

# Caregivers of family members with chronic diseases: coping strategies used in everyday life

Bento Miguel Machado<sup>a</sup>, Daniel Ferreira Dahdah<sup>b,c</sup>, Leonardo Martins Kebbe<sup>a</sup>

<sup>a</sup>Universidade de São Paulo – USP, Ribeirão Preto, SP, Brasil.

<sup>b</sup>Centro Universitário Claretiano – CEUCLAR, Ribeirão Preto, SP, Brasil.

<sup>c</sup>Unidade de Emergência – UE, Hospital das Clínicas de Ribeirão Preto – HC, Ribeirão Preto, SP, Brasil.

**Abstract:** Introduction: Caring for a family member with a disease causes an adverse daily life involving suffering for the caregiver. The literature on occupational therapy does not debate coping strategies that caregivers adopt with family members with chronic illness, or how perceptions about the role played interfere with occupations and projects. Objective: To characterize the caregivers' coping ways in daily life after a month of hospital discharge from a family member with chronic noncommunicable disease (NCDs) and to identify the perception they elaborate about themselves. Method: Descriptive study with qualitative-quantitative approach and cross-sectional design composed of 30 family caregivers of familiar members with NCDs followed in medical ward of a general hospital. Instruments used were sociodemographic questionnaire, Barthel index, Coping Mode Scale, and semi-structured questionnaire. Quantitative data analysis was performed with descriptive statistics, analysis of variance (ANOVA) test for repeated measurements, and Duncan and Tukey tests. The thematic content analysis was used to treat qualitative data. Results: The main modes of coping used were focused on the problem and on religious-fantastical thoughts. Participants expressed “feelings about everyday problems”, pointing to the positive perception of the beneficial feelings of care, but also a negative perception of changes in occupational life. The “coping strategies” of the participants were the accomplishment of “pleasurable activities, spirituality, and search for informal social support” that contributed to alleviate the problems experienced. Conclusion: Characterized the coping strategies of family caregivers with NCDs, highlighting how complex the experience of being a caregiver.

**Keywords:** *Caregivers, Chronic Disease, Coping.*

## Cuidadores de familiares com doenças crônicas: estratégias de enfrentamento utilizadas no cotidiano

**Resumo:** Introdução: Cuidar de um familiar adoecido gera um cotidiano adverso envolvendo sofrimento para o cuidador. A literatura da terapia ocupacional não aborda as estratégias de enfrentamento que cuidadores adotam com familiares com doença crônica ou como a percepção sobre o papel desempenhado interfere nas ocupações e projetos. Objetivos: Caracterizar os modos de enfrentamento dos cuidadores no cotidiano após um mês de alta hospitalar de um familiar com doença crônica não transmissível (DCNT) e identificar a percepção que eles elaboram sobre si. Método: Estudo quantitativo-qualitativo, descritivo e transversal composto por 30 cuidadores de familiares com DCNT acompanhados em enfermaria clínica de um hospital geral. Instrumentos: questionário sociodemográfico, Índice de Barthel, Escala de Modo de Enfrentamentos de Problemas e questionário semiestruturado. A análise dos dados quantitativos foi realizada com estatística descritiva, testes ANOVA para medições repetidas e teste de Duncan e Tukey. A análise temática de conteúdo foi empregada para tratamento dos dados qualitativos. Resultados: Os principais modos de enfrentamento foram *focalizados no problema e em pensamentos religiosos e*

*fantasiosos*. Os participantes expressaram os “sentimentos frente aos problemas cotidianos”, apontando a *percepção positiva* em face dos sentimentos benéficos advindos dos cuidados, mas também uma *percepção negativa* pelas alterações da vida ocupacional. As “estratégias de enfrentamento” dos participantes foram a realização de *atividades prazerosas*, a *espiritualidade* e *busca por suporte social informal*, que contribuíram para aliviar os problemas vividos. Conclusão: Foram caracterizadas as estratégias de enfrentamento dos cuidadores de familiares com DCNT, destacando quão complexa é a experiência de ser um cuidador.

**Palavras-chave:** *Cuidadores, Doença Crônica, Estratégias de Enfrentamento.*

## 1 Introduction

In Brazil, there is currently a reversal of the fall in the prevalence of communicable diseases due to the increase in non-communicable chronic diseases and due to external causes. These diseases can not be treated in a short time and the treatment can last for years or there is no cure. Even with investments in actions and treatments that aim to prevent and improve the clinical picture, change in lifestyle and improvement of the quality of life, non-communicable chronic diseases are challenges to public health, and the population must collect the investment in actions of prevention and promotion to the health of the population from their governments (PORTAL..., 2015).

The role of the caregiver has become critical with increasing life expectancy and the development of more efficient resources to treat diseases. The experience of caring for a sick family member can represent a great burden on the caregiver, leading to deprivation and changes in family dynamics (DELALIBERA et al., 2015).

“Caregiver” is defined as being formal and informal. The formal caregiver is the professional who is academically prepared to meet the specific needs of the patient, while the informal caregiver is conceived as a family member or friend requested to ensure most of the day-to-day care of the patient in the family context (OLIVEIRA; QUEIRÓS; GUERRA, 2007).

With the onset of a chronic illness in the family, the sick family member needs to be cared due to the clinical complications of his state of health, and the occupational life of the caregiver is compromised in the areas of occupational self-care, work, and leisure, because he has less time to take care of himself and to relate outside his family nucleus. He has difficulties as negative consequences in his daily life, such as overload, depressive symptoms, anxiety and increased levels of stress (PINTO; NATIONS, 2012).

For caregiver overload, two dimensions are understood: the objective, referring to the “visible” consequences of the problems arising from the caring functions, characterized by an excess of patient care, a change in the family routine and life projects; subjective overload, directly associated with subjective issues, such as the degree of discomfort perceived by the family member in the care given to the patient in daily activities (SOARES NETO; TELES; ROSA, 2011).

The consequences of family overload can be aggravated when all the responsibilities of caring are focused on the figure of a single caregiver, who, in a solitary way and without adequate guidance, he will be subject to a greater chance of worsening his quality of life, health, fatigue and depression (ALMEIDA et al., 2010).

Often, besides to not having the help of other people to share care, they have deficient social support and low levels of education, which contribute to difficulties in understanding the procedures required for effective care. Knowing the profile of this group can contribute for the health professionals to establish intervention strategies to improve the health conditions of these people, contributing to improve the quality of life (YAMASHITA et al., 2010).

According to Lazarus e Folkman (1984), coping strategies are cognitive changes and the behavioral effort to deal with stress arising from stressful situations, such as those mentioned above, that are assessed as a burden or that exceed one’s resources. The coping strategies used by caregivers are related to educational level, cognitive ability, life experience, social skills, social support, personality factors, self-esteem, considering that health professionals can help caregivers to seek more effective coping for the relief of the suffering experienced (ROCHA, 2009). The responses to stress involve cognitive and behavioral efforts, and this is related to the search for social support, through religiosity and distraction (ARAGÃO et al., 2009).

Social support can be understood as a process of interaction between people or groups that may involve a relationship of friendship or access to information through systematic contact structuring links. Social support is an important ally for the caregiver because of its protective effects in situations of lifelong stress since the number of friends and relatives with whom social contact is maintained seems to be associated with the reduction of mortality and increasing longevity (ANDRADE, 2015).

The definitions on social support are diverse. However, for this study, it was chosen to exemplify two types of social support: formal and informal social support.

According to Dunst and Trivette (1990), social support can be classified as formal when social or professional organizations are organized to provide assistance or help to those in need; informal social support refers to individuals and social groups who can provide support in day-to-day activities in response to life events.

It is important to investigate the perceptions that the caregiver elaborates on the role that he or she plays with the family member under their care, because, such perceptions may interfere with the performance of significant occupations and life projects, depending on the social support received.

In a descriptive qualitative study, Fogaça, Carvalho and Montefusco (2015) analyzed the perceptions and feelings expressed by caregivers of family members who were hospitalized with chronic-degenerative diseases. The perceptions and feelings expressed were insecurity, fear, anxiety, worry, feelings of deprivation of freedom and, at the same time, gratitude for care, comfort, safety and close to the control of care. The study highlights the importance of home hospitalization as humanized and innovative care, in which the health team plays a fundamental role in supporting families with emotional difficulties.

The study by Sena, Souza and Andrade (2016) identified the perception of caregivers of people with Alzheimer's disease about their future prospects. The results showed that care does not prevent the family caregiver from seeking the future planned and that the knowledge of self, of the other and about the illness allow the caregiver to re-signify their life projects, allowing the elaboration of new projects. The authors point out the importance of creating mutual aid groups among caregivers in different community and health settings.

The occupational therapist is one of the health professionals who contributes significantly to the maintenance or restructuring of the health of different populations, through the therapeutic use of daily activities (occupations) intervening directly in impaired occupations such as work, leisure, self-care, providing possibilities for facing an adverse daily life (AMERICAN..., 2015). By the difficulties experienced by caregivers of people with CNCD, the occupational therapist has a relevant role with this population.

The bibliographic production of occupational therapists with caregivers of different populations with chronic diseases has addressed aspects such as the impact and the overload of these caregivers from the assumed role, the occupational therapy interventions in an extra-hospital context in the care of the family member and caregiver as well as interventions with groups as devices for the care and guidance to the caregivers on the tasks of caring (ARAÚJO; KEBBE, 2014; DAHDAH et al., 2013; OTHERO, 2012; MAZER, 2011; RAFACHO; OLIVER, 2010; CAMPOS; SOARES, 2005).

Campos and Soares (2005) carried out an investigation on the impact of the representation of the overload by caregivers of chronic patients in mental suffering. Data were collected through a semi-structured interview. The results point to the emotional overload perceived as being the most difficult to face and indicate its effects on adherence to alternative services in mental health, emphasizing the importance of interventions with family members to instrumentalize them as caregivers and prepare them for the best care of the people under their responsibility. The need to support women caregivers is highlighted, through psychological assistance, and also to the development of coping strategies to address the daily difficulties.

Othero (2012) discusses occupational therapy practices in extra-hospital contexts involving caregivers, including support and guidance to the family caregiver, home-based procedures to be performed with the patient (such as daily life activities training and construction of alternative means of communication) and interventions with support and guidance groups in hospital and community settings as important strategies for caring for the caregiver. Challenges to be faced in these contexts, such as the construction of support networks, the need to improve the specific training of the occupational therapist for this work, the reorganization of care

and the complexity of the home environment are highlighted.

Rafacho and Oliver (2010) highlight the role of the occupational therapist as one of the most relevant of the Family Health Centers (NASF) teams, since they propose interventions that influence in the health and disease processes of its members and the community through knowledge and direct contact with family dynamics, and thus help caregivers cope with the emotional overload and occupational changes generated by the role of caregiver. The authors point out that there is little research that deals with caregivers in Primary Care, noting that Family Health Teams will be able to assist the family caregiver in their individual needs, as well as consider them as a specific group, subjects, and actors in health actions.

In a qualitative and quantitative study, Mazer (2011) analyzed focal elements of a family guidance group for caregivers of children with physical disabilities in a rehabilitation center. The group provided guidance, welcome, moments of reflection and exchanges of experiences, providing support to family members. According to the author, being a fundamental professional to favor the re-signification of the daily life of the individual, the occupational therapist is able to contribute to the restructuring of the routine of these caregivers, promoting reception and guidelines pertinent to each case. The author suggests the need for acceptance and understanding of the diagnosis by the parents, division of care among the family, offer of family support, reception, and guidance to parents.

In a qualitative descriptive study, Araujo and Kebbe (2014) analyzed occupational therapy groups with caregivers of family members with schizophrenia in a mental health outpatient clinic of a general hospital and emphasized that the use of interventional strategies, such as occupational therapy groups, in which situations lived by caregivers can be approached and shared with other people in similar situations, contributes to attenuate the suffering of these caregivers. However, they point out that care should be extensive beyond verbal orientations and should structure concrete care actions in the actual life contexts of caregivers.

In this sense, the family caregiver becomes a potential client for occupational therapy, since, in addition to deficits in their occupational performance caused by episodes from the clinical condition of their sick family member, they experience stress, fear, and sadness (DAHDAH et al., 2013).

The literature emphasizes the need to receive and provide information to caregivers and suggests interventions in hospital and community settings that are able to guide caregivers towards more effective care. However, what is observed is that these studies do not point out the coping strategies that caregivers adopt in dealing with the family with chronic illness.

Faced with the need to increase actions in health equipment aimed at supporting and orienting coping strategies that help to improve the quality of life of caregivers and to family members who have an impoverished daily life (MENDES, 2012), this study aims to caretakers coping in daily life after one month of hospital discharge from a family member with chronic noncommunicable disease (CNCD); and as a specific objective, to identify the perception that elaborates as his role of caregiver and which strategies he uses in the confrontation of the daily problems.

## 2 Method

**Research approach:** this is a quantitative-qualitative study of the descriptive type and with a cross-sectional design, according to Minayo and Sanches (1993), while quantitative research seeks as a field of practices and objectives to bring data, indicators and observable trends, qualitative research works with values, beliefs, representations, habits, attitudes, and opinions. Thus, both approaches are complemented, so the quantitative study can generate questions to be qualitatively deepened, and vice versa. The quantitative cut was performed through the application of three instruments: Sociodemographic questionnaire, Barthel Index and Scale of Modes of Confronting Problems (EMEP).

The qualitative cut was made with the application of a semi-structured interview script prepared by the researchers, containing two questions.

**Participants:** The study participants were 30 family caregivers of patients with chronic noncommunicable diseases monitored at a clinical ward of the State Hospital of Ribeirão Preto (HERP), accessed one month after discharge.

The following criteria were adopted: the main family caregiver of the patients assisted in the HERP ward; be a caregiver of a patient with a diagnosis of chronic noncommunicable disease; were 18 years old or more; residing in Ribeirão Preto; be available for the study and in accordance with the research requirements. Family caregivers were excluded from

patients diagnosed with acute conditions (who had a short course of less than three months), younger than 18 years old, who were not residents of Ribeirão Preto and those with an academic background in the Health area .

The sample was defined for convenience, considering the research schedule and the dynamics of the hospitalizations of the service where the contact was made with the caregivers. Participants were identified via electronic medical records and contacted by phone after the inclusion criteria were applied.

The instruments were applied individually by the researcher to the research participant, face to face. The data collection had a maximum duration of one hour and the researcher assisted the participants who presented difficulties in understanding the items and questions to facilitate the completion of the instruments.

**Context of the research:** The HERP has a ward composed of 50 beds, and the occupation is according to the need of care, and there are no designated beds for specialties. The Medical Clinic occupies 40 beds on average, and the surgery has reserved 10 beds for hospitalization, which also serve as a support area for post-surgical recovery.

The idea for this study came from practices with occupational therapy groups with caregivers of hospitalized patients that were developed in a university extension project. The purpose of this project was to promote and prevent the mental health of caregivers, welcoming them in their difficulties, favoring the sharing of experiences and identifying problems experienced in occupational life, as a result of the role of caregiver. In the course of these practices, it was identified the need to know the coping strategies used by the caregivers and also to think about possibilities to improve the interventions offered in the OT groups.

#### **Data collection instruments and procedures:**

The first instrument applied was the sociodemographic questionnaire elaborated based on the Dahdah (2012), to obtain information about the profile of the caregivers, completed in an average of 5 minutes. This instrument is composed of topics such as personal and occupational data (profession, time in function, daily workload) of the caregiver, degree of kinship with family care, education, religion, became chief caregiver; personal data and diagnoses of the sick family member.

Afterward, the Barthel Index was completed to evaluate functional independence in the personal

care and mobility of relatives with CNCD (MINOSSO et al., 2010), using about 3 minutes.

The Conflict Mode Scale (EMEP) is a five-point Likert type questionnaire, composed of 45 items, which aims to access coping strategies used by people experiencing stressful situations or even illnesses. It consists of thoughts and actions that people use to deal with the internal or external demands of a specific stressor. The possibilities for answers are 1 = I never do this; 2 = I do this a little; 3 = I do it sometimes; 4 = I do this a lot and 5 = I always do it (SEIDL; TROCCOLI; ZANNON, 2001). In this study, the instrument was completed in 15 minutes.

EMEP presents four types of strategies for coping strategies: problem-focused, focused on religious-fantasy thoughts, seeking social support, and focused on emotion (SEIDL; TROCCOLI; ZANNON, 2001).

The adoption of problem-focused coping strategies includes approaches to the stressor by the subject in an attempt to solve the problem, dealing with or managing the stressful situation, and re-evaluating the problem to perceive it in a positive way (SEIDL; TROCCOLI; ZANNON, 2001).

Strategies for coping with problems focused on religious-fantastical thoughts are shaped by religious thoughts that help to confront the problem, and fanciful thoughts permeated by faith and hope (SEIDL; TROCCOLI; ZANNON, 2001).

The coping strategies of problems focused on the search for social support are characterized by the caregivers' demand for formal or informal help. Emotional coping strategies are negative emotional actions, unrealistic thoughts aimed at solving the problem in a magical way, elusive responses and blame of the other or self, seeking to distance the stressor (SEIDL; TROCCOLI; ZANNON, 2001).

Finally, with the objective of identifying coping strategies or aspects not covered in EMEP, the two questions in the interview script stand out: "How do you feel about the problems you face?" "Do you have done something else to face or deal with problems related to the care of your family member?" These questions were completed in writing in 7 minutes. For the collection of all data, an average of 30 minutes per caregiver was used, and in some cases, the procedure took about an hour, specifically for participants with reading and comprehension difficulties.

Data were collected from August to November 2014.

**Ethical aspects:** The project was approved by Research Ethics Committee (Process HCRP n° 5700/2013). The study participants (considered by the family group as the caregiver reference of the patients being followed in the ward) were invited to respond to the data collection instruments, after signing a free informed consent form (TCLE). Data collection was done at the home of those who agreed to participate, before an appointment. The names of the participants were replaced by the letter n in the analysis of qualitative results to preserve their anonymity.

**Data analysis:** The quantitative data were tabulated and the arithmetic means of the sample were obtained to reach the results of the instruments: Barthel Index and EMEP. For Barthel's Index analysis, each item was scored according to the patient's performance in performing tasks independently, with some help or in a dependent manner. A general score was formed by assigning points in each category, depending on the time and attendance required for each patient. Scoring ranges from 0 to 100 in five-point intervals, and the higher scores indicate greater independence. Thus, scores between 90 and 100 points are considered independent; 60 and 89 points are considered to be slightly dependent; 40 and 55 points are considered moderately independent; 20 and 35 points are considered severely dependent, and less than 20 points are considered as totally dependent (MINOSSO et al., 2010).

For the analysis of the EMEP, a descriptive data relationship was made for each of the variables verified in the sample, the arithmetic mean of the 45 items of the scale and the arithmetic mean (Me) and standard deviation (SD) obtained from each one of the four factors, in which the mentioned items are grouped in modes of confrontation *focused on the problem, the emotion, religious or fantasy thoughts and search for social support* (SEIDL; TROCCOLI; ZANNON, 2001).

Considering that four subcategories in EMEP and belonging to a single group of people were compared, the data were related following a normal pattern (evidenced by the Shapiro-Wilk test). Statistical ANOVA was used for repeated measurements, being considered a p-value <0.05 as statistically significant. Multiple comparisons were made by the Duncan and Tukey test. The analyses were done in Minitab software 17.

The analysis of the qualitative data was based on the thematic analysis of content, which consists of floating reading, and the organization of the data is

necessary. It is a procedure in which the transcribed data are read repeatedly, aiming to enable the researcher to develop the first impressions about them to group them into analytical categories (BARDIN, 2011). According to Bardin (2011, p. 42), Content analysis helps to identify recurring themes, and it is

[...] a set of communication analysis techniques aiming at systematically and objectively describing the content of the messages, indicators that allow the inference of knowledge regarding the conditions of production/reception of these messages.

Regarding the organization and use of the technique, there are distinct phases in the content analysis, organized in three chronological poles, followed for the execution of this study: A) Preanalysis; B) Exploitation of material and C) Treatment of results (BARDIN, 2011).

**Pre-analysis:** it involves procedures for organizing the material to be analyzed to facilitate and systematize the initial ideas (BARDIN, 2011; MINAYO; SANCHES, 1993). In this study, the documents analyzed were full transcripts of respondents' answers to the two interview script questions: 1. *How do you feel about the problems you face?* 2. *Have you done anything to address or deal with your difficulties in caring for your family member in your day to day life?*

**Material exploitation:** consists of operations of codification, classification, and categorization of the subjects, obtained through the transformation of the raw data to reach nuclei of understanding of the text. From the exhaustive readings of the answers to the aforementioned questions, two analytical categories were identified: 1. Caregivers' feelings about the problems faced; 2. Caregivers facing everyday difficulties. At this stage, the contents of the caregivers responses were identified according to similarity and grouped in the mentioned categories, following the general guidelines proposed by Bardin (2011).

**Treatment of the results:** this phase allowed the identification of constitutive subtopics of the analytical categories, denominated thematic units. According to Bardin (2011), these units are the result of gross results and highlight information obtained, allowing the analyst to propose inferences and interpret the data obtained according to its theoretical framework or the objectives foreseen by the research. In this work, the analytical categories and thematic units are highlighted in a table.

### 3 Results and Discussion

The results of the study are presented below, according to the sequence of application of the instruments. Thus, the information obtained from them followed this order:

1. Sociodemographic questionnaire; 2. Barthel Index; and 3. EMEP. Finally, the answers obtained from the semi-structured questionnaire are presented and analyzed with thematic content analysis.

Table 1 shows the data of the sociodemographic questionnaire, according to the composition of the sample about gender, mean age and standard deviation, kinship family members with illness, education, work, religion, time related to caregivers care in years and daily hours spent, receiving or not receiving help from third parties, regular monitoring of their own health, reasons that led to the care and diagnoses of non-communicable chronic illness of the family member.

The information obtained from the sociodemographic questionnaire shows that most of the participants are women, with a low level of education (<8 years), with incomplete elementary education and with some religion. Most of the daylight hours are dedicated to caring for the family member, 43% of whom do not receive help from others to share care tasks, and 60% have been in the care for more than three years.

Most caregivers studied are female, involving a gender issue, that is "caring" would be intrinsically linked to a feminine task, and care must be taken in this aspect, since taking care of the whole care dimensions of a woman's occupational life, especially if there is interference in the care for one's own health.

The literature on family caregivers also points out the predominance of the female, with women dedicating more than 10 hours a day to caring tasks with an average of more than three years (OLIVEIRA et al., 2011; DAHDAH, 2012; PINTO; NATIONS, 2012). It is observed that when the caregiver is not the spouse, the one with the closest

**Table 1.** Descriptive statistics of the values corresponding to the Sociodemographic Questionnaire.

| Caregiver                              |   |                            |                                    |                         |                     |
|--|---|----------------------------|------------------------------------|-------------------------|---------------------|
| <b>Gender</b>                          | 87% (n=26)<br>Female                                | 13% (n=4) Male             |                                    |                         |                     |
| <b>Average Ages</b>                    | 49 years old  |                            |                                    |                         |                     |
| <b>Minimum and Maximum</b>             | 20 years old  | 78 years old               |                                    |                         |                     |
| <b>Standard deviation</b>              | 15 years old  |                            |                                    |                         |                     |
| <b>Kinship</b>                         | 54% (n=16)<br>children                              | 13% (n=4) mothers          | 13% (n=4)<br>partner               | 20% (n=6)<br>others     |                     |
| <b>Education</b>                       | 47% (n=14)<br><8years                               | 23% (n=7) 11years          | 23% (n=7) 8<br>years               | 7% (n=2) ><br>11 years  |                     |
| <b>Job</b>                             | 33% (n=10) yes                                      | 37% (n=11) retired         | 30% (n=9) no                       |                         |                     |
| <b>Religion</b>                        | 40% (n=12)<br>Catholic                              | 23% (n=7)<br>Evangelic     | 20% (n=6)<br>believe in God        | 14% (n=4)<br>Spiritist  | 3% (n=1)<br>Atheist |
| <b>Care spent</b>                      | 60% (n=18)<br>3years                                | 27% (n=8)<br>1 à 3years    | 13% (n=4)<br>3 months and<br>1year |                         |                     |
| <b>Hours per day referred for care</b> | 67% (n=20)<br>18 to 24h                             | 20% (n=12)<br>6 to 12h     | 6.5% (n=2)<br>12 to 18h            | 6.5% (n=2)<br><6h       |                     |
| <b>Receive help from third parties</b> | 57% (n=17) yes                                      | 43% (n=13) no              |                                    |                         |                     |
| <b>Perform Health Follow-up</b>        | 60% (n=18) yes                                      | 40% (n=12) no              |                                    |                         |                     |
| <b>Reason for becoming caregiver</b>   | 43.5% (n=13)<br>They already lived with the patient | 44% (n=13)<br>own decision | 13% (n=4)<br>family decision       |                         |                     |
| <b>Diagnosis of family care</b>        | 26% (n=11)<br>cardiological                         | 26% (n=11)<br>diabetes     | 16% (n=7)<br>respiratory           | 14% (n=6)<br>neoplasias | 18% (n=8)<br>others |

parental relationship is the person who plays this role, and the woman is the main caregiver (CATTANI; GIRARDON-PERLINI, 2006).

Considering that 67% of participant have a full-time care and 43% do not rely on third-party help, besides to 60% of respondents being in charge of care for more than three years, it is reflected on how much caregiver role can interfere in life participation of the participants, for example by compromising sleep and rest, work, leisure and social participation.

In addition to the fact that most caregivers were involved in care for a long period of time, the number of hours they reported to care for the family with CNCD was high. Caregivers are considered to relate not only the time spent on the maintenance activities of the family with CNCD but also the continuous coexistence with them, which may influence the high number of hours reported by them.

The family member with CNCD may present comorbidities, that is, one or more chronic diseases, which may have acute episodes, leading to hospitalizations or recurrent demand for health services. The prevalence of chronic diseases of the sample (cardiological, diabetes, respiratory, neoplastic, among others) are similar to recent research found in the literature, such as the data from the National Health Survey of (INSTITUTO..., 2014), the main chronic diseases of the Brazilian population, such as cardiovascular diseases, cancer, diabetes, chronic respiratory diseases and neuropsychiatric diseases, which have increased the number of deaths before 70 years old and generated loss of quality of life by altering work activities and people affected by these diseases. Added to this, there are the impacts on caregivers' lives, since dealing with a family member with complex clinical settings increases the demands for care.

Table 2 shows data from the Barthel Index instrument used to quantify the following aspects: functional independence in personal care and mobility of relatives with CNCDs in relation to the primary caregiver; the frequency of the age group; mean age, minimum and maximum age, standard deviation and level of dependence for the basic activities of daily living.

The largest number of relatives with CNCD with the lowest need for functional care is due to the characteristics of the service where the research was performed (secondary hospital), which offers medium complexity care. It is observed that using the Barthel Index (used to quantify the functional capacity and mobility of patients), the data point out most caregivers presenting mild dependence of the caregiver or independent of functional care, suggesting that their caregivers would not have significant impacts on occupational life. However, the results of the sociodemographic questionnaire suggest that there is an impact, which points to the need to relativize these data, according to the specificity of each instrument used or to capture data that can not be identified by these instruments with an approach qualitative.

Figure 1 summarizes data from the Likert Scale (EMEP), presented by the means obtained in the coping strategies, showing how caregivers face stress in general, presenting the mean of the four coping strategies present in EMEP.

The chart shows that caregivers adopt strategies focused on the problem (Me 4.02 and Dp 0.707), followed by strategies focused on religious and fanciful thoughts (Me 3.98 and Dp 0.650), for the search for social support (Me 3.19 and Dp 1.021) and, finally, use strategies focused on emotion (Me 2.44 and Dp 0.722). According to the ANOVA test for repeated measurements, the four means were statistically significant (p-value <0.001).

**Table 2.** Descriptive statistics of the values corresponding to the instrument Barthel Index.

|                            | Family member         |                     |                         |                      |                           |
|----------------------------|-----------------------|---------------------|-------------------------|----------------------|---------------------------|
| <b>Age group</b>           | 67% (n=20)<br>elderly | 23% (n=7)<br>adults | 10% (n=3)<br>adolescent |                      |                           |
| <b>Average Ages</b>        | 65.5 years old        |                     |                         |                      |                           |
| <b>Minimum and Maximum</b> | 14 years old          | 93 years old        |                         |                      |                           |
| <b>Standard deviation</b>  | 22.3 years old        |                     |                         |                      |                           |
| <b>Dependency</b>          | 47% (n=14)<br>Light   | 13% (n=4) total     | 7% (n=2) severe         | 3% (n=1)<br>moderate | 30% (n=9)<br>independents |



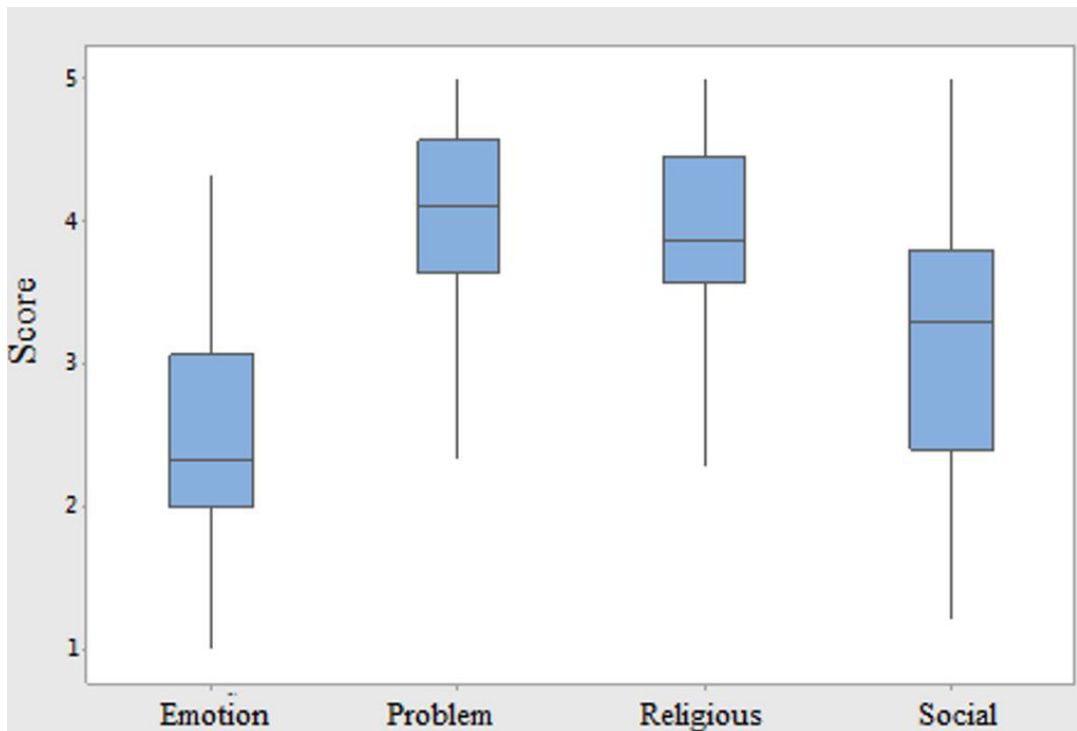


Figure 1. Strategies for coping with problems.

According to Duncan's test, when the categories were compared - focused on the problem and religious-fanciful thoughts -, they had no statistical difference between them, with averages close (p-value = 0.829). When comparing the category of social support search with the other categories, this one has statistical difference, it occurs when compared to the category focused on the emotion with the others (p-value <0.05).

The results indicate that these caregivers face the stress situation by directly contacting the problem in an attempt to solve it, dealing with or managing the stressful situation in the most beneficial way because there is no withdrawal from the stressor, in this case, the family member who needs care, as well as using religion and spiritual beliefs to deal with the difficulties of everyday life.

Strategies associated with thoughts based on faith and hope can provide a search for the re-signification and momentary relief of suffering, based on spiritual values and religious beliefs (DAHDAH, 2012).

The coping strategies of problems focused on the search for social support that the caregivers seek formal or informal help appear as the third most used strategy, which suggests that these caregivers

are in solitary situations in the care and need to be stimulated to seek social support. There is also the need to expand the formal support networks in healthcare equipment aimed at promoting the health of the caregiver (CATTANI; GIRARDON-PERLINI, 2006; PINTO; NATIONS, 2012).

Although as a less used strategy, *strategies focused on emotion* are negative emotional actions, unrealistic thoughts aimed at solving the problem in a magical way, responses of avoidance and blame of the other or himself, seeking the distress of the stressor, configuring only as palliative strategies and therefore not effective.

Table 3 shows the analytical categories and thematic units obtained from the content analysis (BARDIN, 2011).

### 3.1 Category 1: caregiver's feelings about the problems faced

In this analytical category, it is considered that the same interviewee can refer positive and/or negative feelings regarding the task of caring. Two thematic units constitute *Positive Psychological Perception and Negative Psychological Perception*.

**Table 3.** Analytical Categories and Thematic Units.

| Analytical Categories                            | Thematic Units   |
|--|--|
| 1. Caregiver's feelings about the problems faced | <ul style="list-style-type: none"> <li>• Positive Psychological Perception</li> <li>• Negative Psychological Perception</li> </ul>   |
| 2. Caregivers facing everyday difficulties       | <ul style="list-style-type: none"> <li>• Pleasant Activities</li> <li>• Spirituality</li> <li>• Informal Social Support</li> <li>• Changes in Occupational Life</li> </ul> |

It is observed that most of the caregivers of the sample have a positive perception regarding care, evidencing that the caregiver may also have positive feelings about care and the way they see and adapt to it. This can be observed in some speeches:

*Taking care of her makes me feel capable, that I am useful, that someone always needs me (n.12).*

*I feel better taking care of him here because he is well when I take care (n.20).*

*I feel very happy taking care of my mother (n.24).*

Regarding the caregivers' feelings about the problems they face, there are two aspects that should be highlighted: the first aspect is that care involves not only negative but also positive emotions, while the second aspect is that the care depends on a subjective evaluation that he elaborates on himself, from his personal, social, cultural and even relational resources with the entity under his care.

This data may be related to the level of independence presented by family members, which according to the Barthel Index results, most of them have slight needs (47%) or are functionally independent (30%), which would denote less expense of care, and may not happen in case of severe needs.

In this sense, the caregivers' perception of care may vary according to the needs and characteristics of the diseases of family care. Thus, caring for someone with severe needs due to the limitations caused by the disease and/or high dependence can generate negative emotions for the caregiver due to the complexity of the tasks performed by the caregiver.

However, data from the sociodemographic questionnaire point out that 67% of caregivers report developing care between 18 and 24 hours a day, 43% without help from other people, and 60% have been doing this care for more than three years. Thus, it is considered that there is a high investment of female caregivers in family care tasks, which interferes with a "linear" psychological perception.

On the contrary, it is emphasized that this perception oscillates from feelings of ambivalence experienced by these caregivers.

The perception of the beneficial aspects of being a caregiver is intrinsically linked to the perception of burden (DAHDAAH, 2012). This makes the relationship between caregiver and caregiver ambivalent, which also generates psychological distress for the caregiver.

In this sense, the negative perception of being a caregiver was also characterized as a burden, emphasizing the complex task of caring and the direct contact with the family that needs care, according to the following statements:

*I feel cheated and betrayed (n.4).*

*Caring is very difficult, shaken and without ground (n.5).*

*I do not feel well, I can not get what I'm trying, I am sad and angry (n.6).*

*I feel sad and lack the strength to go forward (n.15).*

Feelings of revulsion are felt, which contributes to fragile family relationships between the caregiver and the nuclear family, and this makes care an obligation instead of being a caregiver's life choice.

There are also contradictions in the psychological perceptions of some caregivers regarding the care they perform. Although the caregiver mentions difficulties in departing from the person under his care, he also assumes negative feelings in the situation of taking care of himself.

*I do not do anything, only housework and take care of my mother, I feel bad if I stay away from her, so I avoid leaving ... But it is only fatigue, sadness, revolt and agitation (n.22).*

As noted, the difficulty of coping with the situation may lead the caregiver to feel pressured, and while he may have positive feelings about his role and the caregiver's family, he may simultaneously

experience negative feelings that distress him and favor the increase of psychic suffering. In affective ambivalence, there are feelings that occur in an absolutely simultaneous way, in which the individual feels for a person or object, hatred, and love, rancor and affection (DALGALARRONDO, 2008).

The participants' discourses related to the psychological perception of the offered care in relation to the strategies used indicate that some caregivers are not able to adapt or solve problems, presenting behaviors that can lead to an increase in the suffering experienced. This aspect indicates the need for intervention of the health professional.

### 3.2 Category 2: caregivers coping with everyday difficulties

In this analytical category, it is considered that the caregiver uses more than one type of strategy that assists him in coping with the daily problems of care. Thematic units are composed of different strategies that contribute to the coping of problems: *Pleasant Activities, Spirituality and Informal Social Support*.

*Pleasant Activities*: Engaging in pleasurable activities is a strategy for coping with problems. Such strategies are leisure activities (individual or group), physical activities and altruistic actions, such as reading books, watching movies and television, traveling, doing crafts, hiking, and other physical activities, visiting sick people and helping known. Some of the speeches of the caregivers said:

*I do crochet, I watch soap operas, I chat to distract people, sometimes I do a course of painting (n.9).*

*I walk, crosswords and watch soap operas and some movies (n.10).*

*Since I stay with my mother at home a lot, taking care of myself, I enjoy the computer with the games (n.17).*

*I practice physical activities, gym, running and cycling (n.25).*

Faleiros (2009) developed a therapeutic intervention composed of psychoeducational groups associated to individualized care for caregivers of elderly people with Alzheimer's disease. The author identified the beneficial effects of this intervention since the sharing of experiences carried out by the caregivers pointed to the fact that they perform activities such as sewing, walking, watching television, visiting

friends, among others, as a way of alleviating the difficulties experienced in due to caring tasks. This aspect is similar to the findings of this study since the participating caregivers perform activities with the same objectives.

*Spirituality*: It was the second coping strategy most used by caregivers, characterized by support in religious beliefs and thoughts. Among the actions involved in spirituality there are praying, trusting in God and practicing Christian teachings:

*I pray I fast, I hear good music, I watch good movies and I work very much for the benefit of others whenever I can (n.2).*

*To relieve myself of the difficulties I have a lot of faith, I believe a lot in God, we are not here by chance, I think God has a purpose of life for each one of us and the reward to God is all power (n.3).*

*I am very attached to God. I ask that nothing bad happen. I dedicate with much prayer. I have faith to give me great health to help my children and all who need me (n.7).*

*[...] every day, I participate in evangelization, I am always in touch with people who need spiritual help, I really like what I do (n.30).*

Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connection with the moment, with themselves, with others, with nature, with what is significant or sacred (PUCHALSKI et al., 2009 apud AMERICAN..., 2015, p. 7).

Spirituality can be an important tool to deal with adversity, traumatic events and everyday stressors for the caregiver. Spirituality can aid in a re-signification of life history and promote a reorientation of self-care and of the other, involving several dimensions of life (MACHADO, 2014).

According to the results of EMEP (religious-fantastical thinking) and data from the sociodemographic questionnaire, the caregivers studied rely on religion, and this favors coping with adverse situations. The qualitative approach corroborates this data.

As a coping strategy, spirituality becomes an important ally for dealing with difficulties, and it is an important form of support and well-being for caregivers. However, it must be understood to what extent it can be used to atone for the caregiver's suffering as a result of conflicting relationships established throughout life with the caregiver's

family, and even with the family group. One should investigate to what extent these actions are being effective or only as a way of relieving feelings that bother the caregiver.

*Informal Social Support:* It is a coping strategy in which caregivers rely on informal social support, such as family, friends, and church, as well as seeking help from the family member who needs care.

*I can count on the support of family and friends, always present in my life (n.1).*

*I talk with my family and participate in church activities (n.11).*

It is essential to know the forms of informal social support of caregivers. Guadalupe, Costa and Daniel (2016) identified the social support networks of informal caregivers of disabled adults. The authors point out that the networks were composed by six family members on average with a high frequency of contacts and with geographical proximity, in which emotional support was the most perceived, however, with the need for economic support and future residential support. It is similar to the findings of this study, the attending caregivers also seek support from close family and friends.

*Changes in Occupational Life:* Reactions to the management of the stressor were identified in the deponents' discourses, as strategies that helped them deal with the difficulties, although they did not result in a permanent solution. However, they reflected changes in the occupational life of these caregivers:

*[...] lock in a room and stay alone (n.4).*

*I take care of the house, facing as it comes, I do not feel like doing anything else (n.5).*

*I watch television 24 hours because it is a way to calm me, to forget the problems and to feel a little happy because normal happiness is something that I think does not exist, except on the television screen (n.12).*

*At the moment, to take care of her, I am not doing any activity, because before I went out more to walk and dance (n.27).*

*At the moment, I have not done anything, because I do not feel like leaving the house to have fun. It seems that my life has stopped and I find no way out (n.15).*

Relationships involving caring for the sick family member can generate feelings of sadness that interfere, according to the above discourses, in the performance of important occupations such as social participation and leisure. These aspects were addressed in the study by Kebbe et al. (2014), developed with caregivers of family members attended in a day-care hospital in mental health. According to the authors, the care offered to a family member with a mental disorder may interfere with daily activities, such as work, leisure, self-care and interpersonal relationships, especially when care tasks accumulate with few possibilities of sharing them with other people.

The reduction of the caregiver's time to perform leisure activities, together with the difficulties of caring and lack of social support, contribute to feelings of discouragement and loss of interest, which may increase the risk of illness.

Fava, Silva and Silva (2014) observed the predominance of moderate and severe overload in caregivers of relatives with mental disorders, indicating the need to offer interventions to caregivers, instrumentalizing them for the adequate care of their relatives, as well as for the care of one's own health.

*There are moments that I feel very fragile at the same time, I ask for the strength of God to give me wisdom [...] (n.8).*

*I feel I live a life of renunciation, very tired, stressed and getting sick (n.21).*

These aspects indicate once again the relevant contribution of occupational therapy to the health care of caregivers, using, for this purpose, intervention strategies that include host groups and guidelines, besides to move the field of actions to the real contexts in which caregivers take care of the family member and also their own occupations, such as at home, in the territory and in the community. In this sense, contextualizing the professional practices to consider the singularity of the caregiver and his family group, respecting the social, cultural, economic and occupational characteristics (KEBBE et al., 2014).

Barrozo, Nobre and Montilha (2015) observed that caregivers of visually impaired people performed fewer occupational roles after assuming the role of caregiver, especially the role of worker, student and family member. For the authors, it is necessary that the occupational therapist considers the changes in the occupational roles of the caregiver, helping them in the daily difficulties.

Ballarin et al. (2016) identified the presence of moderate and severe overload in family caregivers of people assisted in an occupational therapy outpatient clinic, pointing to the need to implement support, training and orientation actions to caregivers in this service to assist them in the accomplishment of the activities of care, and minimizing the overload experienced and contributing to a relationship of integral and singular care.

The possibilities of therapeutic-occupational care devices for the health of the caregiver are several, aiming to promote health and prevent aggravations arising from the tasks and relationships assumed within the families, such as home visits, external care and therapeutic follow-ups that favor caregivers identify or recognize, in these contexts, the points of support (formal and informal social support, community resources, among others).

## 4 Conclusion

The study was able to identify and characterize the coping strategies of caregivers of relatives with CNCD, highlighting the complex experience of being a caregiver.

The research points to the fact that “being a caregiver” implies oscillations in the caregivers’ perception of their feelings, sometimes ambivalent, as a consequence of the caregiver role played. This can be accessed by the qualitative approach employed.

The results of this study explain that the accomplishment of pleasurable activities, spirituality and the effective search for social support constitute coping strategies that can be considered and operationalized in the practices of health professionals, including occupational therapists, active in different equipment and services, instead of helping to reduce the caregiver suffering, contributing also to the prevention of diseases and health promotion, aiming to improve the quality of life.

In this study, the family member’s dependence on the instrumental activities of daily living was not identified, which could indicate a greater dependence on the caregivers, since there could be limitations in performing complex tasks. This aspect is considered as a limit of this research. Also, there is a need for further studies that advance the proposals for intervention strategies for caregivers (other than guidance and care) and to evaluate their effectiveness. It is also suggested the need of elaboration and evaluation of therapeutic-occupational strategies directed to the health of the caregiver to help him

to the full exercise of a satisfactory and qualified occupational life.

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### **Author's Contributions**

Bento Miguel Machado was responsible for the design and writing of the text, data collection, preliminary analysis of the research data and organization of the sources. Daniel Ferreira Dahdah contributed in the elaboration and review of the text, as well as with method suggestions. Leonardo Martins Kebbe was responsible for designing and guiding the research, contributing to the definition of methodological design, data analysis and article writing. All authors approved the final version of the text.