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CAREGIVERS AND IMPLICATIONS FOR HOME CARE

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ABSTRACT: This was a descriptive and exploratory study, qualitative in design. Its aims were to understand how caregivers experience the home care situation and the contribution of home care teams to continuity of care. The data were collected using a semi-structured interview with 10 caregivers in their homes. Their statements were subjected to thematic content analysis, which resulted in three thematic groups: caregiving decisions; care routine; and the social dimension of care in the context of the Home Care Program. The results indicated low income and education levels among caregivers, severe dependence of care receivers, and difficulties of home care teams to provide material resources. Moderate overload and moderate to severe overload were observed among 60% and 40% of caregivers, respectively, in addition to social life restrictions. Home care presented weak points and compromised domains due to conditions of a socioeconomic nature.

DESCRIPTORS: Caregivers. Home nursing. Homebound persons.

SER CUIDADOR E AS IMPLICAÇÕES DO CUIDADO NA ATENÇÃO DOMICILIAR

RESUMO: Estudo exploratório descritivo de abordagem qualitativa, com o objetivo de apreender na vivência dos cuidadores, a prática do cuidado domiciliar e a contribuição das equipes de assistência domiciliar para a continuidade do cuidado. Os dados foram coletados por meio de entrevista semiestruturada, aplicada a dez cuidadores, em seus domicílios. Os depoimentos foram submetidos à análise de conteúdo na modalidade de análise temática, emergindo três temáticas: decisão para o cuidado, cotidiano dos cuidados e a dimensão social do cuidado no contexto da atenção domiciliar. Identificou-se baixa renda e escolaridade entre os cuidadores, dependência severa dos sujeitos cuidados e dificuldades das equipes de atenção domiciliar para suprimento de recursos materiais. Houve sobrecarga moderada e de moderada a severa em 60% e 40% dos cuidadores, respectivamente e privação das atividades sociais. O cuidado domiciliar apresentou fragilidades e domínios comprometidos pelas condições socioeconômicas.

DESCRIPTORES: Cuidadores. Assistência domiciliar. Pacientes domiciliares.

SER CUIDADOR Y LAS IMPLICACIONES DEL CUIDADO EN LA ATENCIÓN DOMICILIARIA

RESUMEN: Investigación exploratoria descriptiva de abordaje cualitativo, con el objetivo de aprehender la experiencia de los cuidadores, la práctica de los equipos de atención domiciliar y la contribución de asistencia domiciliar a la continuidad de la atención. Los datos fueron colectados por medio de entrevista semiestructurada, aplicada a diez cuidadores. Los testimonios fueron sometidos a un análisis de contenido en la modalidad de análisis temática, acerca de la cual se emergió tres temáticas: decisión para el cuidado, cotidiano de los cuidados y la dimensión social del cuidado en el contexto de la atención domiciliar. Entre los cuidadores se identificó baja renta y escolaridad, dependencia severa de los sujetos cuidados y dificultades de los equipos de Atención Domiciliar para suministrar los recursos materiales. Hubo sobrecarga moderada y de moderada a severa en 60% y 40% de los cuidadores, respectivamente, y privación de actividades sociales. Por las condiciones socioeconómicas el cuidado presentó fragilidades y falta de dominios.

DESCRIPTORES: Cuidadores. Atención domiciliar de salud. Personas imposibilitadas.

INTRODUCTION

Home care (HC) is a recent modality of health care provided by the Brazilian public health system and it is permeated by the interaction between caregivers, care receivers, and the health teams who provide such services. It has become an important health service in Brazil over the last few decades, stimulated by changes in the country's demographic profile, population aging, an increase in chronic-degenerative diseases, and hospital overcrowding.¹

Ordinance N. 963/13 of the Brazilian Ministry of Health establishes the need for HC to be marked by the active participation of health professionals, users, families, and caregivers.² However, studies on HC reveal contradictions between what these directives recommend and what actually happens. Thus, more studies are needed to promote reflections on and responses to this scenario and to provide a perspective on the meaning of care in the lives of all involved.³⁻⁵

Studies on the experiences and demands of caregivers provide contributions in the sense of allowing health care teams to assist them in their individual needs, as well as to consider them as a specific group, namely subjects and participants in health care actions.⁶⁻⁷ In light of the above, the present study aimed to understand how caregivers experience the practice of HC and the contribution of HC teams to continuity of care.

METHODS

This was an exploratory and descriptive study using a qualitative design. It was conducted with the main caregivers of patients enrolled in an educational program for home care in a university teaching hospital in the state of Paraná, in Southern Brazil.

The caregivers were registered in the home care educational program between March 2012 and March 2013 and were included in the Home Care Program during the period of the hospital stay. In order to be included in the study, the caregivers had to be at least 18 years old and had to be caring for individuals with a level G of dependence (complete dependence) as assessed by the Katz index. This index is a validated instrument that rates different levels of independence/dependence presented by individuals (bathing,

dressing, toileting, transferring, continence, and feeding).⁸ We excluded hired caregivers who were not related to care receivers, who resided in other municipalities, or who had not been referred to the Home Care Program.

According to these criteria, 10 caregivers took part in the study. The data were collected in respondents' homes using a semi-structured interview, which was recorded and later transcribed. The data collection instrument included personal and socioeconomic information and open-ended questions about the experience of being a caregiver in the context of HC. The data were submitted to thematic content analysis. This method consists of three phases: pre-analysis and exhaustive reading of the text; exploring the material and constructing thematic categories; and processing and interpreting the results. In this manner, after reading and reflecting on the statements in the transcripts, we aimed to answer the questions raised by the objectives of this study. Subsequently, data were categorized, which consisted of reducing the text down to meaningful words and expressions. This process seeks to reach the nuclei of text comprehension, or the meaningful categories or words around which the content of a discourse is organized. We then drew inferences and wove interpretations based on the meaning of the messages provided by the subjects and by correlating them with the researched theoretical framework.⁹ This analysis resulted in three thematic units: caregiving decisions; care routine; and the social dimension of care in the HC context. The following table summarizes the process of constructing thematic units:

To assess the risk of caregiver overload, we applied the Zarit Burden Interview, a reliable scale that measures objective and subjective burden by gathering data on the health, social and personal life, financial and emotional situation of the caregiver, and type of relationship.

This instrument provides a global score that ranges from zero to 88. A score equal to or less than 21 corresponds to little or no burden; 21 to 40, mild to moderate burden; 41 to 60, moderate to severe burden; and equal or greater than 61, severe burden.¹⁰ In this study, we used the validated and translated version of this scale for the Brazilian population.

Table 1 - Construction of thematic units

Aspects presented in statements	Significant nuclei/convergence	Thematic units
Reasons for providing care, caregiver's choice, family involvement.	<i>First of all, because I'm his wife. Second, because, unfortunately, his family has always been very distant (INT.2). Because there are no other family members; they are all in the state of Mato Grosso (INT.3).</i>	Caregiving decisions
Activities and techniques conducted at home, routines, complications.	<i>Diet, general hygiene, the jejunal stoma dressing, changing position every two or three hours, shaving. I don't have to aspirate anymore, but I used to, and I used to care for the oxygen (INT.2). [...] I bathed him in his room. Then I washed the wounds with saline, dried them up, put on his clothes and diaper (INT.4).</i>	Care routine
Social demands, resources available, implications of care, support provided by the health teams.	<i>Our church gives us diapers (INT.6). The hard part was just buying his food so I could make soup. I had this neighbor and she would buy it for me, because I had no money, and she brought food so I could make it for him (INT.4). [...] in the beginning I had to wait for my husband to come have lunch, but then his diaper would go without changing from morning to noon (INT.1).</i>	Social dimension of care in the context of HC

This study abided by national and international ethical norms regarding research with human subjects. Furthermore, it was approved under Resolution N. 018/2013 by the research ethics committee of a public university in the state of Paraná, Brazil, in accordance with Resolution 466/2012 of the Brazilian National Health Council (CNS), in force at the time of data collection.¹¹ The participations were coded by the abbreviation INT, followed by a number that corresponded to the order of interview.

RESULTS AND DISCUSSION

Mean caregiver age was 50.6 years; however, most were between the ages of 70 and 75. Family income of participants was up to one and a half times the monthly minimum wage*, and most income came from government benefits or care receivers' retirement pensions. Two caregivers continued at their jobs by working from home; four quit their jobs to become caregivers; and four were retired or in the process of retiring. In terms of level of education, most had up to seven years of formal education, although one caregiver reported not having any formal education. Most caregivers relied on public transportation. All participants were homeowners and resided in an urban region with good sanitary conditions. For five caregivers, the number of persons per household was three or less, and for the other caregivers, greater than three.

Regarding the caregivers' health conditions, the results showed a prevalence of cardiopathies and systemic arterial hypertension. Less frequently, caregivers reported respiratory diseases, diabetes mellitus, and gastritis. However, three caregivers reported health problems that had developed after taking on this role, such as lower back and neck pain.

The sample consisted of highly dependent care receivers, of whom eight were men and two were women, with a mean age of 55.7 years. There was a prevalence of debilitating neurological conditions, namely cranioencephalic trauma and cerebrovascular accidents. In addition to being dependent on caregivers for comfort, safety, and hygiene activities, all subjects received an enteral diet via a nasogastric tube, gastrostomy, or jejunostomy at the moment of hospital discharge; eight were tracheostomized and dependent on intermittent aspiration, and eight depended on oxygen therapy.

The main determinants of home care were advanced patient age, low income and education levels, and the complexity of the care receivers' condition at the moment of hospital discharge. Beyond assessing the technical capacity and the availability to receive scheduled home visits, health teams had to consider whether caregivers are in a condition to act as care providers at home and if they prioritize patient and family autonomy as a care strategy.¹²

* The monthly minimum wage in Brazil at the time of data collection was 790.00 Brazilian reais, approximately 250.00 U.S. dollars.

As mentioned, most caregivers were between the ages of 70 and 75 and this, coupled with the complexity of care procedures and the high level of dependence of the care receivers, results in clear exposure to a state of vulnerability. Furthermore, we emphasize the existence of previous diseases and the development of organic or functional problems while in the role of caregiver. This context warrants reflection, as it can lead to negative results for both caregivers and care receivers. Little is known about which interventions are more effective for supporting caregivers in the home, and more studies are needed to test the most promising interventions.¹³

In consonance with other studies, family income of caregivers stood out as a variable that negatively influenced the quality of home care, among other factors.¹⁴⁻¹⁵ The health condition of care receivers at the moment of hospital discharge and their special care needs (such as specific nutritional demands [enteral diet], various care devices [diapers, air mattresses, hospital beds], electric equipment [tracheal aspirator], transportation, and the need to make physical adaptations to the home environment), when not provided by public health services, compromised the family budget and the quality of life of care receivers. Another aggravating factor was the need for caregivers to abandon their jobs so that they could take on home care activities, thus becoming dependent on the benefits or retirement pension of care receivers and hostages to their own decisions.

Objectively, it can be said that, before reducing costs, dehospitalization requires that new care instruments take on the functions that were once the hospital's responsibility, such as feeding logistics, increased electricity consumption, medication, materials, and the provision of professional care. Therefore, the HC policy, which among other goals aims to unburden the health care system, must not ignore or disregard the comprehensive needs of care receivers and caregivers in all dimensions of home care.

The low levels of education presented by the caregivers together with patient complexity points to the crucial need for educational practices, both at the hospital and at the home level. Activities such as bed baths, tracheal aspiration, oxygen therapy, enteral tube feeding, and jejunostomy or tracheostomy, not only require manual and technical dexterity, but also specific knowledge on behalf of caregivers. In this sense, health education initiatives and the inclusion of caregivers in the

professional care plan must transcend technical information, as meeting educational demands is not enough to guarantee full and ideal care conditions.

Considering the objective of this study, which was to describe how caregivers experience their care practice within the context of HC, aspects related to their experience as a caregiver resulted in three categories: caregiving decisions; care routine; and the social dimension of care in the context of HC, as presented and discussed below:

Caregiving decisions

For most of the interviewees, the impossibility of sharing care activities with other relatives was the determining factor in choice of caregiver: *I was forced to care for him, because what was I to do? I couldn't leave him filthy, I couldn't not change him. This is very tiresome, I'm very tired* (INT.6).

Only one of the interviewees stated that the decision to become the caregiver was made to comply with the wishes of the care receiver: [...] *actually, when my father passed away a couple of years ago, my mother chose to come live with me, and she lived a while at her house, but then she started to get sick and chose to live with me, it was her choice* (INT.7).

A small number of caregivers reported having considered aspects that would ensure better living conditions for the care receiver: *how are they going to care for the boy? I told them, "You are in no conditions!" Since my house is so big, I never stop, I get up at six in the morning; I have to aspirate him, then I make his food, give him a bath, wash all the bed linens!* (INT.3).

The two requirements for conducting HC are the presence of a caregiver and the family's consent. The caregiver's participation as a subject in the process of care, as well as that of the family and of the professionals involved in the process is fundamentally important. Home care cannot be imposed. It is recommended that the entire family be aware of the care process, and that they make the commitment together with the health team to conduct the necessary activities. It is also recommended that the main caregiver or care receiver (if conscious) sign an informed consent form.¹⁶

Even when caregivers committed themselves "voluntarily" to the home care teams and took on the responsibility for the care receiver, the extracts above show that the decision to become a caregiver was, for most interviewees, conflicting at the least. Evidently, the ethical dilemma present and made evident in statements such as, *I was forced to care for*

him (INT.6) do not refer to an imposition made by the HC or hospital teams. However, the absence of other family members to share the responsibilities of home care made these caregivers hostage to their own decisions. Thus, they ended up taking on routines and procedures to which they would not have submitted themselves if they truly had had other options.

In home care, the family takes on the responsibility for complex procedures and care that were previously conducted by health professionals and that they have never performed before. In this sense, it is extremely important that health professionals conduct a previous family assessment, respecting the family's conditions and limitations. If caregivers are not capable of adapting to and living with the reality of the HC situation, it can be a detriment to them, the family, and the care receivers.¹⁶

Although the Brazilian Ministry of Health recommends that the family be aware of the care process, this experience is unique to each of the subjects involved. Caregivers are tested daily on their capacity to discern, adapt, and cope with situations inherent to care. Even the most resilient are subject to some physical and emotional overload, with the possibility of becoming ill.

Caring for a dependent adult requires good physical condition, as it involves complex and heavy tasks. It also demands the ability to quickly recover from exhausting activities or a poor night's sleep.¹⁷ In this sense, advanced caregiver age, and the absence of other physically capable family members or those who have a better ability to perform care activities, can lead to greater caregiver overload and possible limitations to the care provided.

Even though the HC policy aims to provide benefits to the users of the public health care system that serve the current demographic and epidemiological context, it must respect autonomy regarding the decision for home care, both on behalf of the care receiver and of the family caregiver. This choice must not be imposed, even if unconsciously, by the hospital.¹⁷

Care routine

Some of the activities reported by caregivers to meet the needs of care receivers were: assisted oral feeding; enteral feeding (via a tube of jejunostomy); bathing; hygiene and comfort activities;

oxygen therapy; medication; dressing; and tracheal aspiration. *Diet, general hygiene, jejunal stoma dressings, changing positions every two or three hours, shaving. I don't have to aspirate anymore, but I used to, and I took care of the oxygen* (INT.2).

The statements revealed a harsh routine for caregivers, and although some interviewees reported having help from other family members at least once a day, they also reported having annulled, or seriously compromised, their social life: *social life is abolished, we have no social life; everything revolves around him. Any time I go out, it is on a clock, either to schedule an appointment or to expedite something, but everything relates to him. I even had to stop my daughters' treatment, because I live for him almost 24 hours a day* (INT.5).

One caregiver reported a pause or break in care activities at least once a week to care for personal needs: *so we made a deal with my other brothers that on Sunday they would either take care of her or pay someone to care for her so I can rest* (INT.7).

The impossibility of working, or having to abandon paid work activities, was among the changes caused by the process of becoming a caregiver: *oh, everything changed; there's no comparison. I used to work before, I was independent from my husband, I didn't depend on him for anything, and today even the grocery store has to be him. I don't do anything anymore; I am dedicated to him, my girl, the house and my son, nothing else* (INT.1).

Nevertheless, regarding the experience of being a caregiver, all mentioned positive aspects of their relationship with the care receiver and with the activities performed: [...] *so, I think that the human part of my life has changed a lot. This was something I never thought I could do: caring for someone, because I was very afraid, because it changes your life so much. So, it was good for me, it was very important* (INT.7).

Participants also reported feelings of sorrow and sadness in view of the chronicity of the care receiver: *I think that the only unavoidable thing is a certain level of stress. It's unavoidable, both because of the frustration of wanting to be more useful and not being able to, and because you want to see them evolve faster. If we do not center ourselves we can even become depressed maybe* (INT.5).

The statements also revealed critical moments for the caregiver after their first experiences in this role: *in the beginning it was very hard for me, because we went to the hospital a lot, the PAC [continued emergency care]. [...] I was scared; I almost killed him in the*

beginning, because at first, everything is more difficult, and he wasn't doing as well as he is now (INT.1).

Care overload also emerged as a theme within the care routine. The results of the Zarit Burden Interview revealed moderate burden and moderate to severe burden in 60% and 40% of the caregivers, respectively. This is a relevant finding, as the instrument presents good psychometric properties for assessing burden related to caregiving and has been used to diagnose and monitor/evaluate intervention programs directed at caregivers in different countries.¹⁸ The caregivers with the highest scores on the Zarit scale reported not receiving help from others with care activities and developing health problems during this period: I have a lot of back pain, I suffer a lot; I only take care of him because nobody else will. Some days I cry and I say 'Lord, have mercy on me!' I've been sick recently; I felt very dizzy and ended up at the PAC, and they told me my blood pressure was very high. I was coughing a lot and my blood pressure was 20-something, and then I would look at him *and I did not feel like changing him, but I had to change him (INT.6).*

In consonance with other studies, caregiver overload - far from being considered an isolated finding - has become trivial. A study conducted by the University of Porto in Portugal investigated physical, emotional, and social overload and the psychopathological profile of 52 informal caregivers of Alzheimer patients. The caregivers in the study provided care for an average of 11 hours and 23 minutes per day and, in most cases, it was their first experience with caregiving. The help they received came essentially from the informal system, and 48.1% of caregivers were taking psychoactive drugs.¹⁹ Another study conducted in Lisbon, Portugal, with a sample of 17 formal caregivers and 11 informal caregivers indicated the presence of expressions of emotional distress among caregivers. In the case of the informal caregivers, there was a predominance of subjective meanings related to the search for social support.²⁰

The issues mentioned above refer to the importance of implementing support programs for main caregivers and even for the family of care receivers. These programs can be implemented in the form of individual or group sessions, as such caregivers are also users of the health care system. Strategies for supporting caregivers, known as respite care, are a reality in various countries, among them Portugal. The objective of respite care is to provide caregivers with periodic relief of the

responsibility and demands inherent to care. However, generally speaking, there are not enough of these centers in Portugal directed toward these patients, and coverage for such services does not include them.¹⁹

In Brazil, although there are positive aspects related to home care provided by health professionals, such as the bonds formed between care receiver, caregivers, and health professionals, there is a prevalence of strategic and nuclear actions when defining therapeutic plans, when prescribing the care to be implemented, and when ranking and classifying complexity of care.²¹ In addition to effective policies that support caregivers, they must be allowed breaks, or periods in which they can distance themselves from the patient both physically and mentally. If this requirement is not met, there is no way of ensuring that the health of caregivers will not be compromised.¹⁷

The social dimension of care in the context of HC

Although some caregivers received help from other family members in their caregiving activities, participants reported difficulties in mobilizing the help of family or friends in the case of more extenuating activities: [...] *and turning him over, because he's heavy too, put his diaper on, everything, because I needed someone to help me, but there's no one! (INT.6).*

In some cases, caregivers reported depending on the solidarity of others:

there is this man from church who comes over to help me give him a bath. He places him on the chair so I can give him a bath, and when he doesn't come over I give him a bed bath, because the children don't help. It's very difficult (INT.6).

Such difficulty in getting help for some tasks lead to situations of risk for the care receiver's health: [...] *in the beginning I had to wait for my husband to come have lunch, but then his diaper would go without changing from morning to noon (INT.1).*

Financial difficulties were another relevant aspect of the quality of life of caregivers and care receivers. Considering that the family income of most participants was up to one and a half times the monthly minimum wage, they reported direct implications for care, among them difficulties in maintaining enteral feeding: *the hard part was just buying his food so I could make soup. I had this neighbor and she would buy it for me, because I had no money, and she brought food so I could make it for him (INT.4).*

Caregivers frequently reported the absence or rationing of resources from the Home Care Program. They mentioned having to take on some of the expenses with oxygen therapy: [...] *she uses oxygen, not much, but she does. We paid 40 reais, it seems, just the first time, because of the equipment, but then we don't have to pay anymore. It's like a rental fee or something like that* (INT.7).

The most frequent difficulty reported by participants was the provision of diapers: [...] *to tell you the truth, we have to use some sort of home-made diaper, we have to invent something, because the diapers from the program are not enough. They've even sent us more than one pack a month, but even so, it was not enough, because we have to change him more than once a day. Some days we change four diapers, so it's never enough. They tell us to use one a day, but that's impossible! There's no way. In his case, there is no way* (INT.10).

Of all the patients registered in the rehabilitation service, none gave continuity to the treatment due to lack of adequate public transportation (ambulances) to take them to this service. Even though some caregivers owned a car, patient complexity required stretcher transportation: *He was taken good care of by the university, but the municipal government did not want to take him. And there was no way to fold him up and put him in a car* (INT.6). In this regard, caregivers reported that the Home Care Program had provided transportation for patients to be initially assessed and registered to receive support materials (bath chairs and wheelchairs), after which the service was suspended.

Costs of home care interventions correspond to a third of those conducted in the hospital setting. Thus, it is advantageous not only to hospitals, but also to the health system as a whole, to rely on home care. Given the primordial role of the family in making home care viable, governments must take measures and responsibility for these subjects.^{12,22} Dehospitalization policies must ensure qualified and sufficient and physical and human (interdisciplinary teams) resources to meet all the demands of home care equally.

Such lack of planning concerning proper transportation (ambulances) and of articulation between hospital services, basic care, and HC made it impossible to provide continuity of services that are alternative and complementary to the care provided by HC professionals, thus determining, for example, the suspension of activities offered by the rehabilitation center. This scenario reveals the absence of an effective health care network for

individuals with special needs (chronic conditions) and the frailty of the principles that are supposed to underpin primary health care - longitudinality, comprehensiveness, and coordination in the context of primary health care.

FINAL CONSIDERATIONS

Even though participants reported some positive aspects of the caregiving experience, the prevalence of moderate burden and moderate to severe burden associated with advanced age and the development of musculoskeletal disorders represented important indicators for planning health actions aimed at caregivers. The responses given reveal significant weak points in terms of the supply of materials for home use. Among such difficulties, the inadequate provision of diapers and adequate public transportation (ambulances) were the most frequently mentioned and the greatest cause of grief.

We do not declare that the caregivers in this study had complete autonomy regarding the care activities conducted with the patients or the care strategy in use. Given their socioeconomic condition and the absence of more effective public policies for caregivers, the purpose of HC autonomy is violated when, for example, there are no available means of transportation for care receivers, rendering caregivers helpless before the limitations in terms of the possibilities of choice for treatment continuity.

Due to patient complexity and the need for comprehensive care 24 hours a day, care activities were frequently carried out by the same person, who was responsible for all conduct relative to the care receiver. The scores on the burden scale lead us to infer that the support provided by the health teams was limited in the face of the socioeconomic context and physical and emotional exhaustion of caregivers.

The difficulties reported in conducting hygiene activities, transferring care receivers, changing positions, and others that require strength and the help of another family member proved to be the most extenuating, despite their essential importance to the care receivers' health. The interviews demonstrated that the patients suffer the consequences of the caregivers' limitations and, in some cases, they must wait a long time before receiving help from another family member. This scenario reveals the vulnerability of HC and of primary health care, which is still influenced by a

fragmented model of health care, strongly oriented toward acute conditions, and which disregards the fundamental importance of primary health care in the health care network. Such issues must be duly analyzed and reflected upon if caregivers and care receivers are to benefit from the proposal of dehospitalization and humanization through home care.

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