

“THE LIFE THAT WAS MINE IS NOW HERS”: *BEING AN INFORMAL CAREGIVER OF PEOPLE WITH DISABILITIES*

“A vida que era minha agora é dela”: ser cuidador informal de pessoas com deficiência

“La vida que era mía ahora es de ella”: ser cuidador informal de personas con discapacidad

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Resumo

Introdução: Os cuidadores informais vivenciam uma sobrecarga significativa que acarreta mudanças nas suas perspectivas e qualidade de vida, bem como impactos na sua saúde física e emocional. **Objetivo:** Descrever e analisar o uso do tempo, as dificuldades vivenciadas, as mudanças percebidas e os sentimentos dos cuidadores informais. **Métodos:** A pesquisa foi aprovada pelo Comitê de Ética em Pesquisa sob parecer número 2.668.021. As transcrições das 33 entrevistas foram submetidas à análise de conteúdo temática e por meio delas obtivemos quatro categorias: abandono de ocupações e perda de identidade; mudar perspectivas e valores; dificuldades em aceitar diagnósticos; medos sobre o futuro. **Resultados:** O cuidado do lar e da pessoa com deficiência constitui a maior parte da rotina diária dos cuidadores. As principais dificuldades encontradas em relação ao cuidado de outras pessoas estão relacionadas à acessibilidade em ambientes externos, higiene básica e transferências. Cansaço físico, dores no corpo e sonolência foram as sensações mais relatadas. O abandono de ocupações significativas, as mudanças de valores e perspectivas de vida e o medo do futuro são fatores presentes na realidade dos cuidadores informais. **Conclusão:** Embora seja uma amostra pequena, os resultados da pesquisa apontam caminhos a serem olhados e pensados, a fim de compreender e encontrar formas práticas de atender às demandas dos cuidadores informais como estratégia para ampliar o cuidado.

Palavras-chave: Terapia ocupacional. Cuidadores informais. Qualidade de vida. Pessoas com deficiência.

Abstract

Background: Informal caregivers experience a significant overload that leads to changes in their perspectives and quality of life, in addition to impacts on their physical and emotional health. **Objective:** We aim to describe and analyze the use of time, experienced difficulties, perceived changes and feelings of informal caregivers. **Methods:** The research was approved by the Research Ethics Committee under opinion number 2.668.021. Transcripts of 33 interviews were subjected to thematic content analysis and through them we have obtained four categories: abandonment of occupations and loss of identity; changing perspectives and values; difficulties in accepting the diagnoses; fears about the future. **Results:** Care activities with the house and with the disabled person make up most of the caregivers' daily routine. The main difficulties encountered in relation to caring for others are related to accessibility in external environments, basic hygiene and transfers. Physical fatigue, body pain and drowsiness were the most frequently reported sensations. The abandonment of significant occupations, changes in values and life perspectives and fear of the future are factors present in the reality of informal caregivers. **Conclusion:** Although it is a small sample, the research results point to ways to be looked at and thought about, in order to understand and seek practical ways to meet the demands of informal caregivers as a strategy for expanding care.

Keywords: Occupational therapy. Informal caregivers. Quality of life. People with disabilities.

Resumen

Introducción: Los cuidadores informales experimentan una carga significativa que conlleva cambios en sus perspectivas y calidad de vida, además de impactos en su salud física y emocional. **Objetivo:** Nuestro objetivo fue describir y analizar el uso del tiempo, las dificultades vividas, los cambios percibidos y los sentimientos de los cuidadores informales. **Métodos:** La investigación fue aprobada por el Comité de Ética en Investigación bajo dictamen número 2.668.021. Las transcripciones de 33 entrevistas fueron sometidas a análisis de contenido temático y a través de ellas obtuvimos cuatro categorías: abandono de ocupaciones y pérdida de identidad; cambiar perspectivas y valores; dificultades para aceptar diagnósticos; temores sobre el futuro. **Resultados:** El cuidado de la casa y de la persona con discapacidad constituye la mayor parte de la rutina diaria de los cuidadores. Las principales dificultades encontradas en relación con el cuidado de otras personas están relacionadas con la accesibilidad en entornos externos, la higiene básica y los traslados. La fatiga física, los dolores corporales y la somnolencia fueron las sensaciones más reportadas. El abandono de ocupaciones significativas, los cambios de valores y perspectivas de vida y el miedo al futuro son factores presentes en la realidad de los cuidadores informales. **Conclusión:** Aunque se trata de una muestra pequeña, los resultados de la investigación apuntan a caminos para ser mirados y pensados, con el fin de comprender y buscar formas prácticas de atender las demandas de los cuidadores informales como estrategia para ampliar el cuidado.

Palabras-clave: Terapia ocupacional. Cuidadores informales. Calidad de vida. Personas con discapacidad.

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Introduction

The health-disease process can be considered historical, dynamic and complex, as it directly affects individual and collective balance. Sometimes when care cannot be performed by the sick individual, the important role of the caregiver emerges (Cardoso et al., 2012). When there are no conditions to hire specialized care (formal caregiver), the role of informal caregiver is assumed, that is, family members, mainly female, unpaid, little assisted and guided by health services, which assist in the care in their homes (Karsch, 2003). There is already a consensus in the literature that the role of the family in caring for a person with a disability is extremely important and allows this care to be provided (Azevedo & Santos, 2006).

The care offered varies in different levels of complexity, involving basic tasks ranging from personal hygiene, food, medication administration, to more complex tasks such as going to appointments, to banks or pharmacies and health management. Several factors influence the performance of these tasks, such as the caregiver characteristics, care needs, conditions for providing care and social and cultural factors, and the needs of the sick person (Cardoso et al., 2012).

The informal caregiver is exposed to a series of stressful factors such as the weight of tasks and illnesses arising from work demands and the characteristics of the person receiving care. In addition, they lack information, physical, psychological and financial support to face the routine (Rocha et al., 2008).

People with motor and/or neuromuscular diseases may have limited functional capacity to perform daily activities, such as mobility and self-care. This condition often leads to the search for and use of various support resources and assistive technology, with the wheelchair being the main equipment used by this population (Pousada et al., 2018). Theoretically, the use of AT devices are facilitators and have a significant impact on caregiver burden. However, evidence shows that such overload is more linked to the subjective perception of health, support and social support and mental health issues of the caregiver than to the use of a support/aid device. This demonstrates that it is essential to take into account the needs, well-being and perceived burden of the caregiver in the intervention process (Pousada et al., 2018).

According survey's results conducted by Murphy et al. (2007), parents who care for children with disabilities identified several barriers to promoting their own health, such as lack of time and hours for rest, lack of access to others. Qualified alternative caregivers for their children and low prioritization of their needs. In addition to all the impacts generated on the quality and life of caregivers, evidence indicates that the worsening health of caregivers and the lack of options for their demands also have negative impacts on the health and quality of life of those receiving care (Murphy et al., 2007).

Therefore, it is essential to offer infrastructure and support conditions so that family members can effectively play the role of informal caregivers. Professionals should help family caregivers to understand and assess their own needs as an important element of the process supporting and improving families' ability to care for people with chronic advanced disease (Krug et al., 2016).

However, the lack of a specific protocol of care practices aimed at children with disabilities or special care needs means that professionals generally work with families without the necessary proximity to their real needs. In addition, there is a barrier to the process of building and organizing care together, promoting more adequate and safe care in the home context (Nishimoto & Duarte, 2014). The literature points to the importance of family-focused care and the adoption of a family perspective. Families should be seen as equal partners in the process of decision making (Teixeira et al., 2020).

According to the International Classification of Functioning and Disability in Health (ICF), the contextual factors formed by the environmental components (family, work, laws and beliefs) and personal (age, sex, age, educational level, coping strategies) can configure themselves as barriers or facilitators in a person's life (WHO, 2012). Therefore, it is necessary to identify what these barriers and facilitators are in the lives of caregivers, so that, in this way, they receive full health support (Pousada et al., 2018).

Although the existence of burden on informal caregivers and the need to establish a family-centered practice is already established in the literature, caregiver burden is a subjective and multidimensional aspect, and its levels may be associated with a number of factors (Pangalila et al., 2012). In addition, it is possible to identify a lack of studies for the population of caregivers of people with neuromuscular diseases (Pangalila et al., 2012).

Aiming to contribute to this gap in the literature and to support improvements in the provision of care to informal caregivers, this research aims to describe and analyze the use of time, the main difficulties experienced by informal caregivers of wheelchair users, the changes perceived in life and the feelings generated by assuming the role of caregiver.

Tools and Methods

This is an exploratory study with a qualitative approach. The following inclusion criteria were established: 1-caregivers of wheelchair users who have been providing care for at least 6 months; 2-caregivers who do not receive financial assistance for the provision of care; and 3-caregivers who do not have any training to exercise this function. On the other hand, caregivers who provided care to more than one wheelchair user at the same time were excluded from the sample.

Research participants were recruited through contact with different municipal bodies (Municipal Health Department and Municipal Department of Persons with Disabilities), rehabilitation clinics, special education schools and a non-governmental organization. Initially, a contact list of 76 caregivers was obtained, of which 29 were not counted due to errors or outdated telephone numbers. Of the 47 remaining caregivers, 13 were excluded for not meeting the pre-established inclusion criteria. Therefore, the final sample consisted of 34 caregivers.

For data collection, the authors prepared a script for surveying the sociodemographic data of the participants, as well as a semi-structured interview questionnaire containing multiple-choice questions and open questions addressing the activities that make up the caregivers' daily routine, main perceived

difficulties in care, tasks that generate greater physical fatigue, feelings at the end of the day, changes caused after assuming the role of caregiver and feelings of happiness or unhappiness associated with it.

Prior to the application of the script, the adaptation process was carried out based on an external assessment by judges considered to be experts in the topic addressed. This assessment took into account the structural analysis of the questionnaire and linguistic aspects, always in accordance with the research objective. The analysis of the instruments by a committee of expert judges constitutes a systematized methodology to help the researcher to improve the questions and refine the created instruments, as well as proposes a collaborative strategy, since the joint reflection on the processes can be a method of quality management in research (Torlig et al., 2022).

The study was approved by the Research Ethics Committee with human beings under opinion number 2.668.021.

Data collection procedure

After obtaining the list of caregivers from the aforementioned sources and applying the established inclusion and exclusion criteria, the caregivers who made up the final sample were contacted by telephone, and at that time, the survey was presented prior to scheduling the home visit. During the visits, the participants received further details and clarifications regarding the research and signed the Informed Consent Form (FICF). Under this condition, the interview script was applied by the researcher, and the entire interview was recorded using a cell phone audio recorder and, later, all information was transcribed.

Data analysis procedure The multiple-choice questions that made up the interview script were tabulated in an Excel spreadsheet and the data were submitted to descriptive analysis. Regarding the open questions, they were submitted to the transcription process and the content analysis technique was applied, of the thematic categorical type (Bardin, 2011). This technique has as its main objective the manipulation of messages to confirm the indicators that allow inferences about a reality other than the message (Bardin, 2011).

Furthermore, this type of analysis comprises three stages, namely: pre-analysis, material exploration and treatment of results (Santos, 2012). The data categorization criterion was the expressive type, and, based on the questionnaire, the elements were classified into registration units, namely: (1) main objective of life directed to care for the other; (2) abandonment of significant occupations and loss of identity; (3) changing values and priorities; (4) difficulty in accepting the diagnosis, concern about the health condition and the ability to care.

Results

Quantitative data

Based on the caregivers' sociodemographic characterization protocol, 96.9% of the sample were female, the average age of the caregivers was 45 years old (standard deviation of 10.6) and 60.6% of the

caregivers were married. 72.7% of caregivers did not have paid work, 18.3% had paid work and 9.0% were retired. For education levels, 51.5% had completed secondary education, 18.1% had incomplete primary education, 12.1% had incomplete secondary education, 12.1% had completed higher education and 6.0% had completed primary education. Regarding the degree of kinship, 78.7% of caregivers were mothers of wheelchair users, followed by daughters and grandparents (both 6.0%) and father, sister and wife (3.0% each). The average hours of care provided per day was 19.3 hours, with a standard deviation of 5 hours.

From the collected data, it was also possible to draw a profile in relation to the caregivers' routine and time use. Basic care activities and dedication to domestic tasks were the ones that presented the highest frequency in the studied sample. Table 1 presents in detail all activities reported by caregivers and that make up their daily routine.

Table 1 - Activities reported by caregivers that make up the daily routine.

Activity	Frequency	Percentage
Home Care	31	91,1%
Basic care provided (hygiene, food)	31	91,1%
Visits to family and friends	27	79,4%
Take to therapies/school	20	58,8%
Instrumental activities of daily living (supermarket, pharmacy, bank)	13	38,2%
Tours and leisure (shopping, cinema, restaurant, watching TV)	13	38,3%
Religious activity	9	26,4%
Physical activity	8	23,5%
Paid work	7	20,5%
Aesthetic care	2	5,8%
Medical care	1	2,9%
Studies	1	2,9%

Source: prepared by the authors.

Regarding the difficulties encountered by caregivers, several aspects were mentioned, most of which were related to the care provided to another person. Figure 1 shows all the difficulties scored, as well as the percentage of each one of them in the studied sample.

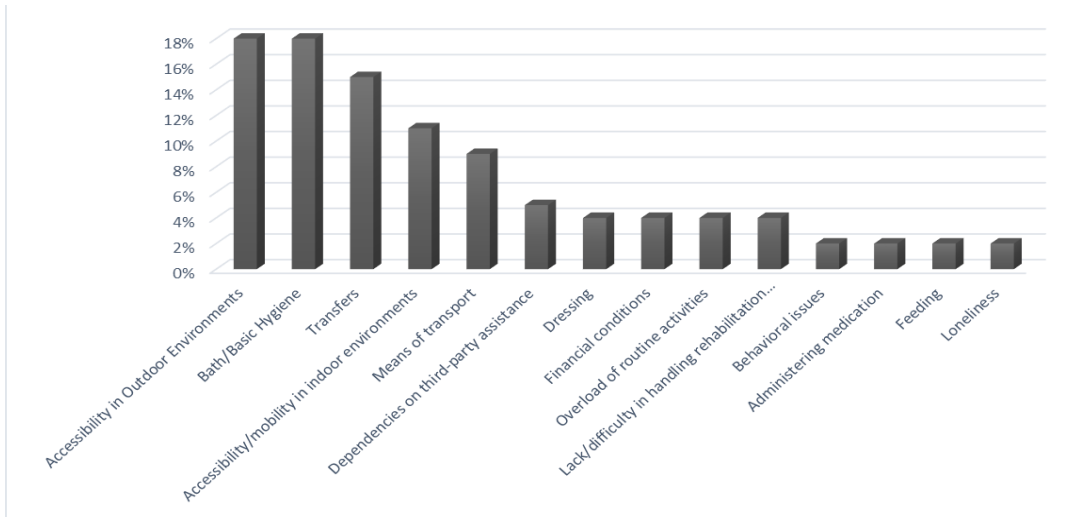


Figure 1: Difficulties reported by informal caregivers.
Source: prepared by the authors.

Another interesting data collected from the semi-structured interview script was in relation to the feelings and sensations present in the caregivers' routine. Figure 2 presents all the aspects mentioned.

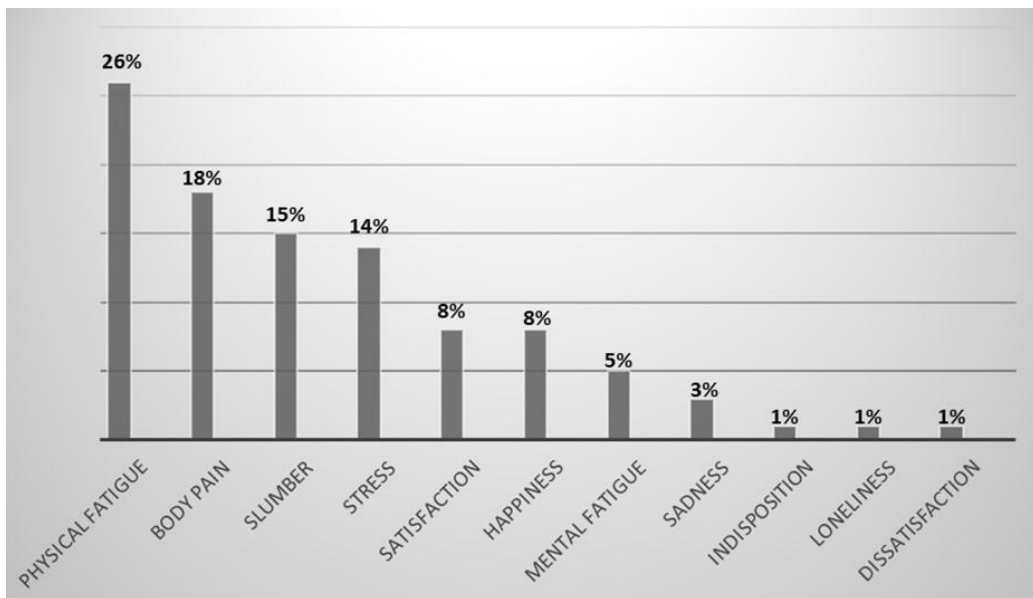


Figure 2: Main feelings/sensations reported by informal caregivers
Source: prepared by the authors.

Taking into account that physical fatigue was the most prevalent aspect in the studied sample, we sought to understand its origin. When asked about the tasks that most generate physical fatigue, the most cited were transfers (30.3%) and mobility indoors (30.3%), followed by bathing (27.3%), feeding (6%), dressing (6%), mobility in outdoor environments (6%) and diaper changing (3%). Given this, it is possible to note that all the factors that cause physical fatigue refer to care activities with the other, reinforcing the impact of the role of caregiver in the daily routine.

Qualitative data

Regarding the first thematic category, "Care and well-being of the other as the main objective of life", it was observed that caregivers emphatically pointed out that the subject to whom they dedicated care was characterized as a central factor of their individual actions and organization of life. It is important to mention that 41% of caregivers gave reports which made up this thematic category.

"She has to be involved in everything" P1

"I'm just taking care of him...where I go he follows" P9

"Our entire life has changed because we direct everything towards it" P21

The second thematic category entitled "Abandonment of significant occupations and loss of identity" was composed of 32% of caregivers. This shows how the role of caregiver has a direct influence on the abandonment of significant occupations for the subject and, consequently, a loss of identity, desires and personal achievements. The following reports illustrate this aspect:

"I only think about her, she comes before me. I can no longer dedicate myself to my career." P2

"Change all my routines and staying connected to him" P18

"L. ceased to exist, right? (referring to herself) I think I've lost some of my identity. People don't report to me to know what I want, it's all for him" P31

"The life that was mine is now hers" P11

The third thematic category called "Changes in values and perspectives" was composed of the responses of 18.2% of caregivers and focuses on the aspect of how the way of looking at life was changed from the moment the caregivers took over that role.

It is interesting to note that such changes stand out for a positive aspect, that is, having contact and living with a person with a disability significantly contributed to achieving a perspective of life more linked to aspects of overcoming difficulties, valuing achievements and abandoning strictly material concerns.

"I thought myself as a materialistic, today I don't anymore. Today what matters is taking care of him" P4

"He was something that appeared, and we learned with him that we can overcome it" P15

"He woke me up to a lot... He alerted me" P18

"I say that God sent him to me so I could forget about the problems" P27

"My values, the whys, everything changed... I think it is part of human growth, we learn to pursue certain things" P28

"It changed everything... Even the way you see life" P33

The fourth and last category "*Difficulty in accepting the diagnosis, concern about the health condition and their ability to care*" was composed of responses from 18% (n=6) of the caregivers. This category mainly points to the insecurities and fears of caregivers regarding the health condition and conditions of caregivers to be offered. The following lines illustrate these aspects:

"I think that, in terms of day-to-day worries, like this... Will I make it? How long will I be able to take care?" P20

"I wish that God had given her health" P3

"Sadness right? Seeing him just sitting there, always very still" P19

"No mother wants a child like that, right? It's hard to see her suffer" P25

In addition to the categories presented, two caregivers still reported no perceived change for having a disabled family member and taking care of him.

"It hasn't changed anything... another child, right? She occupies me all the time right? I can't attribute it to her... It's life" P16

"The same way I fought before, I fight him...It's ok" P32

When asked about the feeling of happiness coming from offering care to the other, 87.9% (n=29) reported that they always feel happy, 12.1% (n=4) reported that they sometimes feel happy and 3% (n=1) reported not feeling happy. It is interesting to point out that there is an association with a divine speech, especially on the part of those caregivers who report feeling happy always. The following accounts illustrate this relationship:

"God gave me him... God chose me" P12

"It was a permission, it was something that was given to us" P15

"It's a gift from God...Having a special child isn't for anyone, you know?"P14

"This here, this is wealth, right? A gift from God in our lives." P22

"Because when God gives, he gives to the right people" P25

Discussion

One of the purposes of the present study was to describe the time use variable of informal caregivers of wheelchair users. This aspect becomes relevant in terms of study and practice parameters, since it is based on the composition of everyday activities that new possibilities for discovering, learning and mastering new skills expand the subject's repertoire of experiences (Nunes, Emmel, 2015). Perceived well-being is closely linked to the activities that an individual performs in a given period of investigation. This becomes very relevant in the context of caregiving, as the type and duration of certain activities may not be similar to those of non-caregivers (Urwin et al., 2023).

The data found regarding the structuring and composition of the routine and use of time by informal caregivers demonstrate that there is intense dedication to caring for others, as well as domestic and home care activities. The data obtained from the transcripts of the interviews and thematic categories showed that caregivers reported a decrease in participation in significant occupations related to self-care, leisure and social participation. This result corroborates the literature on the topic, which points out that the burden related to care favors the illness of the caregiver, who has a reality that is very restricted to their household and neglects their own care in favor of caring for others (Masuchi & Rocha, 2012; Cardoso et al., 2012). Furthermore, engagement in leisure and non-market activities can attenuate perceived well-being (Urwin et al., 2022).

The literature points out that the caregiver is accumulating responsibility and tasks, configuring themselves as the provider of care for themselves and also for the other, which can generate a routine that exceeds their physical and emotional limits, not always recognized (Luzardo et al., 2006). Evidence indicates that, even from the perspective of health professionals, the informal caregiver is understood as an individual who does not seek regular health care, does not perform leisure, work or any other type of activity that is not related to the of caring for the other (Masuchi & Rocha, 2012).

Due to the fact that the majority of the studied sample is female, it is possible to affirm that the social and cultural pattern of linking the female figure to the responsibility of care, generates an overload because she is also responsible for other tasks, such as care with other family members and with the house (Figueiredo, 2009).

Regarding the main difficulties reported by caregivers, it is clear that there was a great variability of responses, from those related to the physical demands of care, even those related to relational and financial aspects. A study by Matos (2019) aimed, among other things, to identify the difficulties perceived by informal caregivers of dependent people, and the results pointed out the following aspects as main: relational problems, reactions to the provision of care, physical demands, restrictions in social life, scarce family and professional support and financial problems.

Dias et al. (2019) found that the factors of precarious home infrastructure, lack of adapted equipment, lack of information about the general care to be performed, difficulties in accessing health services and difficulties in social inclusion of children with some type of disability, are configured as obstacles to home care.

It is interesting to note that the three most mentioned difficulties (accessibility in external environments, bathing/basic hygiene and transfers) are directly related to the physical demands of caregivers. This finding corroborates what is presented in the literature that the practical aspects of caregiving tasks, such as mobility and personal care, are factors that clearly contribute to caregiver burden (Conroy et al., 2021).

With regard to the feelings and sensations expressed by the caregivers, 10 of a negative aspect and 2 of a positive aspect (satisfaction and happiness) were listed, and those negative feelings/sensations were linked to the physical and mental health of the caregivers. This result is in line with the research carried

out by Murphy et al. (2007), which shows that almost all informal caregivers reported adverse aspects to their physical and mental health, attributing this to a combination of concrete and daily care tasks and the anxiety generated about the health and future of those receiving care.

It is essential to consider that the care process and its repercussions in terms of feelings and sensations are completely subjective, that is, the context, differences and individual experiences of the caregiver can influence the way in which they adapt to the care requirements (Souza et al., 2015). This may explain the great variability of responses obtained in this category in the studied sample.

However, it is equally important to take into account that the existence of a prolonged illness of a family member, combined with the absence of mechanisms for solving immediate problems, makes the caregiver subject to a psycho-social maladjustment, which is often accompanied by negative feelings (Souza et al., 2015). When this state is not tolerated for a long time, the caregiver tends to adopt ways of dealing with the crisis that can lead to an unhealthy adjustment with an increase in negative emotional repercussions and overload (Pereira et al., 2013).

The four thematic categories listed from the application of the interview script demonstrate crucial aspects of the informal caregiver's life. The first one, called "Care and well-being of the other as the main objective of life", represents how care has become the central aspect of caregivers' lives. According to the "Caregiver's Practical Guide", a document prepared by the Ministry of Health (2008), some recommendations are strongly listed so that the caregiver can exercise self-care, avoid stress and overload. Among them are mainly the participation of other people in the division of care and joint work between the State, community and family with co-responsibility of all these parts (Brasil, 2008).

However, we see that these recommendations are generally not followed, as evidence points to the so-called "time-dependent overload", that is, caregivers have restrictions in the use of time, constantly dedicating themselves to the care of others. This fact is usually linked to the lack of help from other people, characterizing care centered on a single family member and of constant character (Aires et al., 2020; Valer et al., 2015).

The second thematic category "*Abandonment of significant occupations and loss of identity*" complements the first, considering that the dedication often exclusively to the care of the other generates the abandonment of significant occupations and loss of identity by the caregiver. Much evidence is in line with this aspect, and the experience of being a caregiver is characterized by negative changes in daily life, which require adaptations that can interfere with the caregiver's own needs, accumulation of responsibilities, costs, stress and even postponement of personal plans (Martens & Addington, 2001; Franco, 2007).

By having a disabled person in their midst who requires constant and long-term care, the family can undergo several changes in their daily functioning, functions, life projects, social relationships and identity (Barroso et al., 2015). Time constraints and limited possibilities for personal and social interaction, combined with the feeling of increased pressure and extra responsibilities, are very present factors in the case of informal caregivers of people with neuromotor diseases (Conroy et al., 2021).

The third thematic category called "*Changes in values and perspectives*" reflects the perception of caregivers in relation to practical changes and ways of seeing life that occurred after assuming this role. Most caregivers listed positive changes mainly related to values and ways of facing life. Murphy et al. (2006) found similar findings in their study where informal caregivers of children with disabilities described positive and lasting impacts in the sense that they would have become more compassionate, receptive, emotionally stable and prepared for new challenges (Murphy et al., 2006).

An interesting aspect to relate to this thematic category is the significant reference to faith and divine instances as a way of justifying the feeling of happiness linked to the role of caregiver. According to Pereira (2011), becoming a caregiver happens in such an immediate and unexpected way that, combined with insecurities about the ability to care for the other, generate various forms of coping to deal with the situation. One of these forms is the so-called theological perspective, that is, the conception of care based on religious beliefs.

Religion can be one of the possible types of coping with situations of illness, trauma or stress, as it is configured as a form based on emotion, based on each person's history, values and personal and social resources (Simonetti & Ferreira, 2008). Spiritual support for overcoming difficulties is perceived by caregivers as divine training for child care, translated by the help of people, financial resources and strength to move forward (Dias et al., 2019).

A study by Marshall et al. (2003) showed that informal caregivers of children with disabilities reported that caring for their children has a positive spiritual impact. Therefore, it is possible to assume that, for some caregivers and families, these emotional and spiritual rewards outweigh the negative impacts generated on physical and psycho-social health (Murphy et al., 2005).

The last thematic category "*Difficulty in accepting the diagnosis, concern about the health condition and their ability to care*" reflects the main insecurities of caregivers and fears about the future.

Evidence indicates that caregivers express concerns regarding the future of those who receive care, since the progressive deterioration of their health condition puts their ability to continue meeting the needs presented at risk (Murphy et al., 2006). In addition, Silva & Stelmake (2012) highlight that becoming a caregiver brings many responsibilities beyond those related to daily care, but also with regard to the caregiver becoming a custodian of the fears and responsibilities of all family members. This condition favors, in addition to the loss of the caregiver's identity, the emergence of difficulties in planning for the future.

It is still a predominant reality that the care and support of character informally by family and friends, the same indispensable and low cost (WHO, 2012). In view of this, more in-depth and individualized knowledge regarding the sociodemographic and occupational profile, perceived overload and use of these caregivers' time is characterized as an important starting point for establishing effective clinical interventions not based only on the analysis of specific variables linked disabilities or those receiving care (Van Houtven et al., 2011). The urgency of this demand is also justified by the increased incidence of

disabilities that cause significant functional limitations, increasing the demand for support services for both people with disabilities and their caregivers (WHO, 2012).

It is noteworthy that, although the sample size was small and with a similar profile (parents of children with disabilities), the results and discussions presented by this article significantly contribute to broadening the understanding regarding the demands, experiences and expectations of caregivers of people with disabilities and wheelchair users.

It is suggested that new studies be carried out to propose and test new interdisciplinary health care practices that include this broader perspective in relation to the informal caregiver. The results of this and other studies that address the issue of burden and perspectives of informal caregivers can serve as a starting point for the development of new forms of assessment and assistance that promote the integrity and individuality of people with disabilities and their families.

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