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# Perception regarding the quality of care of Care Network for People with Disabilities

# *Percepção quanto à qualidade do cuidado de usuários da Rede de Cuidados à Pessoa com Deficiência*

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**Keywords**

Disabled People
Quality of Health Care
Health Evaluation
Health Services
Scales

## ABSTRACT

**Purpose:** verify the perception of Care Network users for People with Disabilities in Minas Gerais regarding the quality of care. **Methods:** This is an observational, descriptive and cross-sectional study of 871 informants, users and caregivers of Care Network for People with Disabilities in Minas Gerais. Interviews were carried out based on three instruments, the *User Interview Roadmap* and *Brazil's Economic Classification Criteria* for sociodemographic, clinical and care characterization, as well as the *Quality of Care Scale* to assess the quality of care for the interviewees. **Results:** the majority of users were male, single, unworked and had income of a minimum wage. A higher proportion of elementary school is incomplete, white in color, with household income greater than one and up to two minimum wages. The average age of 98.9% of the users was 28.6 years, of which 50.0% was up to 14 years. The majority reported having a type of disability with no associated comorbidity. Regarding the quality of care referred to, at least a quarter of the interviewees evaluated negatively the Access, Social Needs and Received Information axes. **Conclusion:** It will be necessary to improve the waiting time to receive care and also the services offer where the user resides, to facilitate access to consultations, to contribute intersectorally in leisure and social activities and to improve communication with users to increase the quality of care.

**Descritores**

Pessoas com Deficiência
Qualidade dos Cuidados de Saúde
Avaliação em Saúde
Serviços de Saúde
Escalas

## RESUMO

**Objetivo:** Verificar a percepção de usuários da Rede de Cuidados à Pessoa com Deficiência de Minas Gerais quanto à qualidade do cuidado. **Método:** Trata-se de um estudo observacional, descritivo e transversal, realizado com 871 informantes, usuários e acompanhantes da Rede de Cuidados à Pessoa com Deficiência de Minas Gerais. Foram realizadas entrevistas com base em três instrumentos: Roteiro de Entrevistas com Usuários e Critério de Classificação Econômica Brasil para caracterização sociodemográfica, clínica e assistencial, além do *Quality of Care Scale* para avaliação da qualidade do cuidado. **Resultados:** A maioria dos usuários participantes é do sexo masculino, solteiro, não trabalha e possui renda de um salário mínimo. A maior proporção tem ensino fundamental incompleto, é de cor branca, com renda domiciliar maior que um e até dois salários mínimos. A idade média dos usuários foi de 28,6 anos, dos quais 50,0% tinham até 14 anos. A maioria declarou possuir um tipo de deficiência sem comorbidade associada. Quanto à qualidade do cuidado referida, pelo menos um quarto dos entrevistados avaliou negativamente os eixos Acesso, Necessidades Sociais e Informações Recebidas. **Conclusão:** É necessário melhorar o tempo de espera para receber atendimento e a oferta de serviços no local onde o usuário reside, facilitar o acesso às consultas, contribuir de forma intersetorial em atividades de lazer e sociais e melhorar a comunicação com os usuários para aumentar a qualidade do cuidado.

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## INTRODUCTION

The term disability can be characterized by loss or abnormality in body structure or in biological, psychological, or anatomical functions that cause inability to perform different activities(1). According to the 2013 *Pesquisa Nacional de Saúde*, there are 6.2% of people with disabilities in Brazil(2).

By assisting this population, the action of healthcare network is based on the model proposed by the *Sistema Único de Saúde* (SUS), with comprehensiveness, decentralization and universality, and including disability based on a functionality model expressed by the person, as the result of the relationship between the health condition and the external factors, by conditions in which the individual lives(3).

Therefore, it is necessary to know the individual and his environment, and the characteristics of disability, identifying the personal changes produced with this interaction. This knowledge could gather situations and available quality of care, being important to increase the individual's functionality and reducing health inequalities.

The term "care" is related to attention, well-being, safety, and comfort for others. It can be regarded as humanized welcoming; establishing a relationship between professional and patient based on understanding and respect to subjectivities(4). The term "quality" is multidimensional and to sum up, it is characterized as an attribute positively or negatively. The World Health Organization (WHO) underlines that quality in health systems requires attention according to six dimensions: effectiveness, efficiency, patient-centered care, accessibility, equality, and safety(5).

In this sense, the *Rede de Cuidados à Pessoa com Deficiência de Minas Gerais* (RCPD-MG) was created in 2012 to offer primary care services, specialized care in intellectual, physical, auditory, visual, ostomy and multiple disabilities rehabilitation, hospital care, and urgency and emergency services. In a coordinated way, the care centers are engaged in welcoming, assessment and diagnosis, therapeutic interventions, monitoring, support and guidance to family members for comprehensive and continuous care, seeking assistance for a better quality of life and for inclusion of people with disabilities(6). However, long-term adherence is only possible if the patients consider the care offered as good quality care, therefore the increase in service quality results in patient satisfaction growth(7). Ensuring and monitoring quality care through assessment become a particular challenge in assisting people with disabilities.

The term assessment attributes value to something, being demonstrated without commitment or based on a specific method(8). In the health area, the assessment of services or programs requires well-defined procedures to verify associations between operations and their results. The assessment should enhance the impacts of developed activities, explaining the service's operation, and facilitating decision-making through fault correction and conduct change(9,10).

However, the evaluation should not be an exclusively technical process because incorporating subjectivity in the patients´ relationship with the health service is essential, investigating the practical success of health actions and assuming the scope of care as a fundamental practice(11).

Thus, this study aimed to verify the perception of the patient at RCPD-MG regarding their quality of care.

## METHODS

This is an observational, descriptive, and cross-sectional study, conducted with a probabilistic cluster sample.

The sample size calculation used a method to estimate proportions for finite populations(12). There were three stages, with a proportional allocation of the sample through the 13 expanded health regions, health region and service modality: hearing, physical, intellectual, visual and ostomy. The following parameters were considered for the sample calculation: 95% of confidence level, 5% of margin of error and 23.9% of prevalence of disability, according to 2010 Census data. The sample size defined by the calculation was 385 according to the margin of error adopted.

Data from 36 services of the specialized component of RCPD-MG were obtained in the 13 expanded health regions. The specialized component of RCPD-MG includes: *Centro em Especializado em Reabilitação* (CER), *Serviço Especializado em Reabilitação Intelectual* (Serdi), *Serviço de Atenção à Saúde Auditiva* (Sasa), *Serviço de Reabilitação Física* (SRF), *Serviço de Atenção à Pessoa Ostomizada* (Saspo) *e Serviço de Reabilitação Visual* (SRV). The majority of interviews were conducted in the Center region (20.3%) and the CER was the most present service among the 13 expanded health regions visited by the researchers (43.7%) (Figure 1).

The *Comitê de Ética em Pesquisa* (Coep) of the *Universidade Federal de Minas Gerais* (UFMG) approved this research under the ETIC number 913612. All the participants signed the informed consent form and received clarifications regarding the research objectives, the voluntary nature of the study, and the guarantee of confidentiality of the informations provided.

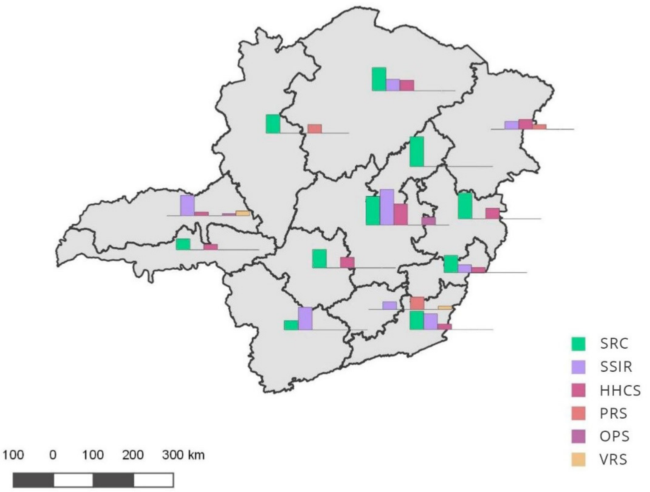

**Figure 1.** Distribution of services visited by Expanded Health Regions. Source: Elaborated by the authors

The inclusion criteria was: being an RCPD-MG patient or caregiver (parents/guardians, relatives, caregivers, and friends) over 18 years old. The exclusion criteria was: attending only one consultation in the services of RCPD-MG.

Three questionnaires were used as the research instruments. The first instrument called Patient Interview Guide was developed by the researchers and addressed the following axes: socio-demographic (gender, age, education level, ethnicity, marital status, work and income); clinical (type of disability and characterization of disability for personal and environmental factors); care (type of service and expanded health region in which he/she is attended).

The second instrument was the *Critério de Classificação Econômica Brasil*(13) (CCEB), created by the *Associação Brasileira de Empresas de Pesquisa* (Abep), which classified families economically based on the estimated purchasing power. As greater the amount of household items possession and education degree of householder, higher score is achieved. It was divided among classes A, B1, B2, C1, C2 and DE.

The third instrument was the Quality of Care Scale(14), validated in Brazil that assessed the quality of care reported by people with disabilities. This instrument consisted of 19 questions divided into four axes: Professionals and Assistance (1 to 4), Access (5 to 8, 18 and 19), Social Needs (9 to 13) and Information Received (14 to 17). The researchers conducted the questions and the informants had to choose one of three suitable answers for this study: no, partially or yes. They also had the option to make comments on the answers if they wanted. A pilot study was performed for calibration, competence of the questionnaires and the instrumentation of four interviewers.

Data collection was conducted between April and September 2016 through an individual approach to patients and companions in the waiting rooms of the services on the visit day. The interviews were written up in questionnaires and recorded in audio through digital recorder. The questionnaires were tabulated in a database developed in Excel version 2016, and the answers were categorized and checked.

Descriptive statistics were performed with absolute and relative frequency distribution of categorical variables. Continuous variables were described using the following measures of central tendency and dispersion: mean, standard deviation, median and minimum and maximum values. The IBM SPSS version 21 program was used for data analysis. The results were organized in tables.

## RESULTS

The study was attended by 871 participants, including patients and companions. The largest proportion of participants were consisted of accompanying parents or legal guardians (56.9%), females (78.9%), and with incomplete elementary school (38.0%) (Table 1).

The analysis of the socio-demographic characterization showed that the highest proportion of patients participating in the study was male (56.1%), with incomplete elementary school (47.1%), white (42.7%), single (70.3%) and not working (93.9%) because they were minors (58.4%). In CCEB, the highest proportion of patients was classified in the C2 class (28.9%), with an informed income of one minimum wage (55.5%) and informed household income greater than one and up to two minimum wages (34.1%) (Table 2).

Differently from the total sample, the stratification by age group had females with a higher proportion in the age group over 59 years old (55.6%); while brown color had a higher proportion in the age groups up to 17 years old (43.8%) and from 18 to 59 years old (42.4%); the reason for what patients from 18 to 59 years old (51.6%) and over 59 years old (86.3%) did not work was the benefit and the highest proportion of patients up to 17 years old did not have informed income (50.7%) (Table 2).

The measures of central tendency and dispersion of the socio-demographic variables showed that the mean age was 28.6 years old (SD = 27.8), and 50.0% were up to 14 years old. Patients´ disability time mean was nine years (SD = 9.7), and 50% of these patients were up to six years (Table 3).

In the stratification by age group, the means were 6.8 years old (SD = 4.4) for age and 6.3 years (SD = 4.4) for time of patients' disability up to 17 years. For patients aged from 18 to 59 years old, the means were 39.1 years old (SD = 12.7) for age and 16.5 years (SD = 14.4) for time of disability. For patients over 59 years old, the means were 72.4 years old (SD = 8.3) for age and 7.7 (SD = 9.4) for time of disability (Table 3).

In terms of the characterization of patients´ disability, when these patients were asked about the probable etiology of the disability, they answered: disease (51.5%), congenital (19.0%), accident or violence (3.3%), advanced age (2.2%), another (6.1%) and "I don't know" (17.9%).

According to the participants, with respect to their personal factors, their disability prevents them from performing school activities (79.3%), working (77.4%) and having leisure activities (60.7%), but not hindering or preventing to have children (59.5%) and having impact on personal care (54.6%). The patients need help with personal care (60.0%) and routine activities (61.9%).

**Table 1.** Socio-demographic characterization of the participants

| Variables | n | % |
|---|---|---|
| **Interviewee** | | |
| Patient | 206 | 23.7 |
| Parents/Guardians | 496 | 56.9 |
| Relative | 147 | 16.9 |
| Formal caregiver | 7 | 0.8 |
| Other | 15 | 1.7 |
| **Gender** | | |
| Male | 184 | 21.1 |
| Female | 687 | 78.9 |
| **Education level** | | |
| They never attended school | 12 | 1.4 |
| Adult Literacy | 6 | 0.7 |
| Incomplete Elementary | 331 | 38.0 |
| Complete elementary school/incomplete high school | 145 | 16.6 |
| High school/incomplete high school | 297 | 34.1 |
| Complete Higher education/Graduation | 79 | 9.1 |
| Not informed | 1 | 0.1 |

**Caption:** n: sample size

**Table 2.** Socio-demographic characterization of stratified patients by age group

| Variable | Up to 17 years old n = 475* (%) | 18 to 59 years old n = 198* (%) | > 59 years old n = 189* (%) | Total n = 871 (%) |
|---|---|---|---|---|
| **Sex** | | | | |
| Male | 300 (63.2) | 100 (50.5) | 84 (44.4) | 489 (56.1) |
| Female | 175 (36.8) | 98 (49.5) | 105 (55.6) | 382 (43.9) |
| **Education level** | | | | |
| Never attended school | 123 (25.9) | 13 (6.6) | 31 (16.6) | 169 (19.4) |
| Child education | 99 (20.9) | 3 (1.5) | 0 (0.0) | 103 (11.8) |
| Adult Literacy | 9 (1.9) | 18 (9.3) | 3 (1.6) | 30 (3.4) |
| Incomplete Elementary school | 230 (48.3) | 76 (38.3) | 101 (53.4) | 410 (47.1) |
| Complete elementary school/incomplete high school | 7 (1.5) | 31 (15.6) | 19 (10.0) | 58 (6.7) |
| High school/incomplete high school | - | 40 (20.2) | 19 (10.0) | 59 (6.8) |
| Complete Higher education/Graduation | - | 12 (6.0) | 14 (7.4) | 26 (3.0) |
| Not informed | 7 (1.5) | 5 (2.5) | 2 (1.0) | 16 (1.8) |
| **Ethnicity or skin color** | | | | |
| White | 205 (43.1) | 70 (35.4) | 92 (48.7) | 372 (42.7) |
| Brown | 208 (43.8) | 84 (42.4) | 69 (36.5) | 363 (41.7) |
| Black | 50 (10.6) | 34 (17.2) | 15 (7.9) | 99 (11.4) |
| Yellow/indigenous | 5 (1.0) | 3 (1.5) | 3 (1.6) | 12 (1.4) |
| Not informed | 7 (1.5) | 7 (3.5) | 10 (5.3) | 25 (2.9) |
| **Marital status** | | | | |
| Single | 475 (100.0) | 108 (54.5) | 23 (12.2) | 612 (70.3) |
| Married | - | 67 (33.8) | 89 (47.1) | 159 (18.3) |
| Widower | - | 5 (2.5) | 54 (28.6) | 59 (6.8) |
| Divorced/separated | - | 14 (7.1) | 20 (10.6) | 34 (3.9) |
| Stable union | - | 4 (2.0) | 3 (1.6) | 7 (0.8) |
| **Working** | | | | |
| No | 475 (100.0) | 158 (79.8) | 176 (93.1) | 818 (93.9) |
| Yes | - | 40 (20.2) | 13 (6.9) | 53 (6.1) |
| **The reason they did not work** | | | | |
| Minor | 473 (99.6) | 0 (0.0) | 0 (0.0) | 478 (58.4) |
| Benefit | 2 (0.4) | 102 (51.6) | 163 (86.3) | 271 (33.1) |
| Deficiency | - | 26 (13.1) | 4 (2.1) | 30 (3.7) |
| On leave | - | 25 (12.6) | 5(2.6) | 30 (3.7) |
| Option/Other | - | - | 4 (2.1) | 9 (1.1) |
| Not informed | - | 45 (22.7) | 13 (6.9) | - |
| **Economic Classification Criteria of Brazil** | | | | |
| A | 3 (0.6) | 1 (0.5) | 3 (1.6) | 7 (0.8) |
| B1 | 15 (3.5) | 5 (2.5) | 13 (6.9) | 34 (3.9) |
| B2 | 75 (15.7) | 36 (18.2) | 34 (18.0) | 146 (16.8) |
| C1 | 157 (33.0) | 36 (18.2) | 50 (26.4) | 245 (28.1) |
| C2 | 137 (28.8) | 61 (30.8) | 50 (26.4) | 252 (28.9) |
| DE | 85 (17.8) | 55 (27.8) | 38 (20.2) | 178 (20.4) |
| Not informed | 3 (0.6) | 4 (2.0) | 1 (0.5) | 9 (1.0) |
| **Reported Income** | | | | |
| No income | 241 (50.7) | 26 (13.2) | 5 (2.6) | 277 (31.8) |
| < 1 minimum wage | 8 (1.7) | 5 (2.5) | 6 (3.1) | 19 (2.2) |
| 1 minimum wage | 225 (47.4) | 127 (64.2) | 128 (67.8) | 483 (55.5) |
| 1 ├ 2 minimum wages | 1 (0.2) | 27 (13.6) | 23 (12.3) | 51 (5.9) |
| 2 ├ 4 minimum wages | - | 7 (3.5) | 18 (9.5) | 25 (2.8) |
| 4 ├ 6 minimum wages | - | 1 (0.5) | 4 (2.1) | 5 (0.5) |
| > 6 minimum wages | - | 2 (1.0) | 2 (1.0) | 4 (0.5) |
| Not informed | - | 3 (1.5) | 3 (1.6) | 7 (0.8) |
| **Informed Household Income** | | | | |
| No income | 2 (0.4) | 1 (0.5) | - | 3 (0.3) |
| < 1 minimum wage | 13 (2.7) | 1 (0.5) | 2 (1.0) | 16 (1.8) |
| 1 minimum wage | 148 (31.2) | 55 (27.8) | 47 (24.9) | 250 (28.7) |
| 1 ├ 2 minimum wages | 163 (34.4) | 74 (37.4) | 56 (29.7) | 297 (3.1) |
| 2 ├ 4 minimum wages | 92 (19.4) | 37 (18.7) | 43 (22.7) | 173 (19.9) |
| 4 ├ 6 minimum wages | 14 (2.9) | 8 (4.0) | 11 (5.8) | 33 (3.8) |
| > 6 minimum wages | 10 (2.1) | 5 (2.5) | 9 (4.8) | 24 (2.8) |
| Not informed | 33 (6.9) | 17 (8.6) | 21 (11.1) | 75 (8.6) |

*Nine patients did not inform their age

**Caption:** n: sample size

Their problem requires some assistance (92.2%), and they receive the assistance they need (78.4%). In addition, the patient's disability did not generate physiological changes that required special devices (56.9%). With respect to environmental factors, the home is not adapted (69.0%), the school is adapted (78.7%), and the work is not adapted (93.0%) (Table 4).

Regarding the types of disability, 31% of the participants declared an intellectual disability, 26% physical disability, 22% multiple disabilities, 19% hearing impairment and 2% visual impairment.

In the "Professionals and Assistance" axis of Quality of Care Scale instrument, the participants answered that people who assist them work well (86.5%), they know enough about the condition or disability (78.5%), they meet the needs of the patient (81.0%) and they involve the patient in decisions regarding his/her health and social care (77.4%). In the "Access" axis, the participants responded that they did not have to wait long to see the people assisting the patient (67%), they did not have to fill out a lot of paperwork (81.6%), and they did not have to struggle to receive care and support (65.3%). According to them, the lack of services in which the patient lives limits the care and support they receive (53%), on the other hand, it is easy to offer consultations with medical professionals (44.9%) and other health professionals (58.3%). (Table 5).

According to informations in the "Social Needs" axis, the participants said they had the help they need to live at home (84.2%), they provide help to participate in leisure (71.4%) and social activities (72.1%), they receive sufficient care and support (70.1%) and they feel safe with the care they receive (72.4%). Regarding the "Information received" axis, the participants receive sufficient information on disability (73.5%), they are aware of the services and support they can find (60.5%), they

**Table 3.** Measures of central tendency and dispersion of socio-demographic stratified variables by age group

| Variables | n (%) | Mean | SD | Median | Minimum | Maximum |
|---|---|---|---|---|---|---|
| **Patient Age** | | | | | | |
| Up to 17 years old | 475 (54.5) | 6.8 | 4.4 | 6.0 | 0.1 | 17.0 |
| From 18 to 59 years old | 198 (22.7) | 39.1 | 12.7 | 41.0 | 18.0 | 59.0 |
| Over 59 years old | 189 (21.7) | 72.4 | 8.3 | 72.0 | 60.0 | 97.0 |
| Total* | 862 (98.9) | 28.6 | 27.8 | 14.0 | 0.1 | 97.0 |
| **Patient disability time in years** | | | | | | |
| Up to 17 years | 468 (53.7) | 6.3 | 4.4 | 6.0 | 0.1 | 17.0 |
| From 18 to 59 years | 195 (22.4) | 16.5 | 14.4 | 14.0 | 0.1 | 59.0 |
| Over 59 years | 189 (21.7) | 7.7 | 9.4 | 5.0 | 0.1 | 60.0 |
| Total** | 858 (98.5) | 9.0 | 9.7 | 6.0 | 0.1 | 60.0 |

*Nine patients did not inform their age; **13 patients didn't report disability time
**Caption:** n: sample size; SD: standard deviation

**Table 4.** Characterization of patients´ deficiency in personal and environmental factors

| Personal Factors Variables | n (%) | No (%) | Yes (%) |
|---|---|---|---|
| Associated comorbidity | 867 (99.5) | 65.1 | 34.9 |
| | | | |
| Difficulty in: | | | |
| School activities | 464 (53.3) | 20.7 | 79.3 |
| At work | 53 (6.1) | 22.6 | 77.4 |
| Leisure | 860 (98.7) | 39.3 | 60.7 |
| In having children | 309 (35.5) | 59.5 | 40.5 |
| | | | |
| Impact on Personal Care | 870 (99.9) | 45.4 | 54.6 |
| | | | |
| They Need help with: | | | |
| Personal cares | 866 (99.4) | 40.0 | 60.0 |
| Routine Activities | 867 (99.5) | 38.1 | 61.9 |
| | | | |
| The problem requires some assistance | 862 (99.0) | 7.8 | 92.2 |
| Receiving the assistance they need | 861 (98.9) | 21.6 | 78.4 |
| Needing for special devices | 868 (99.7) | 56.9 | 43.1 |
| **Variables of environmental factors** | **n (%)** | **Não (%)** | **Sim (%)** |
| Adaptation of: | | | |
| Home | 871 (100) | 69.0 | 31.0 |
| School | 428 (49.1) | 21.3 | 78.7 |
| Job | 57 (6.5) | 93.0 | 7.0 |

**Caption:** n: sample size

**Table 5.** Distribution of Quality of Care Scale Questionnaire Answers

| Professionals and Assistance axis variables | No (%) | Partially (%) | Yes (%) |
|---|---|---|---|
| The people who assist are good at their job | 18 (2.1) | 99 (11.4) | 754 (86.5) |
| People who assist know enough about your condition or disability | 111 (12.7) | 77 (8.8) | 683 (78.5) |
| The people who assist meet your needs | 67 (7.7) | 98 (11.3) | 706 (81.0) |
| The people who assist involve you in decisions regarding your health and social care. | 160 (18.4) | 37 (4.2) | 674 (77.4) |
| **Access axis variables** | **No (%)** | **Partially (%)** | **Yes (%)** |
| You have to wait a long time to see the people who assist you. | 587 (67.4) | 91 (10.4) | 193 (22.2) |
| You have to fill a lot of paperwork to get the services you need | 710 (81.6) | 43 (4.9) | 118 (13.5) |
| You need to struggle to get the service and the support you need. | 569 (65.3) | 87 (10.0) | 215 (24.7) |
| Lack of services where you live limits the care and the support you receive. | 375 (43.1) | 34 (3.9) | 462 (53.0) |
| Consultation with health professionals is easy | 327 (37.6) | 152 (17.5) | 392 (44.9) |
| Consultation with non-medical professionals is easy | 260 (29.9) | 103 (11.8) | 508 (58.3) |
| **Social Needs Axis Variables** | **No (%)** | **Partially (%)** | **Yes (%)** |
| You have the help you need to live at home | 111 (12.8) | 26 (3.0) | 734 (84.2) |
| You receive help taking part in leisure activities | 221 (25.4) | 28 (3.2) | 622 (71.4) |
| You receive help participating in social activities | 210 (24.1) | 33 (3.8) | 628 (72.1) |
| You receive enough care and support | 185 (21.3) | 75 (8.6) | 611 (70.1) |
| The care you get makes you feel safe | 191 (22.0) | 49 (5.6) | 631 (72.4) |
| **Information Received Axis Variables** | **No (%)** | **Partially (%)** | **Yes (%)** |
| You received enough information about your disability | 186 (21.4) | 44 (5.1) | 641 (73.5) |
| You are aware of the services and support they can find to help you | 274 (31.5) | 70 (8.0) | 527 (60.5) |
| You are aware of the money and other benefits you may receive as help | 386 (44.4) | 76 (8.7) | 409 (46.9) |
| You receive information so that you can easily understand everything | 103 (11.8) | 111 (12.8) | 657 (75.4) |

are aware of money and other benefits they can receive. (46.9%) and they receive information so they can easily understand everything (75.4%) (Table 5).

## DISCUSSION

This study aimed to know the patient profile of RCPD-MG. In the socio-economic conditions of the patients, the data may reflect the use of network by the most vulnerable groups that have received welfare benefits, meeting the expectations regarding SUS performance towards people with disabilities. When compared to people without disabilities, the higher poverty rates of people with disabilities and their families reveal the economic vulnerability they are exposed to. They are less likely to attend school, more likely to be unemployed and earn less, and, moreover, face extra costs resulting from disability(15). Therefore, the existence of patients who do not have their income, especially in age group up to 17 years old, it is necessary to point out the attention to this group.

The characterization of disability in this study showed that most patients had a type of disability, having some disease as an etiological factor and no associated comorbidity. Functionality and disability are the results of the relationship between health conditions and contextual factors(16), and for this reason ensuring the importance of knowing other aspects beyond the characteristics of disability, such as the personal and environmental factors of people with disabilities.

The personal factors in this study were mostly negative, because the patients´ disability prevent them from to performing school, working and having leisure activities and also having impact on personal care and routine activities, which may indicate the need for questioning during the meeting based on care between professionals and patients, such as: what level of functionality the patient undergoes and the factors involved, and the medical interventions required that can be really useful due to the increased functionality.

In relation to the environmental factors, many patients currently use educational institutions that are adapted to people with disabilities, including those accredited by RCPD-MG, such as Serdi and CER. Thus, the data revealed that patients´ school is adapted, turning these important institutions into parts in this process.

A study that analyzed the inclusion of people with disabilities in regular schools in Brazil noticed that between 2000 and 2013, there was a considerable increase in enrollment of this population in basic education. However, the representation of enrollment of people with disabilities compared with the total number of students is still quite small for the government investment(17). When analyzing the inclusion of people with disabilities in regular schools, the effective promotion of a learning and sociability environment still needs care, although the Brazilian legislation enables its access. In addition to teachers' instrumentalization, the integration between family and school is important for the inclusion process.

A study on the inclusion of people with disabilities in the labor market in Belo Horizonte pointed out that the main barriers are the lack of accessibility and offhand companies, besides prejudice and discrimination(18). Another study conducted in the city of Bauru showed that companies generally prioritize the hiring of people with disabilities that do not require changes in the structure of the environment, and only one-third of private companies comply with the regulation(19).

This study corroborates these data, as the participants reported that the patients´ work is not adapted. Thus, even after Federal Law 8,213 of 1991 has modified the inclusion of people with disabilities in the labor market through quotas, inclusion has still been a challenge for the care of this population, indicating the need to adapt companies to comply with the law and constant oversight to ensure inclusion.

Regarding the performance of health professionals, adopting a model of care based on listening, valuing the complaint, enabling the autonomy, citizenship, and co-responsibility in health care is necessary(20). Data from the "Professionals and Assistance" axis revealed that the people who assist the patient work well, demonstrating sufficient knowledge about the condition or disability, meeting the patient´s needs and involving them in decisions regarding their health and social care. Thus, the interviewees showed positive acceptance for the care teams, seeing that the patients´ perspective may reflect in a humanized and well-performing relationship of the health professionals of RCPD-MG.

Data from the "Access" axis revealed that the logic of care networks might be helping to establish system access, besides answering to acute events through outpatient and inpatient emergency care, and makes continuous and active follow-up important for the integration of different levels of attention(21). However, comments about the lack of services where the patient lives were mainly focused on the need of medicines available at SUS.

A study revealed that despite the advances with the National Medicines Policy and the National Pharmaceutical Assistance Policy, only 45.3% of people who have prescriptions in the public system in the country obtain them entirely from SUS, confirming the need for raising finance, efficient use of resources and government regulation of the market(22). Therefore, this axis showed that from the perspective of the interviewess, a better supply of medicines can improve the quality of care of RCPD-MG. On the other hand, the great appreciation of medicalization by the population and the need for education regarding alternative treatments and habits in search of a better quality of life were highlighted.

The creation and establishment of RCPD-MG strengthened the guiding principles of the SUS, bringing universality, equity, and integrality to people with disabilities. Data from the "Social Needs" axis showed that these principles could be further enhanced when care is understood in the set of social relationships. The participants stated that patients have the help they need to live at home, get help participating in leisure and social activities, receive sufficient care and support, and feel safe with the care they receive. The relevance of social needs for people with disabilities is based on the sense of belonging, living with differences and confronting prejudice(23). Thus, the participants´ positive perspective on social needs suggests that the care and support that patients receive from both services and family contribute to the quality of care.

The result of good health literacy depends on the communication process between the system and the patient. Thus, literacy is an important component to eliminate health disparities(24). One study found that people with good health literacy have more adherence to treatments, self-care skills, more disease control and quality of life, and lower hospitalization and mortality rates(25). In the "Information Received" axis, the participants stated that they receive sufficient information about disability, they are aware of the services and support, money and other benefits they can receive, and they also receive the information so the participants can easily understand everything. Thus, the RCPD-MG may be contributing to increase health literacy of its patients, who observe good quality of care offered through the information received in the services.

Although the results of the Access, Social Needs and Information Received axes had a higher proportion of positive evaluations, there was at least one-quarter of the participants revealing negative opinions on these axes, showing an opportunity to improve the network in these aspects. Improving the waiting time to receive care, facilitating access to consultations, contributing in a cross-sectional way in leisure and social activities, and improving communication with patients are actions that can increase the quality of care.

The composition of the types of participants not entirely by patients but also by companions is a limitation of this study. For future research, an instrument that allows broader participation of people with disabilities is suggested, minimizing barriers to patient participation in the assessment.

This study brings contributions related to knowledge of the patients´ profile of RCPD-MG and their perception about the quality of care. The diversity of the sample enabled us to understand the theme in the universe of people with different disabilities, and not only in specific populations, according to other studies.

Also, this study provided a better understanding of the specialized component of RCPD-MG, and this thematic network scenario allows other studies to follow its evolution in the future. Thus, the recent organization and implementation of comprehensive care for people with disabilities in SUS and the importance of researching this area is highlighted.

## CONCLUSION

The results allowed characterizing the patients' profile of RCPD-MG participating in this study. There was a predominance of males, incomplete elementary school, white, single, mean age of 28.6 years old, and males who do not work because they are underage. Their income was one minimum wage and household income greater than one and up to two minimum wages. Most of them reported having a type of disability without associated comorbidity.

Regarding the quality of care, at least one quarter of participants negatively evaluated the axes of Access, Social Needs and Information Received, showing that it is still necessary to improve the waiting time to receive care and the provision of services in the place where the patient lives, facilitating their access to consultations, contributing in a cross-sectional way in leisure and social activities and improving communication with the patients to increase the quality of care.

Therefore, this study may help the planning of health actions for people with disabilities, and allow a broader understanding of the quality of care for this population through its perspective.

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## Authors contributions

*TECD participated in the collection, analysis, interpretation of data, article writing and critical review; AALF was the project co-coordinator, and participated in the conception, design, analysis, interpretation of data and critical review; SMAL was the project coordinator and participated in the conception, design, analysis, interpretation of data and critical review.*