



FAMILY CAREGIVERS COPING WITH TERMINALITY DURING HOME CARE*

O ENFRENTAMENTO DA TERMINALIDADE PELOS CUIDADORES FAMILIARES DURANTE A INTERNAÇÃO DOMICILIAR

EL ENFRENTAMIENTO DE LA TERMINALIDAD POR CUIDADORES FAMILIARES DURANTE INTERNACIÓN DOMICILIARIA

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This study aimed to know how family caregivers cope with the finitude of their close relative in home care. This is a qualitative study, involving 11 caregivers of terminally ill patients, registered in a home care service of a university hospital in the South of Brazil, conducted in the period from January to June 2010. Data collection occurred through narrative interviews which were recorded and transcribed to be analyzed through content analysis. Two categories emerged from data analysis: "feelings involved in terminally ill patients home care" and "repercussions of human finitude in the caregiver's life", which made clear the complexity of home care of patients without possibilities of cure and the sufferings incurred by this situation to the family caregivers that are responsible for a caring of this nature.

Keywords: Home Care Services; Caregivers; Terminally Ill; Nursing.

Este estudo buscou conhecer como os cuidadores familiares enfrentam a finitude de seu ente querido em regime de internação domiciliar. Trata-se de um estudo qualitativo, envolvendo 11 cuidadores familiares de doentes terminais, cadastrados em um serviço de internação domiciliar de um hospital universitário do Sul do Brasil, realizado no período de janeiro a junho de 2010. A coleta de dados ocorreu por meio de entrevistas narrativas, as quais foram gravadas e transcritas para serem tratadas por meio de análise de conteúdo. A partir da análise dos dados, foram construídas duas categorias: "Sentimentos envolvidos no cuidado ao paciente terminal" e "Os reflexos da finitude humana na vida do cuidador familiar", as quais evidenciaram a complexidade da internação domiciliar do paciente sem possibilidades de cura e os sofrimentos gerados por essa situação para os cuidadores familiares que se responsabilizam por um cuidado dessa natureza.

Descritores: Serviços de Assistência Domiciliar; Cuidadores; Doente Terminal; Enfermagem.

El objetivo fue conocer como los cuidadores familiares enfrentan la finitud de su familiar en régimen de internación domiciliar. Estudio cualitativo, con 11 cuidadores familiares de enfermos terminales, registrados en un servicio de internación domiciliar de un hospital universitario del Sur del Brasil, realizado de enero a junio de 2010. La recolección de datos ocurrió a través de entrevistas narrativas, las cuales fueron grabadas y transcritas para ser tratadas por medio de análisis de contenido. Partiendo del análisis de los datos, fueron construidas dos categorías: "sentimientos involucrados en el cuidado al paciente terminal" y, "los reflejos de la finitud humana en la vida del cuidador familiar", las cuales evidenciaron la complejidad de la internación domiciliar del paciente sin posibilidades de cura y los sufrimientos generados por esa situación para los cuidadores familiares que se responsabilizan por la atención de esta naturaleza.

Descritores: Servicios de Atención de Salud a Domicilio; Cuidadores; Enfermo Terminal; Enfermería.

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INTRODUCTION

The care of a person in terminal process, generated by an incurable disease, is the theme addressed by this study. It is the moment experienced by a seriously ill person in irreversible condition, regardless of receiving medical treatment or not. The patient becomes unrecoverable⁽¹⁾ and this situation can also create a great emotional impact in their families and in the healthcare team responsible for their care.

Those patients undergoing a terminal process can be in two situations: in the hospital or at home. The first was consolidated as a result of technological advances, specifically in healthcare, transforming many phenomena pertaining to the course of human life into technical events, such as the birth and problems related to the development and death. These phenomena, which used to occur naturally at home, started to occur in the hospital, from the twentieth century on, even the moment of death, is many times determined by the health team⁽²⁾.

Accompanying the end of someone's life, when death remains somewhat muted⁽³⁾, may not be easy. The predominant practice in the twentieth century and still in the twenty-first century is to keep the patient in ignorance of his death. The health professionals face it daily and, to spare their suffering, keep the patient in ignorance, avoiding emotional stress. This allows them, in some way, to continue with the task of caring in the process of death and dying. Thus, the patient pretends he does not know he will die, the family does not talk about this possibility in order to keep him away from the worry and health professionals protect themselves from the chain of emotional reactions⁽²⁾.

However, more recently, some movements emerged in order to make death happen again at home, due to the warmth of the family environment and the

freedom to the care in this process⁽⁴⁾. For this, one created home care, which can be linked to a Hospital or a *Hospice* - a space with material and human resources, that provides palliative care. Thus, a multidisciplinary team delegates, monitors and oversees the care provided by family caregivers to terminally ill patients⁽⁵⁾. Thus, taking care of a patient at his house has to consider the patient himself, his caregiver, as well as the social support network and the home context⁽⁶⁾.

This movement of return of the terminal patient to be taken care of at home, for being recent, still has issues to be investigated: How does the family member face such care, that is, the monitoring of the finitude of another human being, who, for being a loved one, makes the situation even more delicate? How does the caregiver elaborate on the changes with his sick family member, before active and productive, and who now has a situation of disability?

Faced with these issues related to the imminent possibility of a person's death, one cannot deny that the human being begins to show some embarrassment due to the impositions of the incurable disease. Embarrassment for not knowing what to say when, in fact, there is nothing to be said⁽³⁾. Moreover, such a constraint may become more intense in the household, since the relationship among the caregiver, family and patient is closer than in the hospital. Therefore, one must consider the family members' conflict and suffering when accompanying their loved one in a terminal state, as those may be linked to the development of a family feeling⁽²⁾. That feeling enables an increased human identification with each other, causing the patient's suffering to be present in an intense way in the family.

In this perspective, nurses and health professionals must plan ways to clearly address the death theme, both with terminal patients and their

families, which could cause several reactions, since the meanings attributed to the process of death and dying are constructed and experienced historically and culturally over the life of each person. Therefore, one should have the sensitivity to assess the relevance of the approach to the subject, as well as to investigate the desire and/or the need of patients and their families to discuss the death process⁽⁷⁾.

One justifies the relevance of this research, because studies on the subject addressed mainly the overload⁽⁸⁾ and the development of depression⁽⁹⁾ which may be related to the blame and accountability experienced by the caregivers⁽¹⁰⁻¹¹⁾. Only two studies, one conducted in Japan and another in Sweden, expound briefly on the difficulty of family caregivers to face the decay of a loved one⁽¹²⁻¹³⁾. In this sense, considering that home care is somehow new in Brazil and that there were no national studies which focused on how caregivers face the finitude of the patient at home, one questioned: how do family caregivers face the finitude of a terminal patient at home, in home care regime? Thus, this study sought to know how family caregivers face the finitude of their loved one, in home care regime.

METHOD

This is a qualitative survey developed with family caregivers over 18 years old, of terminal cancer patients linked to the Home Care Service (HCS) of a university hospital in the south of Brazil. The data collection period was from January to June 2010.

One interviewed 11 family caregivers, being four men and seven women. Out of the women, five were in the position of daughters and two of wives. As to the men, two were spouses, a brother, and another one was a father. To determine the number of participants one

used the criterion of saturation of speeches, on the understanding that it is achieved when the introduction of new information produces no changes in the results found previously⁽¹⁴⁾.

In the data collection one used the narrative interview, which allowed the family caregivers to rebuild social events from their perspective. Thus, they were encouraged and incentivized to tell the story of any event⁽¹⁵⁾, that is, in this study, the researcher asked the caregivers to talk about the difficulties of taking care of a terminal patient in home care regime.

The visit to the terminal patient's home for the interview with the caregiver was scheduled in advance, by telephone, and performed individually. There were two situations in which two family members said they were caregivers, therefore, an interview was conducted simultaneously with both. However, data collection was not impaired. The time for each interview varied from one hour to one hour and thirty minutes.

The interviews were recorded and transcribed into a document, from which data analysis was performed. For this step one used the content analysis, which is defined by the explanation of the meaning contained in a document and/or the manner in which it may be transformed in order to give a meaning, taking into account the frequency of repetition of the terms, apparatus and pace of the speech⁽¹⁴⁾. This analysis enabled the construction of two categories, which will be presented and discussed: "Feelings involved in terminal patient care" and "Reflections of human finitude in the life of family caregivers."

Following ethical principles and respecting the Resolution 196/96⁽¹⁶⁾, which regulates research with human beings, one delivered and read the Free and Clarified Consent Term to each participant. In order to preserve the confidentiality and anonymity, one chose to

adopt codes to identify the speeches. Thus, the letters that make up these codes are FC for family caregivers, followed by numbers, plus the letter F (female) or M (male) for the identification of speeches. For example, FC1-M, FC2-F, FC3-F, FC4-M and so on. The research development occurred after the approval of the Ethics Committee of the Universidade Federal de Santa Maria, with the Certificate of Appreciation for Ethics Presentation (CAEP) number 23081.014219/2009-85.

RESULTS AND DISCUSSION

Feelings involved in the care of terminally ill patients

In this category, one will approach the feelings experienced by family caregivers in the care of terminally ill patients at home, which may be related to their affinity with the sick family member, causing distress and physical symptoms such as fatigue, which may even evolve into a psychic disturbance.

Throughout the process of care to the patient who experiences a terminal stage, many caregivers show signs of suffering, expressed by anxiety, distress and depression, being often necessary to search for anxiolytic and antidepressant medications, as confirmed by the speech below: *I undergo treatment for depression. I take medication. I just do not take sleeping pills. Only for anxiety. I do not take it (Sleeping medication), because if I sleep, I will not see what will happen to him... It seems that now I have managed to be strong to go on (CF4-F).*

In the present study, one observed through the speeches of some caregivers that many are making use of anxiolytics and antidepressants to control anxiety and distress. There is a considerable proportion of informal caregivers of patients with primary cancer, in terminal stage, who have anxiety and depression. There is an interrelationship between the family's and the patient's

psychological distress, with direct consequences on both. The caregiver's depression and anxiety can trigger the same disease in the patient and vice versa, that is, if the family is affected by the disease, the family reactions also affect the patient⁽⁹⁾.

The results demonstrate the complexity of care and its influence among the people involved, because caregivers often face some kind of suffering, leading to the need of using medication to endure this situation and provide the necessary care. This pain may be related to the identification that each person establishes with each other⁽³⁾, providing the development of the family feeling⁽²⁾, creating a space for sharing anxieties about death bigger than in other historical periods⁽³⁾.

It was also possible to perceive feelings of guilt and accountability that permeate home care, considering that the caregiver feels more involved in the process than the other family members. The subjects of this study verbalized a sense of fear of being blamed by other family members, especially for the death. This can be seen in the following statement: *Imagine if he's dead? If I find him dead? The only thing still to happen is his death, and they blaming me for killing him. So, you know, a home has all this. Because it seems that the responsibility is enhanced. It is as if we wanted to get rid of the family member. So you have to be very careful (FC4-F).*

The accountability and culpability of the other family members for events that involve the patient cause suffering to the caregiver and it may cause emotional distress. So he can have emotional disturbances⁽¹⁰⁾ and he often feels anxiety, distress, worry, because since he is in the condition of the patient's guard, he avoids the most unexpected situations.

In Japan, family caregivers seem to be more prepared for home care because they emphasize that the monitoring of the patient in the process of death and dying at home is rewarding for both⁽¹⁷⁾. It is

believed that if the patient dies in a moment when the caregiver is not by his side, the latter will feel strongly guilty. One emphasizes that this feeling is not attenuated even if professionals from the health team tell family members that they should not feel guilty, because this feeling is related to potential and actual grievances related to the patient⁽¹¹⁾. Family relationships also influence the dynamics of home care, because the feelings involved in the roles assumed can affect it. The quality of this relationship is often decisive in the impactful experience of the terminal illness, as well as the ability to adapt to it⁽¹⁾.

In the same way the caregiver must deal with the patient's feelings and be ready to support him, he tries to deal with what the rest of the family feels. When the caregiver receives assistance from other members of the family, he feels supported, if not, a difficult relationship of accusations between the people involved is established⁽¹⁸⁾.

Suffering was also expressed through tiredness and exhaustion, present in the speech of caregivers, however, when they think about the sick family member, courage emerges. Furthermore, during an interview, one of the caregivers tore some tea leaves that were on the table, and at the end of the interview, she made a circle with the little bits of leaves, as if, metaphorically, she was expressing her situation: *We get to pieces at times, but we have to have courage. For our father and mother* (CF1-F).

This feeling of "being in pieces" can refer to tiredness, exhaustion and grief due to the helplessness feeling of not being able to do anything to reverse the situation. It seems that, despite the exhaustion, the overload, the deprivation and the feelings of distress, the fact of caring for a loved one motivates caregivers to

continue with strength and courage, in the tiring daily care task.

The caregiver tries not to verbalize his fatigue and anxiety, but this is revealed when he says that he goes out for a walk and that he does not want anyone to go through that, that is, the experience of caring for a patient who will die: *I have nothing to complain about, I'm never too tired. Just sometimes I try to go for a... I go out, take a walk and come back...* (FC7-M).

From this perspective, perhaps because care is inherent to human beings, they do not complain about overload, fatigue of caring, but it is permissible to go for a walk to relax and reduce anxiety. In other words, one cannot complain about the condition of being a chronic or terminal patient's caregiver, but it is acceptable to "escape" from these disquieting thoughts using another activity that is not caring. Therefore, besides the overload, there is the suffering for not being able to complain about the caregiver's condition.

Another study, conducted in Sweden, highlights that home care can be a burden for all parties involved. The need for a family member to assume the role of caregiver can be seen as a moral aspect, and if that person does a good job, he may have a clear conscience⁽¹⁹⁾. This goes back to what a caregiver verbalized in the end of his testimony in this study; he reported he believes that playing that role can teach a lot to future confrontations. However, one has to highlight a lack of research addressing this issue, involving caregivers and strategies of "escaping" care, as reported by the caregiver mentioned.

The suffering present in the stress experienced by informal caregivers is related to the excess of care activities and tasks, with the feelings that permeate them⁽⁹⁾. A study conducted in Australia showed that it

does not matter the amount of support provided, because the stress involved in care is hardly reduced⁽⁸⁾.

Thus, for home care to be effective for the patient and the family caregiver, it is necessary to use strategies not only of drug nature, such as prescription of drugs that can control the emotions of the caregiver, but others, such as strengthening the social support, so that the caregiver does not feel alone in the process of death and dying of his family member. In addition, thinking of ways and actions that can facilitate a discussion on the issue of human finitude can also help strengthen the relationship between the caregiver and the patient who is dying.

The consequences of human finitude in the life of family caregivers

In this category, one will cover topics that provide reflections on the feelings that emerge in the monitoring of human finitude, such as the feeling of powerlessness referred by the family member regarding the care that does not seem to result in improvement, the confirmation of decay and increasing weakness of the patient and his social death.

There is a desolation of caregivers on saying that the care provided is not easy as it seems not to present results on the gravity of the situation, as well as the acceptance of reality. During the interviews one collected feelings of love involved, which seem to strengthen them before this challenge, as noted in the speech: *We were changing her clothes and when we were finishing, she was all wet again. There we go, change her clothes again. It is difficult to deal with it, because everything hurts... Because it is a person we love, it's a shame she is in a situation we cannot do anything. Seeing the suffering, seeing the pain, her pain, it is difficult* (FC3-M).

It is in the moment of providing care that the reality of the disease and suffering of the family member

becomes concrete. Seeing his loved one with limitations, progressively dwindling due to a terminal illness, promotes a transfer of feelings from the patient to the caregiver. Moreover, in this case, for being a young patient, it seems to generate greater desolation in the people involved in her care, complicating the acceptance of death.

The constraints due to the process of death and dying are explicit in today's society, being more easily understood when related to the bigger life expectancy, which prolongs life and postpones death. These constraints hinder a spontaneous conversation with the patient. In this sense, it is noted that it is not the death which is bad, but the pain of the dying person and also the loss suffered by the living people when a loved one dies⁽³⁾. This identification with the pain of the terminally ill patient is intensified when the family shares many limitations of the patient, through love and affection felt for him⁽¹⁾.

The impotence due to the finitude of the human being is also present, because previously the family member had a "normal", productive life; gradually with the progression of the disease, he loses many functions, facing limits, becoming dependent. The speech below expresses this perception: *It is a person, the human being becomes a ... it is very complicated ... sometimes we think ... that is nothing like my mother was, my mother raised us, a housewife, now we see her like that. It is very sad to see the person like that, the disease making her stay like this. ... You see the person who gave birth to you, who raised you... disappearing slowly ... it is very heavy* (FC1-F).

That line may refer to a self-reflection before the other, as it also expresses the loss caused by the disease to the person who existed before. Thus, questions regarding impotence, social death and loss of the loved one arise.

The sense of powerlessness on the part of caregivers is an extension of the patient's own helplessness regarding his disease. It can be expressed through metaphors such as decreasing force or destructive outside forces, such as the "cancer which eats you from inside". The "human being" disappears due to the change in the physical aspects because of the disease, the change in strength, the social functions and the individuality⁽¹²⁾. These findings are in line with the caregiver's speech that seems to feel powerless due to the decay of the mother, which looks nothing like the human being she was before.

About social death, the leaving starts much before the actual end. It is big the weakness of people when they get sick and old, large enough to separate those who get old from the living ones. In short, their decay isolates them⁽³⁾.

Usually, families can "hide" the sick people in their homes or in institutions such as nursing homes or hospitals. Thus, sick people stop receiving visits from relatives and friends by claiming they do not know what to say, increasing the condition of a person who no longer exists even before dying⁽¹⁾. In addition, family caregivers also report concerns about the difficulties of dealing with a decomposing body⁽¹³⁾. In fact, in many homes where the interviews took place, one observed that, in one way or another, the patient was isolated, being in the living room, where a bedroom was adapted or in a smaller house, built exactly to care for the patient in the grounds of the family, or in another empty room of the house.

The pain of the loss of a loved one before death itself may come from the sense that death is a process of loss of autonomy and expressiveness. If autonomy is the ability to govern oneself, that is, the ability to think and to decide according to their own convictions, loss of

autonomy implies losing freedom, the elective ability, which implies dependence. Moreover, dying can mean weakness in the expression of the human being, in his eyes, in his gestures, in his own words⁽²⁰⁾.

The representation built on the home care of a terminally ill person comes from reflection about human life, leading the family caregiver to make comparisons of the person, before active, productive and consistent, now ill, ignoring simple issues of daily routine being dependent. Thus, the living people have difficulty identifying themselves with the dying person, especially because the human being is the only one of all living beings that has an awareness that he will die, which leads to the inability to help those who need the most and who depend on other humans - the person who experiences his finitude. This can occur because the other person's death is a reminder of his own death⁽³⁾.

CONCLUSION

This study enabled the understanding of issues involving the feelings of caregivers and how they affect their lives when confronted with the finitude of a person from their household.

Experiencing the death and dying process of a patient without healing possibilities generates a series of changes both physical and psycho-emotional, either in the patient, or in his household. Thus, due to the need of transforming the way of caring for terminally ill patients in the hospital context, one created the home care with the aim of enabling those people to be cared for and to experience the last days of their lives with the warmth of their family, the warmth of their home.

For terminal patients to receive care at home it is necessary that a family member becomes the primary caregiver; when facing this new way of living and participating in the daily life of their loved one, this

family member faces moments of suffering, and his life is changed and affected by the proximity of death.

These changes underlie the need to assume new roles in the family dynamics, adapt and learn to care. Given these changes and the long periods in which they dispense their care, one identified that family caregivers develop anxiety, distress, depression, and often also require pharmacological treatments to continue meeting the demands that a terminally ill patient presents in daily actions. Furthermore, one observed that many patients develop feelings of guilt, responsibility and impotence, especially regarding death.

It is noteworthy, then, how complex the home care to a patient without healing possibilities is. Likewise, we emphasize that before any complexity and suffering imposed by this situation, family caregivers provide care with a lot of love and dedication to those people who, at other times, also gave care and love back.

Thus, it becomes necessary that home care enables, besides medication, a strengthening and range of relations of social support to the caregiver so that he can find in other people and social networks, strength, courage and support for coping and acceptance of his loved one's death.

Accordingly, this study intends to encourage and support discussions in the academic and professional areas about this topic. Even considering the advances arising from the creation of policies and programs, many questions about the process of death and dying remain veiled. Moreover, the goal is that, through the speeches of family caregivers, health professionals, especially nursing ones, may realize that many questions addressed by them are part of everyday care. Thus, care plans for people in terminal state and their families can be rethought due to the reality explained here.

REFERENCES

1. Sancho MG. *Morir com dignidad*. Espanha: Aran; 2005.
2. Ariés P. *História da morte no ocidente: da idade média aos nossos dias*. Rio de Janeiro: Francisco Alves; 2003.
3. Norbert E. *A solidão dos moribundos: seguido de envelhecer e morrer*. Rio de Janeiro: Jorge Zahar; 2001.
4. Blois JM, Cartana MHF, Dal Sasso GTM, Martins CR. Home care as a possibility of art expression, creativity and access to technology: An analysis on the subject. *Online Braz J Nurs*. [periódico na Internet]. 2008 [citado 2010 jul 30]; 7(1): [cerca de 7 p]. Disponível em: <http://www.objnursing.uff.br/index.php/nursing/article/view/j.1676-4285.2008.1373/314>
5. Ministério da Saúde (BR). *Melhor em casa: a segurança do hospital no conforto do seu lar: Cuidados Paliativos e a Atenção domiciliar*. Brasília: Ministério da Saúde; 2012 (Caderno de Atenção Domiciliar).
6. Martins SK, Lacerda MR. O atendimento domiciliar à saúde e as políticas públicas em saúde. *Rev Rene*. 2008; 9(2):148-56.
7. Oliveira SG, Quintana AM, Bertolino KCO. Reflexões acerca da morte: um desafio para a enfermagem. *Rev Bras Enferm*. 2010; 63(6):1077-80.
8. Hudson P, Quinn K, Kristjanson L, Thomas T, Braithwaite M, Fisher, J et al. Evaluation of a psycho-educational group programme for family caregivers in home-based palliative care. *J Palliat Med*. 2008; 22(3):270-80.
9. Beck ARM, Lopes MHBM. Cuidadores de crianças com câncer: aspectos da vida afetados pela atividade de cuidador. *Rev Bras Enferm*. 2007;60(6):670-5.
10. Tsigaropoulos T, Mazaris E, Chatzidarellis, Skolarikos A, Varkarakis I, Deliveliotis C. Problems faced by relatives

caring for cancer patients at home. *Int J Nurs Pract.* 2009; 15(1):1-6.

11. Mendes JA, Lustosa MA, Andrade MCM. Paciente terminal, família e equipe de saúde. *Rev SBPH.* 2009; 12(1):151-73.

12. Milberg, Anna; Strang, Peter; Jakobsson, Maria. Next of kin's experience of powerlessness and helplessness in palliative home care. *Support Care Cancer.* 2004;12(2):120-8.

13. Tang ST, Liu TW, Lai MS, McCorkle R. Discrepancy in the preferences of place of death between terminally ill cancer patients and their primary family caregivers in Taiwan. *Soc Sci Med.* 2005; 61(7):1560-6.

14. Turato ER. Tratado da metodologia da pesquisa clínico-qualitativa: construção teórico-epistemológica, discussão comparada e aplicação nas áreas da saúde e humanas. Petrópolis: Vozes; 2008.

15. Silva DGV, Trentini M. Narrativas como técnica de pesquisa em enfermagem. *Rev Latino-am Enfermagem.* 2002; 10(3):423-32.

16. Ministério da Saúde (BR). Conselho Nacional de Saúde, Comissão Nacional de Ética em Pesquisa. Resolução Nº 196 de 10 de outubro de 1996: aprova as diretrizes e normas regulamentadoras de pesquisa envolvendo seres humanos. Brasília: Ministério da Saúde; 1996.

17. Sano T, Maeyama E, Kawa M, Shirai Y, Miyashita M, Kazuma K et al. Family caregiver's experiences in caring for a patient with terminal cancer at home in Japan. *Palliat Support Care.* 2007; 5(4):389-95.

18. Pereira LL, Dias ACG. O familiar cuidador do paciente terminal: o processo de despedida no contexto hospitalar. *PSICO.* 2007; 38(1):55-65.

19. Appelin G, Brobäck G, Bertero C. A comprehensive picture of palliative care at home from the people involved. *Eur J Oncol Nurs.* 2005; 9(4):315-24.

20. Roselló FT. Antropologia do cuidar. Petrópolis: Vozes; 2009.

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