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# CHARACTERIZATION OF CAREGIVERS OF PERSONS WITH DISABILITIES: INVISIBILITY AND CHALLENGES OF CARE IN THE RURAL CONTEXT

*Caracterização de cuidadores de pessoas com deficiência: invisibilidade e desafios de cuidar no contexto rural*

*Caracterización de los cuidadores de personas con discapacidad: invisibilidad y retos del cuidado en el contexto rural*

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## ABSTRACT

**Objective:** to analyze the characteristics of family caregivers of Persons with Disabilities in the rural context. **Method:** this is a quantitative study, with 219 caregivers of Persons with Disabilities, who live in the rural context, in eight cities from southern Brazil. Data were collected from September 2018 to June 2019, using a questionnaire with variables for characterization and caregiver and care conditions. Data analysis was conducted by frequency measurement and comparison. **Results:** home caregivers are mostly women, mothers, aged 40-60 years and with low education level. They became ill after they started caring, rest few hours, and need better health conditions to increase their quality of life. **Conclusion:** in the rural context, caregivers of persons with disabilities are often invisible to health services and need to be cared for.

**DESCRIPTORS:** Caregivers; Disability; Nursing; Rural population; Social support.

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**RESUMO**

**Objetivo**: analisar as características dos cuidadores familiares de Pessoas com Deficiência no contexto rural. **Método**: trata-se de um estudo quantitativo, com 219 cuidadores de Pessoas com deficiência, que vivem no contexto rural, em oito municípios do sul do Brasil. Os dados foram coletados no período de setembro de 2018 a junho de 2019, por meio de um questionário com variáveis de caracterização e condições do cuidado e do cuidador. A análise dos dados foi realizada por frequência e comparação de frequência. **Resultados**: os cuidadores domiciliares são, em sua maioria, mulheres, mães, com idade entre 40-60 anos e com baixa escolaridade. Adoeceram após começar a cuidar, descansam pouco e necessitam melhores condições de saúde para ampliar sua qualidade de vida. **Conclusão**: no contexto rural as cuidadoras de pessoas com deficiência são, muitas vezes, invisíveis aos serviços de saúde e necessitam ser cuidadas.

**DESCRITORES:** Cuidadores; Incapacidade; Enfermagem; População rural; Suporte social.

**RESUMEN**

**Objetivo:** analizar las características de los cuidadores familiares de Personas con Discapacidad en el medio rural. **Método:** se trata de un estudio cuantitativo, con 219 cuidadores de personas con discapacidad, que viven en el medio rural, en ocho ayuntamientos del sur de Brasil. Los datos se recolectaron entre septiembre de 2018 y junio de 2019, mediante un cuestionario con variables de caracterización y condiciones del cuidado y del cuidador. El análisis de los datos se realizó mediante frecuencias y comparación de frecuencias. **Resultados**: los cuidadores domiciliarios son en su mayoría mujeres, madres, entre 40 y 60 años y con bajo nivel educativo. Se enfermaron después de empezar a cuidar, descansan poco y necesitan mejores condiciones de salud para mejorar su calidad de vida. **Conclusión:** en el medio rural, los cuidadores de personas con discapacidad suelen ser invisibles para los servicios de salud y necesitan ser atendidos.

**DESCRIPTORES:** Cuidadores; Discapacidad; Enfermería; Población rural; Apoyo social.

## INTRODUCTION

Persons with Disabilities (PwD) are considered to be those who have some physical, mental, intellectual or sensory impairment that in the interaction with everyday life situations present limitations in their full participation in society, on an equal basis with others.[1] People experiencing certain limitations due to disabilities need support and care in the activities of daily living.

In most situations this care is assigned to a family member who lives with the PwD.[2] To understand the experience of the family caregiver is to enter a diverse, complex, and at the same time specific and identitary field of the family and social space.

Studies point out that the family caregiver of PwDs experiences an accumulation of functions inherent to the process of being at home; generally, there is no one with whom to share the care activities and they end up performing multiple functions, such as the responsibility for the meals, home organization, child care, and professional activity. This context generates overload, exhaustion, affective and social isolation for the caregiver. Moreover, the fact that this is routinary can cause or worsen diseases.[3]

Other factors contribute to the overburden of the caregiver such as age, socioeconomic conditions, environmental conditions, and other social determinants of health.[4] The characteristics of the rural areas deprive the population of these resources, which can hinder the process of universalizing rights and imply in the quality of life of the families [5,6], as well as in the invisibility of caregivers.

The support network in the rural context is still incipient and fragile, access to health professionals is not very frequent, and informal care networks are more predominant.[7]

The rural population is considered vulnerable and has weaknesses regarding the organization of services. The health indicators, the health social determinants, and the offer of preventive actions are lower than those of the urban population.[8] The family caregiver experiences specific situations of the rural context, which can be considered challenges or also potentialities in the daily care tasks.

The knowledge of the characteristics of caregivers of PwD in rural areas, justified by the innovation of the theme for epidemiological studies, can contribute to the development of strategies for coping with their needs and difficulties, helping in the construction of public policies that give visibility to caregivers and PwDs and qualify the processes of home care in this scenario.

Thus, the research question is: what are the characteristics of family caregivers of PwDs in the rural context? The objective of the study was to analyze the characteristics of family caregivers of PwDs in the rural context.

## METHOD

This study presents a sample from a matrix project entitled: "Social determinants of health in persons with disabilities, families and support network in a rural scenario: multiple vulnerabilities".

This is a quantitative, analytical study, conducted in the rural scenario of eight cities located in the northwest region of Rio Grande do Sul/RS, with at least 70% of rural population, belonging to the 15th and 19th Regional Health Coordinations (CRS).

The participants of the study were caregivers of PwD who met the inclusion criteria: over 18 years old, who had no mental or intellectual disabilities, and who lived in the coverage area of the studied cities. To select the participants, the researchers contacted the health secretaries and the coordinators of Family Health Strategies (FHS) from the cities by telephone to schedule the data collection. Community health agents helped in the collection organization in households, given their knowledge of the territory and their bond with the families.

The instrument was applied to the caregivers by the researchers at the PwD's home. The researchers and research assistants have experience in data collection, being part of the Center for Studies and Research in Collective Health of the Federal University of Santa Maria – *Palmeira das Missões* Campus (NEPESC/UFSM-PM), and were trained for data collection through systematized meetings that occurred throughout the development of the project.

The following characterization variables were used for analysis [categorical variables]: sex, age, color, education, type of disability, caregiving support, rest and disease development.

The data collection took place in the period from September 2018 to June 2019. Quantitative data were typed into Excel spreadsheets, then submitted to descriptive and analytical analysis (frequency comparison), using the statistical program SPSS, version 18.0.

The ethical aspects were respected, with regard to research involving human beings. The research project was approved by the UFSM Research Ethics Committee (CEP/UFSM), by the Certificate of Presentation for Ethical Appreciation (CAAE) register no. 69973817.4.0000.5346.

## RESULTS

Of the 276 study participants, 219 (79.3%) have a home caregiver. The characterization of these caregivers is described in Table 1.

The caregivers of PwDs in the rural context are adults, in the age group of 40 to 60 years [Σ=51.3 years, minimum of 15 years and maximum of 86 years]. It is worth noting that four caregivers are over 80 years old and that 36% are elderly. The caregivers are female (81%), white (71%), and with low education (90%). Table 2 presents the comparison between the groups of PwDs with caregivers and those without caregivers.

**Table 1** – Characterization of caregivers of PwD in rural areas. Rio Grande do Sul, Brazil, 2021 (N=219)

| Variables of characterization | | n(%) |
|---|---|---|
| **Age** | <40 years | 37 (16,9) |
| | 40 to < 60 years | 103(47,0) |
| | ≥ 60 years | 79(36,1) |
| **Sex** | Male | 41(18,7) |
| | Female | 178 (81,3) |
| **Color** | White | 157 (71,7) |
| | Brown | 57 (26,0) |
| | Black | 5(2,3) |
| **Education** | NAS/ PEI | 174 (79,5) |
| | PEC/ SEI | 23(10,5) |
| | SEC or CEIC | 22(10) |

Abbreviations: NAS= Never Attended School; PEI= Primary Education Incomplete; PEC= Primary Education Complete; SEI= Secondary Education Incomplete; SEC= Secondary Education Complete; CEIC= College Education Incomplete or Complete.

**Table 2** – Comparison between the groups of PwDs with caregivers and those without caregivers Rio Grande do Sul, Brazil, 2021 (N=276)

| | Has a Caregiver n(%) | Does not have a caregiver n(%) | p † |
|---|---|---|---|
| **Type of Disability** | | | |
| Intellectual | 124(93,2) | 9(6,8) | <0,001 |
| Acquired Physical | 29(52,7) | 26(47,2) | <0,001 |
| Congenital Physical | 23(59,0) | 16(41,0) | |
| Multiple | 23(85,2) | 4(14,8) | <0,001 |
| Auditory Congenital | 17(100) | 0 | |
| Visual Congenital | 3(60,0) | 2(40,0) | |
| **Age** | | | |
| < 18 years | 29(96,7) | 1(3,3) | 0,02 |
| 18-59 years | 152(78,8) | 41(21,2) | |
| ≥ 60 years | 38(71,7) | 15(28,3) | |
| **Education of the PwD** | | | 0,001 |
| NAS/ PEI | 193(81,8) | 43(18,2) | |
| PEC/ SEI | 19(73,1) | 7(26,9) | |
| SEC or CEIC | 7(50,0) | 7(50,0) | |

Abbreviations: NAS= Never Attended School; PEI= Primary Education Incomplete; PEC= Primary Education Complete; SEI= Secondary Education Incomplete; SEC= Secondary Education Complete; CEIC= College Education Incomplete or Complete. † Chi-square test.

People with congenital hearing loss (100%), intellectual (93%), and multiple disabilities (85%) have the most caregivers. The elderly PwDs are the ones who have the least caregivers when compared the age groups. Children, adolescents and people with low education are the ones who present the highest caregiver demand ($p<0.05$). Table 3 shows the degree of kinship between the caregiver and the person with disability.

The mother is the main home caregiver and is more frequent in congenital, intellectual, and multiple disabilities. As for acquired physical disabilities, other family members are the main caregivers, such as children, spouses, and cousins. The degree of kinship of the main caregiver varies according to the age group of the PwD. Maternal care is more frequent for children and adolescents (69%), whereas care from other family members is more frequent for the elderly (57.9%). Table 4 presents the description of the caregiving conditions.

It can be observed that 63.5% of the caregivers have never received information about the care for PwDs. Most (75%) can share the caring with another person and have periods of rest at night. They consider that better health conditions would improve their quality of life. Of all the caregivers participating in the study 57.5% have a chronic disease and 70% of them developed it after starting to take care of the PwD.

**Table 3** – Caregiver's kinship degree with the person with disability. Rio Grande do Sul, Brazil, 2021 (N=219)

| | **Family Member n(%)** | | | | | |
|---|---|---|---|---|---|---|
| | **Father** | **Mother** | **Brother** | **Grandparent** | **Uncle/Aunt** | **Others** |
| **Type of Disability** | | | | | | |
| Acquired Physical | 1(3,4) | 6(20,7) | 4(13,8) | 0,0% | 0,0% | 18(62,1) |
| Congenital Physical | 1(4,3) | 11(47,8) | 3(13) | 5(21,7) | 0,0% | 3(13,0) |
| Intellectual | 8(6,5) | 55(44,4) | 29(23,4) | 0,0% | 3(2,4) | 29(23,4) |
| Visual Congenital | 0,0% | 2(66,7) | 1(33,3) | 0,0% | 0,0% | 0,0% |
| Auditory Congenital | 2(11,8) | 7(41,2) | 4(23,5) | 0,0% | 0,0% | 4(23,5) |
| Multiple | 0,0% | 10(43,5) | 5(21,7) | 1(4,3) | 0,0% | 7(30,4) |
| **PwD's age** | | | | | | |
| < 18 years | 2(6,9) | 20(69,0) | 1(3,4) | 4(13,8) | 1(3,4) | 1(3,4) |
| 18-59 years | 9(5,9) | 70(46,1) | 31(20,4) | 2(1,3) | 2(1,3) | 38(25,0) |
| ≥ 60 years | 1(2,6) | 1(2,6) | 14(36,8) | 0,0% | 0,0% | 22(58,0) |
| **Total** | 12(5,5) | 91(41,5) | 46(21,0) | 6(2,7) | 3(1,4) | 61(27,8) |

**Table 4** – Caregivers' conditions for caregiving Rio Grande do Sul, Brazil, 2021 (N=219)

| **Conditions for caregiving** | | **%(n)** |
|---|---|---|
| Received information to provide care | Yes | 80(36,5) |
| | No | 139(63,5) |
| Someone else helps with the care | Yes | 161(73,5) |
| | No | 58(26,5) |
| Rest Shifts | Never | 22(10,1) |
| | Less than a shift | 14(6,4) |
| | A shift | 52(23,9) |
| | Only at night | 130(59,7) |
| Do you have any chronic illnesses? | Yes | 126(57,5) |
| | No | 93(42,5) |
| Did you acquire diseases after being a caregiver? | Yes | 88(69,8) |
| | No | 38(30,2) |
| What would improve your QoL? | Best health conditions | 91(42,1) |
| | Better income conditions | 58(26,9) |
| | Better Education Conditions | 8(3,7) |
| | Sharing Responsibilities | 7(3,2) |
| | Others | 53(24,1) |

## DISCUSSION

This study showed that women are the main caregivers of persons with disabilities. Among the family caregivers, the function linked to the family women, who reside in the same space as the familiar, often performing this function alone, stands out.[9,10] Research shows that the care of the elderly at home is mostly developed by women [11] and the care of children with disabilities is linked to the mother figure.[12]

The profile of caregivers of persons with disabilities was characterized in the study as being mostly women, with complete elementary education and an average age of 49 years.[9] Another research found that caregivers are mostly women, elderly, with a mean age of 65.8 years, presenting formal education between one and four years, most of them are married, do not exercise any paid activities or are retired, self-declared white and catholic.[13]

Caregivers often experience stress, fatigue, and overload in the performance of their function. The fact that they carry out the care work alone has an impact especially on their community and financial life.[12]

The relationship between elderly family caregivers with caregiving variables in a rural context showed a slight perceived burden in the assessment conducted by the Zarit Burden Inventory (ESZ) and 16.2% presented depressive symptoms according to the Geriatric Depression Scale (GDS).[13]

Regarding the care of the elderly, there is a need for support in face of the impacts associated with environmental and social barriers, in addition to the vulnerabilities present in the aging process.[14] A study in Africa showed that the difficulties of access to health care in a rural area is greater for people with disabilities and has implications for older people facing the challenges of caring for this population.[15] As people age, the likelihood of becoming a caregiver for an elderly relatives increase considerably, however, studies with caregivers in the community are scarce, especially when they live in remote areas.[13,16]

Research showed that 57.1% of caregivers have some degree of kinship and fell within the first degree and another 23.7% had no consanguinity.[17]

The role of the family as a social institution, nucleus of affection, support and solidarity is highlighted. The families of persons with disabilities are able to identify the need for care, but the dependence on family care and the illnesses resulting from the disability result in physical and emotional exhaustion.[18]

Children and adolescents with disabilities in unfavorable social and economic conditions demand greater care from the family, requiring financial support to pay for health needs due to the greater risk of acquiring associated diseases.[19]

Mothers are the main caregivers at home, especially for children and adolescents. An international survey revealed that mothers rated the activities related to child care as important and believe they have the skills to develop home care, however, the activities that involve health care cause physical and emotional stress in these mother caregivers.[20]

Mothers are the main caregivers of hearing-impaired children, most of them are married, have other children, and do not exercise paid work.[21] As with hearing impairment, in intellectual disability the main caregivers are mothers, most of whom are housewives, married, have at most five years of education, and do not receive a monthly salary. These women get older and continue to care for people with intellectual disabilities and other elderly members of the family.[22]

Caring for people with intellectual disabilities is stressful for the family, since the daily involvement of fathers and mothers in caregiving activities ends up interfering with their working lives, impacting on their self-esteem, sense of self-efficacy, relationship with other family members and social life.[23]

Caregivers of children and adolescents with multiple visual and hearing impairments assisted in reference services, besides having to rearrange their family routines, feel insecure about the care provided to their children. The doubts are related to the administration of medication, hygiene care and feeding.[24]

The caregivers are concerned about the future of care, think about preparing substitutes, and find in the siblings an alternative.[24] In this study, some caregivers are elderly which shows that, in rural families, relatives do not always replace each other.

The act of care predisposes caregivers to the development of comorbidities, while pathologies emerge in the exhaustion phase of stress, characterized by the beginning of an illness process, causing the deterioration of the most vulnerable organs that compromises quality of life.[25]

A study showed that 52.7% caregivers develop new pathologies after the caregiving role 49.2% make continuous use of medication. The caregiver's chronic disease is a stressful factor, which produces effects on him/her and on the family, for having to deal with the dependence situations of the PwD such as mobility, self-care, and communication, besides factors such as cognitive deficits and depression.[9] In this sense, family caregivers of elderly Alzheimer's patients also presented affected health conditions in the physical, social, and emotional fields.[25]

Contrary to the present study, research with caregivers of people with mental suffering found that they had no complaints of physical health problems, however, they reported how big is the change in life when one becomes the caregiver of a person in mental suffering. This role generates responsibilities that lead them often to suffer alone, for they have no one to share their pain with.[26]

Caregivers have little or no assistance from others. Often the responsibility for care falls on a single family member, the primary caregiver, who has little opportunity for rest in his or her day.[27,10]

In this study, caregivers rested one shift daily, relying on the help of other people. Research with the caregivers of the elderly showed that they devoted approximately 18 hours a day to caregiving.[11]

More than half of them have never received information on care practices for PwDs. According to these data, research showed that most of the caregivers surveyed (96.3%) had no previous training on how to care, only 44.3% received information on care, 26.6% of these in public primary care.[9]

Most of them were family caregivers of a PwD, with no help from relatives, but although they did not indicate they had taken training, they provided the necessary care. Most of the caregivers were of people with intellectual disabilities, presenting pathologies and negative feelings towards care, and stated that the division of responsibilities with other family members could improve their quality of life as caregivers.[9]

Despite the awareness of the role that these family members play, they become invisible in the current care model, with no specific actions aimed to them. Suffering may be present and aggravated by the lack of care and support from health professionals.[26,28]

Research in Colombia has shown that, with regard to the right to health, care is understood as a private welfare service. Most of the revised norms do not take into account the role of the caregiver, and make invisible their importance in the process of social participation and policies for PwDs.[29]

Therefore, thinking about actions directed to the caregiver in mental health can collaborate to the welcoming of these people and minimize the needs that arise as a consequence of the changes resulting from the daily act of care.[26]

The strengthening and expansion of public health policies aimed at training and care for the caregiver must be prioritized, in order to improve quality of life, promote health, and prevent diseases.[9,29]

## CONCLUSION

Family caregivers of PwD in the rural context are essentially women, with low income and low education, overloaded and with great potential for developing chronic non-communicable diseases. The invisibility of caregivers needs to be addressed by health professionals working in PwDs care, considering the impact of caregiving actions on the health and quality of the family caregiver, especially when these reside in the rural context, which imposes a number of barriers to access and accessibility.

With this study, it was possible to give visibility to the characteristics of caregivers of PwDs in rural regions, which can instrumentalize the creation of comprehensive health care strategies for them, as well as the construction of public policies able to meet their demands and needs, improving the quality of life of caregivers and the care processes at home in this scenario.

The epidemiological profile described provides an opportunity to build public policies that address the social and health demands of this population in the rurality and disabilities context. We recognize as a limitation of the study the exclusive locoregional description of a specific population with population selection based on reports from health services, which may not unveil PwDs unknown to health actors in the studied cities.

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## REFERENCES

1. BRASIL. Lei nº 13.146, de 06 de julho de 2015. Institui a Lei Brasileira de Inclusão da Pessoa com Deficiência. Estatuto da Pessoa com Deficiência. Available from: http://www.planalto.gov.br/ccivil_03/_Ato2015-2018/2015/Lei/L13146.htm
2. Fernandes CS, Angelo M. Family caregivers: what do they need? An integrative review. Rev. esc. enferm. USP. [Internet]. 2016 [cited 2021 jan 21];50(4). Available from: https://doi.org/10.1590/S0080-623420160000500019.
3. Costa TF, Gomes TM, Viana LRC, Martins KP, Costa KNFM. Acidente vascular encefálico: características do paciente e qualidade de vida de cuidadores. Rev Bras Enferm. [Internet]. 2016 [cited 2020 jan 12];69(5). Available from: https://doi.org/10.1590/0034-7167-2015-0064.
4. Coimbra Junior CEA. Saúde Rural no Brasil: tema antigo mais que atual [Internet]. 2018 [cited 2020 jan 08];52(1). Available from: https://doi.org/10.11606/s1518-8787.2018052000supl1ap.
5. Winckler M, Boufleuer TR, Ferreti F, Sá CA. Idosos no meio rural: uma revisão integrativa. Estud. interdiscipl. envelhec. [Internet]. 2016 [cited 2020 jan 11];21(2). Available from: https://seer.ufrgs.br/RevEnvelhecer/article/view/60691/44545.
6. Oliveira AR, Sousa YG, Diniz IVA, Medeiros SM, Martiniano C, Alves M. O cotidiano de enfermeiros em áreas rurais na Estratégia Saúde da Família. Rev Bras Enferm. [Internet]. 2019 [cited 2020 jan 06];72(4). Available from: https://doi.org/10.1590/0034-7167-2018-0243.
7. Pavarini SCI, Neri AL, Brígola AG, Ottavianni AC, Souza EN, Rossette ES, Terassi M, Oliveira NA, Luchesi BM. Idosos cuidadores que moram em contextos urbanos, rurais e de alta vulnetrabilidade social. Rev. esc. enferm. USP. [Internet]. 2017 [cited 2021 mar 15];51. Available from: https://doi.org/10.1590/S1980-220X2016040103254.
8. Marques AS, Freitas DA, Leão CDA, Oliveira SKM, Pereira MM, Caldeira AP. Atenção Primária e saúde materno-infantil: a percepção de cuidadores em uma comunidade rural quilombola. Ciênc. saúde coletiva. [Internet]. 2014 [cited 2021 jan 28];19(2). Available from: https://doi.org/10.1590/1413-81232014192.02992013.
9. Câmara FS, Martins WLL, Moura MLN, Melo CS, Medeiros NSR; Gadelha ECM, Souza LS, Ferreira JMS. Perfil do cuidador de pessoas com deficiência. Revista Brasileira de Ciências da Saúde. [Internet]. 2016 [cited

2020 nov 20];20(4). Available from: https://doi.org/10.4034/RBCS.2016.20.04.02.

10. Nunes DP, Brito TRP, Duarte YAO, Lebrão ML. Cuidadores de idosos e tensão excessiva associada ao cuidado: evidências do Estudo SABE. Rev. bras. epidemiol. [Internet]. 2019 [cited 2021 mar 04];21(2). Available from: https://doi.org/10.1590/1980-549720180020.supl.2

11. Souza ID, Pereira JA, Silva EM. Between State, society and family: the care of female caregivers. Rev. Bras. Enferm. [Internet]. 2018 [cited 2021 abr 22];71(6). Available from: https://doi.org/10.1590/0034-7167-2018-0111.

12. Tomaz RVV, Santos VA, Avó LRS, Germano CMR, Melo DG. Impacto da deficiência intelectual moderada na dinâmica e na qualidade de vida familiar: um estudo clínico-qualitativo. Cad. Saúde Pública. [Internet]. 2017 [cited 2020 sep 18];33(11). Available from: https://doi.org/10.1590/0102-311X00096016.

13. Brigola AG, Luchesi BM, Rossetti ES, Mioshi E, Inouye K, Pavarini SCI. Health profile of family caregivers of the elderly and its association with variables of care: a rural study. Rev. bras. geriatr. gerontol. [Internet]. 2017 [cited 2020 jan 12];20(3). Available from: https://doi.org/10.1590/1981-22562017020.160202.

14. Martins JA, Watanabe HAW, Braga VAS, Jesus MCP, Merighi MAB. Older adults with physical disabilities: vulnerabilities relative to the body, the physical and social environment. Rev Bras Enferm. [Internet]. 2020 [cited 2021 mar 15];73(3). Available from: https://doi.org/10.1590/0034-7167-2019-0175.

15. Vergunst R, Swartz L, Hem KG, Eide AH, Mannan H, MacLachlan M, Miji G, Braathen SH. Access to health care for persons with disabilities in rural South Africa. BMC Health Serv Rev. [Internet]. 2017 [cited 2021 fev 10];17(741). Available from: https://doi.org/10.1186/s12913-017-2674-5.

16. Morgan DG, Kosteniuk JG, Stewart NJ, O'Connell ME, Kirk A, Crossley M, Crossley M., Bello-Hass VD, Forbes D, Innes A. Availability and primary health care orientation of dementia-related services in rural Saskatchewan, Canada. Home Health Care Serv Q. [Internet]. 2015 [cited 2021 jan 24];34(3-4). Available from: https://doi.org/10.1080/01621424.2015.1092907.

17. Araújo MGO, Dutra MOM, Freitas CCSL, Guedes TG, Souza FS, Baptista RS. Cuidando de quem cuida: qualidade de vida e sobrecarga de mulheres cuidadoras. Rev. Bras. Enferm. [Internet]. 2019 [cited 2020 apr 08];72(3). Available from: https://doi.org/10.1590/0034-7167-2018-0334.

18. Ferreira PR, Fiamenghi-Jr GA. Relações familiares de cuidadores de pessoas com deficiência intelectual profunda. Pensando fam. [Internet]. 2015 [cited 2021 mar 20];19(1). Available from: http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S1679-494X2015000100011&lng=pt&nrm=iso.

19. Oliveira DAS, Ferreira MS, Neto JLC. Análise de fatores sociodemográficos de duplas cuidador-criança/adolescente com deficiência: um estudo caso-controle. Rev. Bras. Ed. Esp. [Internet]. 2018 [cited 2021 mar 20];24(3). Available from: https://doi.org/10.1590/S1413-65382418000300006.

20. McCann D, Bull R, Winzenberg T. Brief Report: Competence, value and enjoyment of childcare activities undertaken by parents of children with complex needs. J Pediatr Nurs. [Internet]. 2016 [cited 2021 jan 24];31(2). Available from: https:// doi.org/10.1016/j.pedn.2015.10.018.

21. Ramires CMN, Branco-Barreiro FCA, Peluso ETP. Fatores relacionados à qualidade de vida de pais de crianças com deficiência auditiva. Ciênc. saúde coletiva. [Internet]. 2016 [cited 2021 mar 21];21(10). Available from: https://doi.org/10.1590/1413-812320152110.224720.

22. Silva RS, Fedosse E. Perfil sociodemográfico e qualidade de vida de cuidadores de pessoas com deficiência intelectual. Cad. Bras. Ter. Ocup. [Internet]. 2018 [cited 2021 apr 15];26(2). Available from: https://doi.org/10.4322/2526-8910.ctoAO1220.

23. Santos MA, Pereira-Martins MLPL. Estratégias de enfrentamento adotadas por pais de crianças com deficiência intelectual. Ciên. saúde coletiva. [Internet]. 2016 [cited 2014 jan 23];21(10). Available from: https://doi.org/10.1590/1413-812320152110.14462016.

24. Santos KH, Marques D, Souza AC. Crianças e adolescentes com paralisia cerebral: análise sobre longitudinalidade do cuidado. Texto Contexto Enferm. [Internet]. 2017 [cited 2021 mar 20];26(2). Available from: https://doi.org/10.1590/0104-07072017000530016.

25. Cesário VAC, Leal MCC, Marques APO, Claudino KA. Estresse e qualidade de vida do cuidador familiar de idoso portador da doença de Alzheimer. Saúde em Debate. [Internet]. 2017 [cited 2021 jan 10];41(112). Available from: https://doi.org/10.1590/0103-1104201711214.

26. Gomes MLP, Silva JCB, Batista EC. Escutando quem cuida: quando o cuidado afeta a saúde do cuidador em saúde mental. Revista Psicologia e Saúde. [Internet]. 2018 [cited 2021 mar 15];10(1). Disponível em: http://dx.doi.org/10.20435/pssa.v10i1.530.

27. Fonseca NR, Penna AFG. Perfil do cuidador familiar do paciente com sequela de Acidente Vascular Encefálico. Ciên. saúde coletiva. [Internet]. 2008 [cited 2020 dec 15];13(4). Available from: https://doi.org/10.1590/S1413-81232008000400013.

28. Masuchi MH, Rocha EF. Cuidar de pessoas com deficiência: um estudo junto a cuidadores assistidos pela estratégia da saúde da família. Revista De Terapia Ocupacional Da Universidade De São Paulo. [Internet]. 2012 [cited 2020

dec 15];23(1). Available from: https://doi.org/10.11606/issn.2238-6149.v23i1p89-97.

29. Bacca AL, Sabogal JE, Arrivillaga M. Análise da Política Pública de deficiência em relação com os cuidadores. Colômbia, 2013-2017. Hacia la Promoción de la Salud. [Internet]. 2020 [cited 2021 apr 20];*25*(1). Available from: https://doi.org/10.17151/hpsal.2020.25.1.3.