

The activities and quality of life of caregivers of patients with chronic diseases

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Abstract: Introduction: With the increase of the elderly population in our country and, simultaneously, the increasing morbidity rate of chronic-degenerative disease in general, the number of people seeking for attendance at day care centers and hospitals has also increased. Most of the time, these people are also dependent, when they return home, on the care provided by family members: the caregivers. To prevent and treat the problems caused by the stress factors among caregivers contribute to reduce or delay their hospitalization. In addition, improvement on the caregivers' quality of life could allow them to better help the patients. In this context, this research tried to understand the reality of the lives of caregivers of chronically ill patients, and with this knowledge, implement and evaluate the effectiveness of an intervention proposal. **Objective:** The main objective of this intervention was to attenuate the stress conditions of care activities. **Method:** The research used interviews with caregivers; these interviews were taped and later transcribed to analyze the content of answers and elaborate the intervention plan, which, in this case, was a course. The course consisted of informative aspects on the disease and daily life activities, as well as the formative aspect on self-knowledge. A quality of life instrument named Caregiver Burden Scale was also applied. After the intervention (course), the Scale was once more applied to verify the data and check for efficacy. **Conclusion:** Results show the importance of the intervention on the caregivers' quality of life.

Keywords: *Occupational Therapy, Therapeutic Proceeding, Research.*

As atividades e a qualidade de vida de cuidadores de pacientes com doenças crônicas

Resumo: Introdução: Com o aumento da população idosa em nosso país e, simultaneamente, com o crescente índice de morbidade de doenças crônico-degenerativas, temos observado cada vez mais o aumento do número de pessoas buscando atendimento, tanto em nível ambulatorial quanto hospitalar. Essas pessoas são, muitas vezes, dependentes e quando retornam para casa precisam receber cuidados de algum membro da família: o cuidador. Realizar a prevenção e o tratamento dos problemas produzidos pelo impacto de fatores estressantes entre os cuidadores pode contribuir para reduzir ou protelar a institucionalização desses fatores. Com a melhora na qualidade de vida dos cuidadores, eles podem prestar melhor assistência aos pacientes. **Objetivo:** Assim, esta pesquisa teve como objetivo identificar a realidade de cuidadores de pacientes portadores de doenças crônicas e, a partir desse reconhecimento, implementar e avaliar a eficácia de uma proposta de intervenção junto a cuidadores que objetivou atenuar as condições estressantes advindas das práticas de cuidado. **Método:** Utilizou-se para tanto, entrevistas com cuidadores familiares que foram gravadas e, posteriormente, transcritas para análise do conteúdo e elaboração da intervenção, no caso um curso, em

que foram abordados aspectos informativos sobre a patologia e as atividades desempenhadas no cotidiano, assim como aspectos formativos como o autoconhecimento; também foi aplicado um instrumento de qualidade de vida denominado Caregiver Burden Scale. Após a intervenção, o instrumento foi aplicado novamente para averiguar um possível confronto de dados e verificar a eficiência da intervenção. **Conclusão:** Os resultados indicaram a importância da intervenção para melhora da qualidade de vida dos cuidadores.

Palavras-chave: *Terapia Ocupacional, Procedimento Terapêutico, Pesquisa.*

1 Introduction

A recent study with care for caregivers (CARVALHO, 2003) showed that many of the individuals who work directly with chronic diseases sick people with have shown mental disorders, since they are exposed to several sources of stress that may be related to:

- 1) *to disease nature* - such as the unpredictability of the disease;
- 2) *to treatment* – due to the type of intervention that will be used and the use of technology to prolong life;
- 3) *to the decision-making* - choice of alternatives for treatment involving many responsibilities;
- 4) *to morbidity of the patient and his psychologically response* - depending on the stage of the disease and the negative or positive emotional reactions;
- 5) *to exposure of diseases pictures threatening life or out of possible curative therapy* – as imminent death and severe pictures of extreme situation.

When the sources of stress above are not prepared, they cause impacts in the lives of caregivers in the following aspects:

Physical - back pain, frequent cramps, loss of muscle strength, constant body aches, chronic fatigue, loss of energy, wear of joints, loss of appetite;

Psycho-emotional - depressive symptoms, memory impairment, constant crying, sleep disorders, headache, poor concentration, aggression;

Social - difficulty to stay in contact with people, in groups, being isolated, substance abuse such as drugs, tobacco, alcohol;

Cultural - stop doing leisure activities that interfere with the cultural aspect. (CERQUEIRA; OLIVEIRA, 2002).

To reduce stress, it is necessary a specific training focusing primarily in *informational aspects* (theoretical information and practical training) that according to Freitas and Santana (2002), they come from the health education process, where each professional adopts methods of selection, organization and explanation of emerging content in order to direct the teaching activities, describing objectives, methods, organizational forms and means in favor of patient's welfare, together with family-caregiver; and second, the *formative aspects* – self-knowledge, since from the “expression of feelings, the way of being of each one is unfolded, a perception that shows about a particular situation and how it relates with the reality” (BIELEMANN, 2003).

To work with caregivers, it is necessary to promote self-knowledge and let their feelings exposed, to elaborate and put back in acceptance of the inevitable. This promotion allows, as Carvalho (2003) says, repairing the self-confidence and self-esteem of people exposed to limited situations in the health and disease process, in physical demands with patient transport, support to keep from falling, bed transfers to the wheelchair, changing positions in bed, change of bed linen and the patient.

Added to those physical demands, there are also emotional demands, coming from three spheres: the caregiver, the patient and the family. The caregiver emotionally confront issues involving the fear of death, physical, cognitive or mental disability due to the difficulty of memory, low level of concentration, or even by the patient's demands. The patient shows uncertainty on disease process, the installation of disabilities, frustration and having requirements out of context, such as medicines requests beyond what is necessary, constant changing the headrests (pillow, cushion), changing decubitus. There are other demands that are brought by relatives accompanying caregivers, asking them responsibilities far above what is required by their role.

On a stage where the patient does not progress or has no major changes in his picture, he can present dulling sensitivity or denial, fear or regression, magical thinking and unrealistic hopes, appeals, bargains,

disappointments, anger and aggression against caregivers for accusing them guilty for treatment without apparent results (CARVALHO, 2003).

However, caregivers can express several feelings, many of them linked to positive emotions, such as appreciation, gratitude, affection, respect, belief in the treatment. On the other hand, such feelings can also be negative, such as the inability to handle the situation, resentment toward dependence, demanding behavior, possessiveness, difficult to adequate to household routine changes and despair to the seriousness of the disease, getting worse the quality of life of the patient (GARRIDO; ALMEIDA, 1999).

In most developed countries, there are major and smaller organizations that are defined as community care with the objective of keeping the patient in their home providing support for the family and caregiver.

In Brazil, networks establishments predominates, articulated by formal and informal supports that need to be studied, supported and improved to have a more effective role. While developed countries are interested and study caregivers as a way to be prepared for great changes of the century 21, focusing on current issues, such as increase of life expectancy, decrease of family members, wife on the labor market, more separation between couples, increase of morbidity from chronic diseases, developing countries such as Brazil, are beginning this type of study. (MEDEIROS; FERRAZ; QUARESMA, 1998).

It is critical to health professionals, to use teaching-learning strategy to transmit information to family-caregiver in the process of caring for people at home, especially when they are affected by diseases that trigger chronic and irreversible processes, as this condition changes the trajectory of life not only to the person but also to his family.

2 Population aging and its implications

To understand the context of caregivers, we must better understand the aging process of the Brazilian population, since elderly people are those most in need of care from another person, due to some chronic health condition.

From 1940, it began the rapid process of decline in the mortality rate, which would last until the 70s. In the 40s, the mortality rate fell 13%, against

16% in the previous four decades (CAMARGO; SAAD, 1990).

The combination of lower mortality rates and high fertility rates determined the increased vegetative growth and with it, the Brazilian population increased from 41 to 93 million people between 1940 and 1970, with average growth of 2.8% per year. However, the age structure of the population did not change, since the reduction in mortality was mainly due to the decrease of specific mortality rates of childhood. Thus, more infants were "preserved" and the effect on the age distribution was similar to fecundity increase, leading to a "rejuvenation" population (CARVALHO, 1993). In these three decades, the proportion of young people and the elderly were an average of respectively 42.3% and 2.5% of the total.

The aging index of the population (over 64 years old x 100/under 15 years old), which was equal to 6.4 in 1960, reached 13.9 in 1991, meaning an increase of more than 100% in just three decades. If at the beginning of the century the proportion of individuals who could be 60 years old was around 25%, in 1990 exceeded 78% among women and 65% among men; life expectancy at birth then exceeded 65 years old (IBGE, 1994).

United Nations projections (UNITED NATIONS, 1999, 2013), points out that Brazil in 2000 would reach 170 million people, with 49 million under 15 years old and 8.7 million over 65 years old. By 2050, the United Nations project that the national population would increase to 244 million, with 49 million young people and 42.2 million elderly people. Around 2080, the proportion of young and old people should stabilize, with 20% and 15% respectively of the total. Thus, the Brazilian population has suffered what Silvestre et al. (1996) call the demographic transition over the last few years that is the passage from a high mortality and high fertility situation with a young population in weak expansion to a situation of low mortality and gradually of low fertility, with increasing life expectancy causing several social consequences.

These social consequences are the increased spending of hospitalizations, overload of health services by the elderly who have more problems that are frequent, retirements, high consumption of medicines, special transportation and others.

Veras explains the process of population aging as follows:

The cause of the rapid increase in life expectancy in the last century was a replacement of the causes of death, previously resulting from infectious and parasitic diseases, for heart disease, cancer and degenerative neurological diseases. Omran as the epidemiological transition described this change in diseases patterns. According to this theory, as nations modernize, they tend to improve their social, economic and health conditions. Living conditions previously favorable to the spread of infectious and parasitic diseases were quickly replaced by healthier living conditions and improved medical technology. As the risk of death from infectious disease is being reduced, those who escape dying of such illnesses survive into middle age and old age, when they face a greater risk of dying of degenerative diseases or are still incapacitated for a long period, needing care (Veras, 1994, p. 28).

3 Caregivers

For caregiver's role understanding, this item will address the developed studies on the topic, throughout history and the different concepts.

The first studies related to caregivers emerged after the germinal work of Grad and Sainsbury in 1963, highlighting the consequences of mental illness in the lives of family members. Since then, the literature on caregivers is growing, especially in developed countries, notably from the 1980s, due to several changes in the socio-demographic and economic environment, primarily addressing the geriatric area with caregivers of elderly people with dementia (MEDEIROS; FERRAZ; QUARESMA, 1998).

Other diseases also have been studied in this context, such as cancer, AIDS, asthma, Down's syndrome, stroke, epilepsy, Parkinson's disease, chronic renal failure, rheumatoid arthritis, Alzheimer's disease, among others (ANDERSON; LINTO; STUART-WYNNE, 1995; BARNET; BOYCE, 1995; BECKHAM et al, 1995; CLIPP; GEORGE, 1993; HOARE; RUSSELL, 1995; TOWNSEND et al, 1991; WICKS et al., 1997).

In the literature review about home caregivers of dependent elderly, commented by Barer and Johnson (1990) it is similar only to stressful characteristic of caring activity. When talking about caregivers, there is not a clear definition of this term, since different authors use their point of view or results from their studies to formulate a definition often

subjective. However, in a general way and without many specifications, different authors define the term caregiver from their studies with this population, as "who takes responsibility to care for, to support or attend any need for the person cared, aiming to improve their health" (LEITÃO; ALMEIDA, 2000), for carrying out the tasks for which the patient suffering from the morbid episode has no more opportunity to perform. Such tasks are from personal hygiene to financial management of the family. Caregivers are those who try to meet the needs of patients, whether physical, or whether psychosocial (KARSCH, 2003).

Therefore, caregivers can be both the health team and the patient's relatives. According to Carvalho (2003), people by being family abdicating other interests or duties or in need of a job, selling their workforce to care for others, according to Bretas (2003), and family or people whose relationships are less contractual, and more affection or kinship or friendship and neighbourhood with the client being cared and these people have importance and meaning for that human being (TRAVENSOLO, 2003).

Deepening a little more about the use of this term, some authors divide caregivers in formal and informal such as contractors or not. Duarte (1997) says that formal caregiver is a person hired by the patient and/or family, so he is paid to exercise care activities. Stone, Cafferata and Sangl (1987) say that formal caregivers can be a nursing assistant, companion or maid. Thus, informal caregivers are family members, friends, neighbour or volunteers who take care of the sick person often unprepared and without remuneration (DUARTE, 1997; STONE; CAFFERATA; SANGL, 1987).

In this study, the caregiver who was the subject of the research was those having family ties receiving care, called as family caregivers, that is, those people in the family that even not knowing what role they need to play, are next to the patient due to the desire to support him, giving solidarity and interest in contributing to meet the needs, also called as informal caregivers, that is, not from the health area or a spouse, children or any family member who voluntarily or not assume the task of caring for the elderly (BIELEMANN, 2003; BRASIL, 1999; KARSH, 1998).

Given the importance and responsibility of the caregiver in providing the necessary care, they may also be called as primary or main and secondary caregivers. Primary caregiver is defined as the main person responsible for patient care during

the disease and the most intimately involved in the care of the patient (MEDEIROS; FERRAZ; QUARESMA, 1998; STONE; CAFFERATA; SANGL 1987).

The secondary caregiver is about other people who provide patient care, but without the main responsibility (MEDEIROS; FERRAZ; QUARESMA, 1998). Collaborating in this way, Stone, Cafferata and Sangl (1987) define the secondary caregivers as family members, volunteers and professionals who provide complementary activities.

Other studies consider the place of the care activity to define the caregiver. Institutional caregiver is the one requested by the institution where the patient is hospitalized, but hired by the family; the home caregiver is also hired by the family through suggestion of the doctor accompanying the patient or by the family to meet the needs of this patient (BRASIL, 1999).

The definitions do not realize the process of caring for a dependent elderly at home because it tends to reduce the focus of analysis to the activity of caring himself, not giving importance to other dimensions involved in the process, and these activities are seen as an obligation towards the dependent elderly. Thus, it is something inherent and natural to people without a social, historical and cultural context of caregivers' lives.

4 Home care

Patients assisted at home is a practice coming from antiquity and linked to charity and solidarity. According to Cunha (1991), this activity, mentioned in the Old Testament, emerged as a biblical recommendation to the Hebrews for the care of sick and recent mothers in their homes and, among the Jews, there are statements of the rabbis instructing them to visit patients to help them out of suffering.

Silva (1995) says that in the United States of America (USA), home care is becoming a "fluorescent industry and about a third of the country's hospitals now offer this type of alternative". According to this researcher, in recent decades the USA have guided hospital services for two large health care markets: outpatient surgery and home care for the chronically ill and gradually more prolonged illnesses treatment schemes out of hospital. The emphasis on models of "home care" is the integrated approach of the health team, model that does not represent additional costs to the hospital, compared to the traditional hospitalization type.

In Canada, the experience with home care comes mainly from patients with cancer and chronic diseases. Since the 1960s, the movement of deinstitutionalization has been intense, accompanied by the development of new technologies to care for people at home (MC KEEVER, 2000).

In Latin America, there are home care experiences after the 80s, especially in Argentina, where the programs are approved by the health regulatory agency in that country and concerned with primary care (ALBUQUERQUE, 1998; BORN, 2006).

It is important to highlight the Cuban experience that since 1984, it has been developing the model of family medicine. There are 29,646 family doctors in the country providing coverage for 98.3% of the population. It is noteworthy that the Cuban model has influenced many experiences in our country, especially in the home care area, but we are still developing with the Family Health Program (PSF) and also with the Elderly Health Program (ALBUQUERQUE, 1998).

According to Kassab (2000), The State Civil Servant Hospital of São Paulo was pioneer in the implementation of home care programs in 1968, creating norms, routines and selection of professionals to structure and program development. Thus, it was a model for the development of other home care programs, especially those connected to the City Hall of São Paulo, officially open since 1994.

In 1992, the Home Care Program (PID) of Santos - São Paulo was created and in the following years there were several of these programs across the country, such as Hortolândia, Jundiaí and Campinas (1993), Volta Redonda (RJ 1994), Paulínia (SP 1995), Londrina (PR) and Quixadá (CE) in 1996, and São Caetano do Sul in greater São Paulo, including 400 families today (AURICCHIO JUNIOR, 1999).

Although the municipal home care services aimed at improving the quality of life of the population assisted in health, observing that there are not many studies about costs and benefits, pointing at a critical sense that the public sphere have less responsibility for the sick person and also wants to reduce spending on health using at most the existing hospital beds, not needing to invest in buildings and refurbishments of Hospitals and Health Centers.

If health as defined by the 8th National Conference, is a social phenomenon, it would be important to ask "why the citizen who had his health affected by social factors cannot find a network of support services to assist him in cases of degenerative chronic

diseases?”. As family responsibility there are the consequences of a social phenomenon. The family begins to bear all responsibilities for recovery and/or stay of sequels in the individual, without support of a public network of specialized services for chronic degenerative cases (MENDES, 1995).

In this sense, Karsch (1998) says to home care be achieved, a regulatory object in the public sphere is necessary to bring it to the social sphere. It is necessary to uncharacterized it as a personal, individual matter, considering the social determinants of the disease to understand it as a social phenomenon.

In home care, it is necessary to always respect people's homes, their peculiarities, their routines, behaviors, cultures and beliefs, and consider these factors when proposing any changes in the domestic routine or physical plant of the residence.

4.1 Family

As being considered as the basic support of the chronically ill, it is important to highlight the role of the family in the context of caregivers and family caregiver.

Until recently, family was understood as a group of people living under one roof and, among them, they had kinship and affinity ties. These patterns have changed all kinds and there are always those who say, “the family is in crisis” (SULLEROT, 1997).

Longevity and the decrease of births in Brazilian cities and in the world are “verticalizing” family structures and a new way of living is appearing, the “intimacy at a distance”, to which people do not live in the same house, but they visit, telephone and exchange favors (MELLO, 2002).

The home caregiver, when seeing a person of her/his family chronically ill and unable to care for himself and need someone to help, is forced to take responsibility for this care. This obligation is determined by his/her own values and moral principles, but also by bonding. This choice is conscious and dictated by the very situation this caregiver is, or by circumstances that permeate his/her familiar world (MELLO, 2002).

Decisions to take care is more or less conscious and studies reveal that while the appointment of the informal caregiver is the result of a dynamic, the process seems to obey certain rules reflected on four factors:

- Relationship: higher frequency for spouses, always preceding the presence of some children;

- Gender: with predominance of women;
- Physical proximity: considering who lives in the same residence of the person requiring care;
- Affective Proximity: highlighting the marital relationship and the relationship between parents and children (KARSH, 1998)

Neri (2002) points out that national and international research confirms that the largest network of home support to the chronically ill is formed by: spouses, children and/or relatives and friends.

As women are more long-lived than men and usually younger than their husbands, the preferred family caregiver is the spouse. In the absence of his wife and in second place, in commitment of hierarchy there are the descendants of the second generation. In this case, the most likely candidate is the eldest daughter. She is often middle-aged, married with young children. Then the hierarchy comes to the widowed daughter, then the single daughter, also middle-aged, with or without children. Rarely, the caregiver is another relative or young person and rarely is a man (PENNING, 1991 apud NERI, 2002, p. 25).

5 Intervention proposal

The research objective was to promote through activities, as a course, improving the quality of life of family caregivers of chronically ill people. For this, the activities involved specific training, focusing on informative aspects (theoretical information - on the pathology, legislation, information about emerging issues and practical training activities - positions and maneuvers to facilitate the care and activities of daily living) and formative (self -Knowledge - through reflections on life, using role-playing, simulation situations and expressive activities).

In the study about caregivers by Mendes (1995), it was found that the interviews were a source of information for the caregiver and motivation to search for new information about the disease and the treatment being administered to family dependent. The questions led them think about the disease, about behaviors arising in the patient, on the extent of disease, type of treatment the patient needs, recovery time, the importance of health

treatments in the rehabilitation of the patient and the evaluation of care they have received at the hospital and consultations, as well as answer questions.

When the caregiver is the family, it could be individual or group interventions. They may target three objectives: support, problem solving and development of coping skills (CARVALHO, 2003).

Both in United States and Europe have big investments of public policies in order to build and maintain elderly support networks directly or providing support for caregivers: family members, volunteers and professionals. This is recognized as shown in Lechner and Neal research (1999), for public and private programs showing that care come from informal support networks are the most important source of support for the elderly.

When recognizing unprepared and even taking care of other, know-how and know-care constitutes a claim of being caregiver and a goal to be achieved. The need to take care with zeal and care are followed, most of the time, by feelings of fragility, insecurity and abandonment to their own luck (SENA et al., 2000; HUNG et al., 2012). In this context, Mello (2002) states that seeking to learn to care, this caregiver is also taking care of himself, for remedying their difficulties, feelings of insecurity and abandonment are gradually being dispelled, finding out who guide him, who take him doubts, who share with him the moments lived in his daily tasks.

6 Method

6.1 Research participants

Research participants were caregivers of a population with chronic disease and close relatives (wife/husband, son/daughter, brother/sister, father/mother) who performed the care at the

residence and did not participate at any time in support programs or guidance to caregivers.

According to **Table 1**, there were 6 caregivers, female, with mean age of 56 years old, being 5 wives, one daughter and one sister; all with an average of 5 years of care time with the sick family member. These families have an average of 60.3 years old, five have stroke sequel (cerebrovascular accident) and TBI (traumatic brain injury).

6.2 Data collection place

The data collection was in a clinic located in a public university, in a city in the interior of São Paulo, where chronically ill patients in rehabilitation are assisted.

6.3 Material for data collection

A semi-structured interview was used to identify the caregiver, aspects necessary for the care, the impact of routine care for the caregiver, stage of evolution of the patient's disease, social support and topics regarding the private life of this caregiver. The recorder was used to record the content of the interviews.

An instrument called Caregiver Burden scale (CB scale) suitable for measuring the impact of chronic diseases in the lives of caregivers was given for further analysis of the target population's quality of life.

6.4 Procedure for data analysis

6.4.1 CB scale instrument pre- and post-intervention applied

The analysis of the instrument was done according to the procedures defined in the instrument itself, or with the responses from caregivers who might be often, sometimes, rarely and in no way, with a

Table 1. Characterization of the caregivers.

Caregiver	Gender	Age	Relationship	Care time	Disease of the family member	Family member age
C1	female	74	Wife	7 years	AVE	75
C2	female	68	Wife	2 years	AVE	72
C3	female	52	Wife	13 years	AVE	52
C4	female	29	Daughter	2 years	AVE	60
C5	female	57	Wife	3 years	AVE	61
C6	female	56	Sister	3 years	TBI	42

score of 4, 3, 2 and 1, respectively; an arithmetic average for each of the five domains and an average for every instrument (global or total) was made. The closer to 4, the better the quality of life and the closer to 1, the worse quality of life of the caregiver.

The result of applying the pre-intervention instrument along with the answers of the interviews was to prepare the course that is intended to mitigate the stressful conditions arising from care practices.

6.4.2 Interviews

The interviews were applied and transcribed and, soon after, a simple content analysis of the interviews was done, that is the relevant parts of the answer and with some need or emphasis in common by the caregivers were separated as a focus for intervention.

After the activities (course) the CB scale instrument was applied again for coping data and verify the effectiveness of the intervention.

6.4.3 Activities (course)

On the intervention, the analysis was done through observation and the daily record of the researcher on the attitudes and considerations of caregivers about every activity and in every meeting, to verify that the object of every activity or dynamic had been met. The daily record by the caregivers.

The observations made by the researcher as to nonverbal expressions during the proposed activities were also considered, such as smiles, nod indicating agreement, responsiveness of body posture demonstrated by attitude to sit in the chair in a comfortable and relaxed manner, effusive greetings at the beginning and end of the activities. These events were considered as positive attitudes toward the researcher and her proposition, not being observed negative or opposite signs throughout the intervention such as: arms crossed, bushy eyebrows, negative shake of the head, contracted mouth, lack of smile and other indicators.

7 Result

7.1 Interviews

It was found that the caregivers did not know to define their role, had little or no information about the patient's illness, they cared for a long daily period of their family member, showed a mixture of positive and negative feelings toward both the

family and situation they were in at the time and when the patient was dependent for moving they had pain by physical effort. It was found that the caregivers had no time to take care of themselves, leisure time, and no plans for the future.

7.2 Pre-intervention instrument

It was found that the C5 caregiver had the poorest quality of life, that is, with the highest total score, an average of 2.68 of 4 possible points. Caregivers with better quality of life according to the CB scale instrument were C2 and C4. It was observed a correlation with the deficit of social support, since the caregiver C5 does not receive help to realize the care and the C2 and C4 receive family help or have someone hired to assist in the care of their sick relative.

7.3 Activities (course- intervention)

The course had three meetings, totaling 8 hours. the schedule was: theoretical aspects of the pathology, practical activities (dynamic, simulation of situations, including if necessary, role-playing), group discussions on emerging issues in the interviews, guidance for performing daily activities in caring for the sick relative as well as expressive activities that have led to self-knowledge and reflection on their activities.

Professional work with family caregivers included information and reflection. It was necessary to instruct the family on the specifics of care practice, as well as attempt to the feelings that emerged daily dealing with the sick person.

After each activity a field diary was done, in which the researcher wrote down all of the impressions of each participant expressed through opinions (what they think of this activity?) and suggestions, as well as direct observation of the researcher and the most important events that occurred during the activities.

For better explanation of the activities developed, they will be presented as well as their objectives in the field diary with the results of each activity according to participants and direct observation of the researcher who noted the most relevant aspects of each activity.

Presentation: Considering the women in the group knew each other since they were almost every day in the clinic and were together in the reception, while their relatives, who were also part of a same group, were attended by an Occupational Therapist, we

can say that the presentation was not necessary, but it should be made indicating name, likes, dislikes, striking facts of life (positive or negative) and how is taking care of the sick family member.

Sculpture with clay: The participants get: clay, spatulas and water for them to do a free sculpture with the theme feelings. The activity aimed to creativity, expression of feelings and self-knowledge. After the activity, each participant explained what they created with clay.

In addition to provide participants' creativity, since all were able to do something with emotional meaning for them, manipulating clay that was new to almost all, also contributed to touch on feelings, such as giving, caring, care, beliefs and pleasure. During the activity, they exchanged ideas and considerations about the use of the material, making comments such as, "*wow, there are many things to do with clay*".

Creating a story: A participant initiated a story with free theme writing for 1 minute and then changed her story to the participant next door, which should complete the text already written. This would happen until all read and complete the story of everybody, in order to provide creativity, share ideas and opinions, imagination, perception of the feelings that were taking place and identification of difficulties and common situations.

In the activity of creating a story, all participants had a great time laughing, giving hints and anxiety by writing soon. When reading their stories aloud completed by all participants, the comments were: "*how the thought of each one is different, but when writing about the same subject gives meaning*" (C2).

Blind: A person in the group guided another participant with closed eyes to find a ball inside a circle of 3m diameter. To get to this circle, the participant had to walk a small way with mild curves marked by tape on the floor, and the one directing did not allow the other person stepped out of the line through verbal indications on directions to be taken correctly (forward, backward, to the left, to the right) and the number of steps. The purpose of this activity was the development of trust, skill, spatial orientation and self-control.

In this activity, some caregivers were a little afraid of falling or tripping, but on the way there was no obstacles and the path was not very tortuous, because the only difficulty was down to catch the ball. All were placed to have confidence in the person who would guide them and without blindfold all were controlled and demonstrated trust, not opening their eyes in any time. Regarding

the spatial orientation, only caregiver C1 came out of the path at first, having difficulties taking small steps.

At the end of the activity, all reported a welfare because for everything was right and still commented that it is not easy to trust someone until you meet this person. The also commented they understand a bit their sick relatives when they do not want "anyone out of the family" to care because usually they have different customs and habits.

Role Playing: The participants experienced some form of physical or sensory deprivation as the activity aimed to reflect on the problem faced by their relatives, and feel the real difficulties and solving problems.

To simulate a disability or difficulty it was proposed that two participants were mute, two with limited movement in their right hands, one with unilateral vision and other paraplegic without walking. The distribution of the disability was as listed below:

- C1: not talking;
- C2: not moving the right hand;
- C3: blind in one eye;
- C4: not moving the right hand;
- C5: not talking;
- C6: wheelchair user.

The story of one of the caregivers summarizes the difficulties experienced and understanding of the real situation by her family with neurological dysfunction:

It is very difficult ... we have to be patient... it hurts a little ... it gives affliction ... you want but you cannot ... I know what he's going through, it's hard

In this activity, the caregivers asked to do the situations simulations inside the room, because they were a little embarrassed to go to a foreign location; with role-playing, they experienced, in fact, some hardships of the families, the difficulties faced by them and in some way, what they feel with this problem.

Lecture about stroke: to better understand the difficulty by the family member a lecture focusing on aspects of the disease was scheduled, such as diagnosis, probable causes, consequences, treatment, prognosis. The objective was to answer questions,

provide detailed information about the pathology, in clear and objective language.

During the lecture, the caregivers asked questions about the disease and its causes. It is noteworthy that they liked to know that not only is high blood pressure which is a major cause factor, but others such as diabetes, cholesterol, smoking, lack of physical activity, among others. Through this information, they commented on the possible evidence in the family member before having the episode that culminated in the current sequel. By the comments of caregivers, it is seen that the diagnosis often was not made properly and that the information on the disease were superficial, just as the prognosis given by the doctor.

Debate about care: The activity was done in group and divided into two subgroups. One subgroup should defend the idea of why they should care the family member (positively- yes) and the other subgroup why of not caring or sometimes one does not takes care of a family member (negatively-not), whether for health reasons, for financial reasons or for a pre morbid relationship deteriorated with the family who needs care. When the debate was proposed, the caregivers enjoyed the activity, but none of the subgroups wanted to oppose the act of caring, until a caregiver gave an example of a financial difficulty. Then, others joined her to defend this view. However, all made clear they would defend this idea in the activity but they would agree with the other subgroup, on principle.

In this activity, the caregivers could express their views on the care and the difficulties they encounter in everyday life, and think together on the importance of their role as a chronic patient caregiver often with full responsibility for the care of the patient and other family home tasks.

Before the debate, caregivers of both subgroups explained one thing in common on the activity of care. The phrase “To care should be taken above all caring” shows the feelings of the caregivers and the principal value that must have to carry out the activity of caring.

After the debate, the positive aspects of caring were mentioned, such as the ill family member needs support, the caregiver is retired, caregiver does not need to work, caregiver loves and must meet the wife’s duty (married in the church and swear it) live along with the sick person, the children know that the caregiver is capable, there are designs of God-faith and love encourage and give strength, the wife should take care of her

husband, she has to take care, because they cannot afford to hire a person to help and is alone in the house, should take care having responsibility for each other, if can afford to hire someone to help but she should be around.

The subgroup to defend or not caring, listed the factors for such an attitude: the caregiver has health problems, can pay a person to perform the full-time care, have financial help from others, he wants to walk and cannot, if the sick is not the husband why he should care – you did not swear anything, should let others take care of the family member, must put a qualified person, have work or do college (some activity that can not leave) and do not have time.

Interpersonal care activity: The activity was held in couples, one caregiver with another one, doing nails, combing, hairstyles, among other things that the other person wanted such as makeup, massage, etc. The purpose of this activity was the improvement of self-esteem, sharing tastes, intimacy with another person in the group, as well as personal and solicitude care.

7.4 Post-intervention instrument

After the course and reapplication of the CB scale instrument, there was no change in the caregiver with poorer quality of life and greater impact to caring, with the C3 and C5 caregivers had the worst rate, which may be explained by the fact they have no social support in the daily care of their husbands and also by an external source of stress that was commented to the researcher.

According to [Table 2](#), when comparing the results from the instrument scale CB pre and post

Table 2. Comparison of results of the CB *scale* instrument pre e post-intervention.

Caregiver	Pre	Post
C1	1.54	1.68
C2	1.45	1.33
C3	1.95	2.37
C4	1.45	1.13
C5	2.68	2.16
C6	1.86	1.82

intervention, what happened was the decrease in index for 4 caregivers (66.7%), that is, improvement in quality of life index (decreasing the impact) and slight increase to 2 caregivers, which can be explained by external sources of stress that were not controlled in this study.

8 Final considerations

The course was a moment of information to caregivers and self-knowledge. The intervention was effective, bringing guidelines and reflections to the group on the practice of care, as well as aspects of personal life. These gatherings of people with problems and difficulties in common made the caregivers identify people in the same situation that is "sharing ideas makes finding solutions". Through all these, they obtained learning and new experiences, gaining more knowledge and arguments, noticing something in daily life facilitating with new attitudes or actions. They also identified their limitation as caregivers in charge of care to the patient and as human beings who need to care for and cope external activities that were not their function, and continue to take care of the house and sometimes even children.

During the course, love and affection were feeling in the lives of caregivers. Knowing the limitations and importance of dividing the task of caring with others diminish the guilt (fear not taking care so well of the family member) and perception that could postpone some activities and then, if the time was not available.

Working with the mind and identifying what each one likes, made the caregivers idealize more plans for the future, with aid to invest in projects in the long term, as many reported they had not invested before the intervention due to the stagnation of routine or lack of prospects due to stress and demands of caring.

Before the intervention, there was an attitude of exchange of basic information among the caregivers in the waiting room of the clinic that their families attended. After the intervention, this attitude changed completely, seen when two wheelchair family members were disconnected from physical therapy. At that time, a third caregiver provided an informal support of psychological support, encouragement, search conscious solutions to the problem.

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Author's contributions

Leticia Zanetti Marchi Altafim is the author and text organizer of this study. Cristina Yoshie Toyoda is the advisor, editor of the bibliography and final text editor. Danielle dos Santos Cutrim Garros is the final text editor.