	90	72,6
Brown	31	25
Black	2	1,6
Other	1	0,8
Education		
Not Attended School	9	7,3
Elementary School Incomplete	86	69,4
Complete Elementary School Complete	7	5,6
Incomplete High School	7	5,6
Complete High School	10	8,1
Incomplete College	3	2,4
College Complete	2	1,6
Income		
Up to one minimum wage	42	33,9

Two to five minimum wages	82	66,1
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Source: Authors (2019)

According to Table 1, 94 (75%) caregivers were older than 43 years old, the mean age was 52.5 years, minimum of 18 years old and maximum of 82 years old. As for the degree of kinship, 55 (44.4%) caregivers of People with Intellectual Disabilities (PCDI) were the mothers, followed by siblings (n=29, 23.4%). The caregivers were female (n=99; 79.8%), white (n=90; 72.6%) and with family income of two to five minimum wages (n=82; 66.1%). Under an analysis of education degrees, the low level of education stands out, since 95 (76.7%) of the caregivers had never studied or had incomplete elementary school.

Under an analysis of the development of diseases in caregivers, it is highlighted that 106 (85.5%) caregivers of People with Intellectual Disability (PCDI) live with some chronic disease. Table 2 compares some factors associated with the development of these diseases before and after becoming a caregiver of a person with intellectual disability (PCDI).

Table 2 - Factors associated with the development of diseases in caregivers of people with intellectual disabilities living in rural areas in the northwest region of the state of Rio Grande do Sul (n=106). Palmeira das Missões, RS, Brazil, 2019

	Previous Illness	Acquired Disease	p-value
Type of Disability			
Intellectual disability	22(34,4)	11(26,2)	0,04*
Other types of disability	42(65,6)	31(73,8)	
Gender			
Male	12(18,7)	9(21,4)	0,496*
Female	52(81,3)	33(78,6)	
Family Member			
Father	5(7,8)	4(9,5)	0,004*
Mother	31(48,4)	26(61,9)	
Brother	13(20,3)	7(16,6)	
Uncle or Aunt	2(3,1)	0	
Others	13(20,3)	5(11,9)	
Rest			
Never rests	9(14,1)	4(9,5)	0,004*
Less than one shift	3(4,7)	3(7,1)	
One shift	14(21,9)	9(21,4)	
Only at night	38(59,4)	26(61,9)	
TOTAL	64 (100)	42(100)	

*Chi-square test

Source: Authors (2019)



Figure 2 - Difficulties and Challenges of caregivers of People with Intellectual Disability (PCDI). Palmeira das Missões, RS, Brazil, 2019
Source: Authors (2019).

DISCUSSION

The caregivers are women (about 80%) - this finding agrees that historically and socially, women are considered caregivers, either at home or for the health of family members, which can be observed in other studies⁽¹⁷⁻¹⁹⁾. As for the degree of kinship, they are usually mothers and sisters, since they often take upon themselves the attribution of caring for their relatives⁽²⁰⁾. Added to this care are household chores, childcare and self-care, accumulating responsibilities and physical overload related to the double working day. Many women, in the different realities already studied, present physical, emotional, and mental fatigue, development of mental disorders such as stress, anxiety and depression, reasons for the use of medications, because they cannot choose what best fits their reality⁽²¹⁻²²⁾.

Regarding education, 95 (76.7%) caregivers did not attend school or did not finish elementary school, as well as the People with Intellectual Disability (PCDI): 91% did not attend school or did not finish elementary school. The level of education is an indicator of social vulnerability, both caregivers, and of those being cared for. Low education contributes to the reduction of social and economic progress and can condition social weaknesses and precarious access to the necessities of daily life. It is also a situation that interferes in the understanding of rights and care possibilities, guaranteed by public policies. Social vulnerability is one of the elements that favor the insufficiency of individual, family, and social resources to meet the demands of families^(19,23).

These are people with low levels of education, caring for people in the same condition. Low education affects caregiving, may cause difficulty in understanding information and in the ability to develop tasks, affect income and productivity, besides compromising the caregiver's responsibilities towards the one being cared for, since the performance of care includes drug administration, technical and scientific guidance, and the search for a better quality of life for both⁽¹⁹⁻²³⁾.

As life expectancy has been increasing, the number of elderly people caring for other elderly people tends to increase as well, since the mean age of caregivers was 52 years old. Generally, the task of caring stems from the level of health of the caregiver and the one

being cared for, the support received, the prognosis of the illness of the one being cared for, and the quality of family relationships (relationships between the caregiver and the one being cared for). All these characteristics refer to the more experienced caregiver, with a better relationship with family members⁽²³⁾. The accumulation of attributions is one of the difficulties found by the caregiver, especially in old age; however, many caregivers learn to deal well and reconcile their daily life activities with the demands of caring for the other without feeling harme^{d(24)}.

When the cognitive limitation of the People with Intellectual Disability (PCDI) influences their independence, the loss of motor functions or the appearance of some chronic disease in the caregiver hinders the care actions⁽²⁵⁾. The elderly caregiver is susceptible to the onset of diseases typical of old age and caregiving, many times, places him/her as a patient in imminence, with operational capacity at risk⁽²⁴⁾.

The participants of this study, when compared to caregivers of people with other types of disabilities, presented lower rates of developing diseases after becoming caregivers, which may be associated to conditions of physical effort and/or functional limitation (little present in People with Intellectual Disabilities PCDIs) with ergonomic and postural diseases⁽¹⁸⁾.

The overload was one of the difficulties reported by the interviewees, being a significant obstacle in the daily life of the home caregiver. It can be defined by the reduction of the feeling of well-being and occurrence of health complications, which can appear in an acute or chronic way. Performing the role of home caregiver affects the physical and emotional health, especially when the caregiver had some health problem before becoming a caregiver. It is observed the importance of sharing the activities about the care of the People with Intellectual Disability (PCDI) and receiving guidance to optimize time and avoid weariness⁽²⁶⁾.

The challenges experienced by home caregivers in rural areas are numerous: mainly barriers related to accessibility, health services, sanitation, leisure, geographical distance, professional and family isolation, among others. Moreover, the coverage of health services for rural populations is a worldwide difficulty, showing the worst health indicators in these areas⁽¹³⁾. A strategy that can contribute is to invest in the development of intrafamily and extra family social relationships. It is important to have a family structure that enables the involvement between the home caregiver and the People with Intellectual Disability (PCDI) within the family space, promoting a safe, calm, and receptive environment. Likewise, it is necessary to have socialization, interactions, and social skills in other contexts, since they are indicators of mental health, healthy interpersonal relationships, bases of life in society, besides reducing the fragilities of caregiving and stimulating the interaction and exchange of knowledge⁽²⁷⁾.

The overload is related to the level of dependence of the People with Intellectual Disability (PCDI) and may be related to the lack of understanding about the challenges and daily needs of the family, often characterized by the presence of violence, aggressiveness, fear, anger and feeling of being alone in this process, especially in rural areas. To mitigate these fragilities and face the challenges, health professionals and caregivers need to meet, build dialogic and propositional relationships, providing quality of life, reducing overloads, and improving the care provided. The overload also affects the social relationships of caregivers, since the lack of emotional support, lack of time due to the care routine and the needs of the People with Intellectual Disability (PCDI) can influence the affective relationships and generate social isolation for the caregiver⁽²⁸⁾.

The needs of those who live in rural areas are peculiar and require care from different services, especially in the health field⁽¹²⁾. The health services have a fundamental role for the development of care actions provided by the caregiver at home, especially by sensitively welcoming the needs and difficulties of the caregiver of People with Intellectual Disability (PCDI). The fruits of the caregiver-professional interaction are perceived through a dialogical relationship, the effectiveness in problem solving, the involvement and sharing

of objectives, the construction of unique care strategies, and the promotion of positive and continuous meetings⁽²⁹⁾.

The support that the home caregiver and the People with Intellectual Disability (PCDI) receive from family members, friends, and professionals reflects significantly in the well-being, confidence, and in the relationship climate between both, once the caregiver's physical, psychological, and emotional burden is high. Even if positive aspects predominate between the relationships of those who care and those who are cared for, the physical and emotional stresses exist⁽³⁰⁾.

The support networks can be both formal (public policies, welfare, and social assistance, among others) and informal (family, neighbors, friends, and community)⁽²⁴⁾. The support networks contribute to the elaboration of feelings that the role of caregiver awakens and encourages the facing of challenges.

The locoregional description of a specific population, with population selection based on reports from the health services, is recognized as a limitation of the study, which may have excluded People with Intellectual Disability (PCDI) unknown to health workers in the municipalities studied.

CONCLUSION

Women, mothers, adults, and elderly, with weaknesses in many accesses (including school), income, social and professional support, and mainly living in contexts of aggressiveness, tension, and loneliness are some of the characteristics of these caregivers who live in rural areas.

The strengthening of public policies for those who live in the countryside, the implementation of the Rural Family Health Strategy, home visits and health groups in the community are important means to qualify the caregivers, clarify health issues, promote bonding, qualify care, reduce burdens, and understand the experiences of these caregivers. It was observed the relevance of the health team in this context, strengthening the relationships that exist between the caregiver/People with Intellectual Disability(PCDI)/family, ensuring autonomy and quality of life for all.

It is believed that more studies should be conducted on the caregiver who resides in rural areas and their demands, to promote health and minimize injuries and vulnerabilities. Theoretical and practical productions need to be built to reduce distances and contribute to science and popular knowledge about the caregiver of People with Intellectual Disability (PCDI) living in rural areas.

The study identified and characterized the caregivers of People with Intellectual Disability (PCDI) in rural areas and their challenges, showing the weaknesses and gaps to be filled in the theoretical and practical areas of the health field.

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