Moving from reclusion to partial freedom: the experience of family caregivers for disabled elderly persons assisted in a day care center

Resumo O estudo teve como objetivos: compreender a experiência interacional cuidador familiar-idoso dependente apoiada por um Centro-Dia (CD), segundo a perspectiva do cuidador familiar, e desenvolver um modelo teórico representativo da experiência vivida por ele. Utilizou-se como referencial metodológico a Grounded Theory e como referencial teórico o Interacionismo Simbólico. As estratégias para a obtenção dos dados foram a observação e a entrevista. Dos resultados emergiu o fenômeno: sentindo-se apoiado pelo CD, pela força do vínculo com o idoso e pela espiritualidade para continuar desempenhando o papel desafiante de cuidador familiar de idoso dependente. O trabalho permitiu-nos compreender que dentre esses três pilares de apoio para enfrentamento da sobrecarga gerada pelo papel de familiar cuidador dependente, o modelo assistencial promovido pelo CD é o que se configurou como variável interventiva no processo de melhora da qualidade de vida do binômio cuidador familiar-idoso dependente. Isto nos possibilitou identificar a categoria central - movendo-se da reclusão à liberdade parcial: a experiência do cuidador familiar de idoso dependente assistido num CD.

Palavras-chave: Idoso, Família, Assistência diurna

Abstract This study aimed at understanding the interactional experience between family caregivers and disabled elderly persons supported in a Day Care Center according to the caregiver’s perspective. It also aimed at developing a representative theoretical model for the events experienced by such caregiver. The Grounded Theory was used as methodological framework whereas Interactional Symbolism served as the theoretical framework. Observation and interviews were used for data collection. The following phenomenon arose from the results: feeling of support by the Day Care Center, by the strength of the bond with the elderly and by spirituality in order to continue playing the challenging role of a family caregiver for a disabled elderly person. The study made possible to understand that, among these three supporting cornerstones for coping with the burden generated by the family caregiver role, the care model promoted by the Day Care Center was the intervening variable in the process of improving the quality of life of the family caregiver-disabled elderly person binomial. This allowed the identification of the main category – moving from reclusion to partial freedom: the experience of family caregivers for disabled elderly persons assisted in a Day Care Center.

Key words: Elderly, Family, Day care
Beginning the study

Since the 1940s, Brazil has experienced an inversion process in its mortality curves, and a decline in the number of deaths caused by infectious diseases has been observed with a concomitant increase in the number of deceases resulting from non-transmittable chronic disorders and external causes. This process is known as the epidemiological transition phenomenon. It has occurred in all currently developed countries, whose elderly populations are increasingly more expressive.

This epidemiological transition phenomenon has defined a new population profile worldwide and caused a great impact on the various segments of society, which can be explained by the fact that, on one hand, a decrease in fertility and in mortality due to childhood diseases has been observed, while, on the other, an increasing number of chronic-degenerative diseases and typical disorders of older age has also arisen as a counterpart of present day life characteristics.

The frequency of chronic diseases and the present longevity of Brazilians are the two major causes for increased rates of disabled elderly persons. Prevention of chronic and degenerative diseases, health care for disabled elderly persons and support for family caregivers represent new challenges to the health care system installed in Brazil.

This situation implies a rearrangement of Brazilian public policies with the purpose to favor the implementation of holistic measures capable of providing improvement to the quality of life of this population group. However, what is observed in our country is that elderly persons are the ones mostly affected by the crisis influencing the country’s welfare policies, particularly those concerning health care.

In face of this reality, the family constitutes the major support system to the elderly despite the difficulties experienced at contemporary times.

The literature shows that giving care to the disabled elderly brings a variety of adverse effects and acknowledges the emotional impact experienced by family members caring for persons with mental disorders or other problems resulting from ageing. Such emotional impact or burden has been defined as: physical, psychological or mental, social and financial problems experienced by family members as a result of giving care to diseased elderly persons.

The family presents material and emotional needs, including the need for information. The material aspect includes financial resources, housing issues, transportation and access to health care services. On the other hand, the caregiving family needs information on how to provide care, including the adaptation of the environment to the elderly person. Additionally, emotional support as well as a care network connecting the family to support services and ways to ensure quality of life to major caregivers are also important.

It is in this context that the non-institutionalized elderly care modality arises in Brazil under the denominations of Cohabitation Center, Day Care Center (D.C.C.), Day Care Hospital, Home House and Sheltered Workshop, which aim at assisting older persons during a certain period of the day.

The need to carry out this study emerged from our participation in a community service project at the Elderly Day Care Center (Centro de Convivência do Idoso – CCI – Aconchego), located in a city of São Paulo state, Brazil, as well as from the lack of studies assessing the impact of this type of institution as regards the binomial family caregiver-disabled elderly. These were the reasons which motivated us to conduct this study: to understand the interactional experience between the family caregiver and the disabled elderly supported by a D.C.C. for the elderly according to the caregiver’s perspective; and to develop and validate a representative theoretical model of his experience.

Approaching the method

This is a qualitative investigation, conducted in accordance with ethical precepts, on family caregivers for disabled elderly persons assisted at CCI – Aconchego in the city of Botucatu, São Paulo, Brazil. The institution relies on physical facilities provided by the Municipal Administration with afternoon working hours and 35 places for elderly disabled individuals at some level. Nonetheless, it is not capable of assisting all those seeking for its services, thus keeping a certain number of unattended candidates. Its staff consists of a technical team composed of hired professionals: a physical therapist, an occupational therapist and three recreation aides; of volunteers: an undergraduate nursing student, a speech therapist, a social worker, two psychologists; as well as by grant-supported students: one from the field of nursing and one from the field of nutrition. In addition to the volunteers composing the technical team, it is also supported by community members who are responsible for preparing afternoon snacks and
for helping the elderly persons during recreational activities, among others.

In order to conduct this investigation, family members who identified themselves as those assuming the major unpaid responsibility for the elderly home care were regarded as actors.

Interviews were carried out in their own homes by respecting their availability so that they could confidentially answer the following guiding question to the researchers: what has your experience as a family caregiver for a disabled elderly person assisted by D.C.C. been like?

When the recording of each interview was completed, it was transcribed and analyzed according to the basic strategies presented for category formation by the Grounded Theory methodological framework.

Categories, according to the authors, are abstractions of the phenomenon observed in the data, and they form the main analysis unit of the Grounded Theory. The theory is developed through the work conducted with the categories, which leads to the emergence of the core category as a result of the analysis, which is usually a process.

Theoretical saturation was obtained after the analysis of the 10th interview. The family caregivers were usually females due to the difficulty in finding males playing such a role. The level of relationship was distributed between nine daughters and one wife who were 38 to 61 years old and had been experiencing that condition for 01 to 15 years.

A point was made in meeting with the actors participating in this study as well as with other family caregivers for the disabled elderly assisted by D.C.C. in order to present the results of this study during the monthly meeting held by the institution so that they could have an opportunity to evaluate and validate the theoretical model as representative for their experiences. The results were discussed in the light of Symbolic Interactionism according to Charon.

The phenomenon will be described in the form of concepts stemming from the actors’ experiences, according to the components in the process: themes, categories, subcategories and elements.

Feeling supported by the D.C.C., by the family tie and by spirituality
in order to continue playing the challenging role of a family caregiver for a disabled elderly person

The phenomenon shows that the family caregiver for the disabled elderly selects three supporting cornerstones (instrumental, mental and spiritual), which are the D.C.C., the strength from the tie with the elderly person and spirituality as necessary to lead them to the physical and mental balance that is essential to cope with the burden and to continue playing their social role. The D.C.C. is distinguished as a care model that could be implemented and subsidized by the State as a strategy of support for the binomial family caregiver-disabled elderly within the country’s Public Health Policies. The phenomenon joins two themes: feeling forsaken and finding support in the D.C.C., in family ties and in spirituality.

Theme A. Feeling forsaken
The family member experiencing the burden posed by the challenging role of being the caregiver for a disabled elderly feels forsaken as financial and psychological support from the family and the social network or from the State is not provided. Nor does he have the necessary knowledge to play such a role, which also occurs to those with enough financial resources, considering the difficulty in finding a competent secondary caregiver to meet the patient’s needs. Due to the effects of the experience, he perceives the mental suffering which extends to other family members during the process. This theme gathers five categories: feeling unprepared to deal with the disabled elderly, not finding support, interrupting his life plan due to the burden, perceiving his and his family’s sickening as an unpleasant experience.

A1. Feeling unprepared to deal with the disabled elderly
At first, the family experiences a conflicting situation when facing the disease signs and symptoms, especially the elderly behavioral changes and the family members’ impotence to manage the problems due to the lack of knowledge concerning physiopathology and appropriate interventions.

I was not prepared to take care of a sick person. I had never taken any courses on caregiving, so I felt completely lost.
I had heard about that disease on television (Alzheimer's disease), and I thought it was horrible, and now it has happened in my house.

A2. Not finding support
It refers to family caregivers who require support from the State due to financial difficulties and who cannot count on support from the family or from the social network in order to continue playing his role. It also refers to those who do not have financial problems to hire a secondary caregiver, but who face difficulty in finding one according to the competencies that they believe to be essential for such position.

The financial difficulties really disturb us. Every resource necessary to care for the elderly has to be purchased. The family has to provide everything.

I don't get any support from my family. Nowadays, it's very complicated to hire someone to look after an elderly relative so that the family caregiver can take a little more care of his own life.

I feel forsaken by the State.

A3. Interrupting his life plan due to burden
In face of the lack of support and the great demand for his availability to provide the care required by the disabled person, the family caregiver renounces his daily activities and entertainment, thus feeling burdened and many times setting his own life on stand by.

You end up annihilating yourself; you don't do things because you feel afraid that something might happen to your elderly relative.

I feel that I am on stand by, I have given up all the things that I used to do for myself.

I don't have much time to rest.

A4. Perceiving his and his family's sickening
It refers to the experience in which the caregiver's burden when playing his role without support is not restricted to himself, but the mental suffering extends to other family members as if it were a phenomenon characterized by family sickening.

I became depressed; I think the whole family did. I believe the depression started because of my mother's condition.

If the elderly person does not feel well, the family caregiver doesn't feel well either.

A5. As an unpleasant experience
When experiencing the family caregiver role, his life is transformed, and he cannot find satisfaction in everyday living. It is marked by suffering and sorrow, which denounces psychological reactions to those who survive significant losses even though they have overcome the worst phase of caring for a disabled elderly person.

I think it's worse for the caregiver than it is for the patient himself.

In fact, a caregiver's experience is an exhausting task.

Theme B. Finding support in the D.C.C., in family ties and in spirituality
The family member elects three cornerstones necessary for continuing playing his challenging role of a disabled elderly caregiver, which are the D.C.C., the tie with the patient and spirituality. These are elements supporting the instrumental, mental and spiritual conditions that can lead him back to the physical and mental balance which is essential for coping with the burden generated by his role. This topic consists of three categories: feeling supported by the tie with the patient; becoming stronger in spirituality; feeling supported by the D.C.C.

B1. Feeling supported by the family tie with the patient
To continue playing his role, the family member seeks for strength in a set of feelings that bind him to the elderly person and which is based on affection and solidarity for a person who is experiencing a moment of fragility in face of a disease without perspectives of improvement in senescence.

It's a disease that has no cure, at least for now. So, I must endure it.

I do it for love and become rather attached to God. I really love my husband.

B2. Strengthening oneself in spirituality
The disabled elderly family caregiver turns toward God moved by the belief and trust in a transcendental, omnipotent and omniscient being who is capable of emanating the strength necessary for his physical and mental balance while he endures the grief and misfortune from playing his role.

I believe that I can rest when I support myself on God. It's for this reason that I try to have a moment with God.
B3. Feeling supported by the D.C.C.

When experiencing the service given by the D.C.C., the family caregiver positively evaluates the care model developed by the professionals and volunteers in favor of the family caregiver-disabled elderly binomial. The process shows that he gradually develops enough confidence on the institution so as to easily place his dear one under its care and to take advantage of informational and mental support for coping with the situations resulting from the disease, in addition to perceiving the re-socialization of the elderly patient. Thus he undertakes a movement and begins to enjoy his free time, although partially, in order to resume his life plan and consequently recover self-esteem. This category consists of four sub-categories: overcoming the caregiver’s and the elderly person’s resistance; learning to deal with the elderly person’s disability; feeling satisfied with the service; partly resuming his life plan.

Overcoming the caregiver’s and the elderly person’s resistance

The elderly person’s family caregiver, when finding the D.C.C. as a possibility of support for the burden experienced, ends up showing two types of resistance: the feeling of guilt for leaving his relative in the Institution for a few hours and the elderly person’s refusal to re-socialize. This sub-category gathers two elements: feeling guilty at first and coping with the elderly person’s resistance to attending the D.C.C.

At first, I had the impression that my husband was going to an asylum. As time passed, however, I realized that the treatment was different.

At first, you feel a little remorseful for leaving your older relative at CCI. I felt like I was abandoning him.

At first my older relative didn’t want to go, but he got used to the idea later.

Learning to deal with the elderly person’s disability

With the knowledge obtained from the professionals at the D.C.C. and through the experience itself, the family caregiver gradually learns to operationalize strategies to cope with the everyday problems generated by the elderly person’s disease without consuming too much of his own energy. He acknowledges that in order to continue playing his role and take good care of the patient, it is necessary to preserve himself psychologically.

When you don’t know about the disease, you become irritated; she keeps moaning at times, and then you say: Mother, stop! That gets into my head, and then I play some music. I’ve learned that you eventually learn as you go through the experience. She likes music. She pays attention to the music and stops moaning; then I leave and go to another room.

I didn’t know exactly what the disease was; I only knew that it progressed; I didn’t know how to deal with the situation, and it was through D.C.C. that we learned to accept the disease and to live with my mother the way she is.

Feeling satisfied with the service

At D.C.C., the caregiver finds an environment that provides peace, allowing him to express his emotions, clarifying doubts concerning his relative’s disease, and, at the same time, he perceives the elderly improvement. As a result, the family caregiver becomes confident on the service, leaves his dear one at the Institution and takes advantage of this free time to resume his life plan. This sub-category embodies three elements: the D.C.C. helping the elderly person, the D.C.C. helping the family caregiver and the D.C.C. helping the family caregiver-disabled elderly binomial.

I sincerely value it, in all aspects, for the good it has done to my mother, because she has improved 300%, not only 100%.

When she began to attend, she didn’t speak. All she wanted to was sleep because she couldn’t sleep all night, so he slept during the day. … then, when she began to go there, she started to improve. A month and a half later, she started to talk, to participate in things a little. Today, she is talking and greeting people.

I think that my mother’s self-esteem has improved a lot after being with people her age and with the D.C.C. professionals.

I’ve learned a lot from D.C.C. I’ve learned that I must continue leading my life without feeling guilty. In the past, I didn’t feel good when I went out.

D.C.C. has helped me not to feel like an empty ball or a withered leaf and to start dedicating a few hours to myself.

D.C.C. is for both the elderly person and the family. The elderly person’s relationship with people his age takes him away from isolation while the caregiver acquires knowledge to deal with situations experienced with older people and even changes his values.
Partly resuming his life plan

The support provided by the D.C.C. allows the caregiver to partly resume his life plan which was interrupted when his role was taken up. He acquires self-confidence to deal with the older person’s disability, which, associated with free time, gives him the opportunity of self-care and self-esteem recovery.

Today, I try to enjoy each moment in my life, because the beginning of my experience as a family caregiver was very difficult. Over time, I learned to deal with my older relative, that is, I learned to cope with the difficulties.

At the beginning, I used to be a little depressed, then I got used to taking care of the older person more easily.

Discovering the core category

The strategy used to discover the core category was to inter-relate the two themes aiming at comparing and analyzing them in order to understand how the interaction between their components occurred. This strategy allowed for identifying that the categories, subcategories and elements composing the phenomenon undertake a movement in search for support in face of the burden generated by the experience, leading to the identification of the core category as: moving from reduction to partial freedom: the experience of family caregivers for disabled elderly persons assisted by a D.C.C.

The process of discovery of the core category began to corroborate our first perceptions when we took possession of all the diagrams that showed us the two themes and all their components.

At that moment, it was possible to visualize, in the chain of categories composing the first theme feeling forsaken, a movement of meanings which conducted us to the second theme finding support in the D.C.C., family ties and spirituality; nevertheless, the day care center constituting an essential variable for the caregiver to undertake the movement towards the partial resumption of his life plan.

Based on the interrelation of the two topics composing the phenomenon, it was possible to abstract the theoretical model denounced: moving from reduction to partial freedom: the experience of family caregivers for disabled elderly persons assisted by a D.C.C.

Feeling forsaken is the first challenging process experienced by the family caregiver upon the realization that he is unprepared to deal with the disabled older person since he is not instrumentalized with knowledge concerning disease physiopathology or the necessary interventions to cope with problems. Added to such condition is the lack of support from the family or factors preventing the help of a secondary caregiver as well as the inexistence of a specific service in the Brazilian Unified Health System to promote care to the family caregiver-disabled elderly binomial. In such circumstances, he eventually interrupts his life plan in face of the burden generated by his role and perceives his own sickening as well as that of his family.

It is an unpleasant experience that leads him to undertake movements in search for energy to continue providing his relative with care. The cornerstones that help him achieve physical and mental balance and seek help are: the strength of the tie established with the elderly person and spirituality.

In this search process, he eventually finds, in the D.C.C., the third cornerstone that will support him with the partial resumption of his life plan. He feels satisfied with the service since it provides him with a peaceful environment which allows him to express his emotions, clarifying his doubts and leading him to learn how to deal with the disability caused by his relative’s disease, and, at the same time, perceives the elderly person’s improvement. As a result, he becomes confident on the service, leaves his dear person in the Institution and uses his time for self-care.

By going through the experience, the caregiver eventually feels supported by the service provided by the D.C.C. and evaluates it as care model for the family caretaker-disabled elderly binomial which promotes informational and mental support in addition to the re-socialization of the elderly person and his caregiver.

Hence, we presented the theoretical model to the actors participating in this study, who evaluated and validated it as representative for their experiences since it was capable of portraying their experiences with the support provided by D.C.C.

Discussing the results

The study made it possible to understand the experience of family caregivers for disabled elderly patients assisted by a D.C.C. as well as to develop and validate a representative theoretical model for it.

The decision to conduct this study, based on a theoretical and methodological perspective supported by the Grounded Theory and Symbolic Interactionism, allowed for advancing our knowledge concerning the studied object by understanding that, among the three supporting corner-
stones for coping with the burden generated by the role of family caregivers for disabled elderly persons, the care model promoted by the D.C.C. was configured as an intervenient variable to change the course of such experience, which is surrounded by feelings of abandonment and circumscribed to the elderly home care, for the partial resumption of the caregiver’s life plan.

This process only takes place during experiences in which the family caregiver can feel supported in the process of caring; when he becomes secure about leaving the patient to resume outside activities, which will awaken the feeling of freedom from an exhausting role.

Partial isolation is one of the aspects that generate burden, particularly due to changes in lifestyle which reduce, modify and cause dissatisfaction in the family caregiver’s social life as a result of the limiting conditions posed by the disease, bringing feelings of isolation to relationships circumscribed to household activities.

The functional and cognitive deficit, personality or behavioral change as well as communication change are alterations that eventually compromise the patient and the family.

The burden is frequently associated with the level of physical disability and the compromising of ambulation is a significant factor interfering with the caregiver’s quality of life; however behavioral change is what causes the most exhaustion.

By evaluating family caregivers for CVA patients, it was observed that 55% of them showed evidence of psychological burden, particularly those who were nursing patients with dementia and behavioral disorders.

Aspects related to mental health in chronic disease are more stressful to caregivers than physical aspects. Among the problems found are behavioral disorders (apathy, agitation, perambulation) and mood disorders (depression, anxiety).

Additionally to the aspects above, there are financial difficulties to hire a secondary caregiver and to cover the extra expenses resulting from giving home care to a disabled person as well as a lack of knowledge concerning the most appropriate ways to assist the patient, which eventually generates dissatisfaction, incapacity and insecurity in taking up the caregiving role.

Exposed to physical and mental burdens, family caregivers are affected by tiredness, sleep disorders, cephalalgia, weight loss or gain and high blood pressure, which contributes to high depression levels among such individuals and is regarded as unfavorable to the caregiving process.

However, this study shows that the access of the family caregiver-elderly disabled binomial to the service provided by the D.C.C. foresees the possibility of partial resumption of the life plan which had been abandoned by the caregiver in solidarity for a relative that is experiencing hard times in his senectitude.

The experience with support revealed that the caregiver became confident and unworried about leaving the elderly person under the care of the Institution’s professionals and volunteers when he realized that it provided informational and psychological support for coping with the situations resulting from the disease, in addition to promoting re-socialization for both. Becoming self-confident about dealing with the elderly person’s disability and now counting on his partial free time while the patient is being nursed by the D.C.C., the caregiver redirects his attention to self-care, which allows for the recovery of his self-esteem and the possibility of having better quality of life to continue playing his social role.

According to Symbolic Interactionism, actions are caused by an active decision-making process by the action subject. This process involves the definition of a situation, which, in its turn, involves interaction with oneself and with others. Hence, the definition of a certain situation made by an actor is the key factor to how action will occur. The human being is free in what he does. All of us define the world on which we act and part of such definition is ours; it involves a conscious choice, the direction of our actions in face of this definition, the identification of such actions and of the actions by others, and our own redirection.

In view of the movement undertaken by the experience, we suggested that the care model operationalized by the D.C.C. as a possibility of support to the family caregiver-disabled elderly binomial to be implemented by Brazilian Public Health Programs.

These are the reasons showing that the service types most appreciated by caregivers were those of home care and help with housework. However, those provided by the day hospital and the care in the form of free time enabled them to rest and were, therefore, the most valued.

It is noticed that these types of support are important for the performance of the caregiver’s role as shown by studies comparing individuals participating in this type of care with non-participants. The results show caregivers with lower depression levels and greater ability to play their roles and, hence, with better quality of life.

In spite of the changes occurring in the Brazilian scenario in relation to social protection
policies for the elderly, such policies are still very restricted as regards the provision of public health services and programs, which is exemplified by the amplitude of their intervention. The State presents itself as a punctual partner with reduced responsibility that attributes to the family the major role in home care for the disabled elderly. It is found that more powerful policies lack as regards the roles attributed to families and to support under the responsibility of a service network provided to disabled elderly individuals and their families. It is pointed out that new forms of care and new approaches to disabled ageing and the caregiver must exist in public health policies1.

Hence, this study contributes by proposing a care model for the family caregiver-disabled elderly binomial which has been recommended and validated by the social actors experiencing the possibility of counting on the support provided by a D.C.C.

Making final considerations

This study, under the theoretical and methodological perspective supported by the Grounded Theory and Symbolic Interactionism, allowed for understanding the experience of family caregivers for disabled elderly persons assisted by a D.C.C. and led to the development and validation, by the subjects themselves, of a theoretical model that is representative of their experiences and has been denominated: moving from reclusion to partial freedom: the experience of family caregivers for disabled elderly persons assisted by a D.C.C.

The conduction of this study made it possible to understand that, among the three supporting cornerstones (spirituality, strength of the tie with the elderly person and the D.C.C.) for coping with the burden generated by the role of a family caregiver for a disabled person, the care model promoted by the D.C.C. was configured as an intervenent element for changing the course of the caregiver’s experience, which is surrounded by feelings of abandonment.

The experience with support revealed that the caregiver became confident and unworried about leaving the elderly person under the care of the Institution’s professionals and volunteers when he realized that it provided informational and mental support for coping with the situations resulting from the disease, in addition to promoting re-socialization for both. Becoming self-confident about dealing with the elderly person’s disability and now counting on his partial free time while the patient is being nursed by the D.C.C., the caregiver redirects his attention to self-care, which allows for the recovery of his self-esteem and the possibility of having better quality of life to continue playing his social role.

Based on this knowledge, we suggest that the State implement the care model discussed in this study as one of the strategies for support to the family caregiver-disabled elderly binomial.

Collaborations

SCM Bocchi conceived the research project, analyzed and argued the data, as well as elaborated the report of the research. KCU Cano and L Baltieri collected and assisted in the collect and data analysis. DC Godoy, WC Spiri and CMCM Juliani assisted in the data discussion and elaboration of the paper.

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