EXPERIENCES OF CAREGIVERS IN THE PALLIATIVE CARE AND SUPPORT NETWORKS

EXPERIÊNCIAS DE CUIDADORES NOS CUIDADOS PALIATIVOS E REDES DE SUPORTE EXPERIENCIAS DE CUIDADORES EN LOS CUIDADOS PALIATIVOS Y REDES DE SOPORTE

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ABSTRACT

Objective: to understand the experiences by the family caregivers of patients eligible for palliative care. **Method:** this is a qualitative, descriptive and exploratory study, based on social phenomenology. There were 20 caregivers interviewed who were enrolled in primary health care in a city of Minas Gerais, Brazil. Data collection was performed through a phenomenological interview and interpreted through the description, reduction and understanding phases. As for the analysis of the data, the categorical thematic modality was used, with the help of the program ATLAS TI 7. **Results:** the following categories were identified: Support networks for the caregiver family; Dynamics and daily routines of family care; Physical and mental overloads of the family caregiver. **Conclusion:** The caregivers experienced important changes in their daily routines, which led to a physical and mental overload, leading to the need for formal and informal support networks for these care. There was a lack of a formal support network for caregivers and a lack of adequate training and guidance for the care of the family member. The importance of the performance of PHC equipment is highlighted, by supporting the biopsychosocial needs of these caregivers. **Descriptors:** Health Primary Care; Palliative Care; Caregivers; Social Support; Psychosocial Support Systems; Perception.

RESUMO

Objetivo: compreender as experiências vivenciadas por cuidadores familiares de pacientes elegíveis para cuidados paliativos. **Método:** estudo qualitativo, descritivo e exploratório, fundamentado na fenomenologia social. Entrevistaram-se 20 cuidadores cadastrados na atenção primária à saúde. Realizou-se a coleta de dados por meio de entrevista fenomenológica e interpretada através das fases de descrição, redução e compreensão. utilizou-se a técnica de Análise de Conteúdo na modalidade Análise Temática categorial, com o auxílio do programa ATLAS TI 7. **Resultados:** identificaram-se as categorias: Redes de apoio ao familiar cuidador; Dinâmicas e rotinas diárias de cuidados prestados pelo familiar; Sobrecargas físicas e mentais do cuidador familiar. **Conclusão:** vivenciaram-se pelos cuidadores importantes mudanças em suas rotinas diárias, o que acabou por ocasionar uma sobrecarga física e mental aos mesmos, levando à necessidade de redes de apoio formais e informais para estes cuidados. Observou-se a inexistência de uma rede de apoio formal aos cuidadores e a falta de treinamento e orientação suficientes para realização do cuidado junto a seu familiar. Ressalta-se a importância da atuação dos equipamentos da APS, por meio do apoio às necessidades biopsicossociais destes cuidadores. **Descritores:** Atenção Primária à Saúde; Cuidados Paliativos; Cuidadores; Apoio Social; Sistemas de Apoio Psicossocial; Percepção.

RESUMEN

Objetivo: comprender las experiencias vividas por cuidadores familiares de pacientes elegibles para cuidados paliativos. **Método:** estudio cualitativo, descriptivo y exploratorio, fundamentado en la fenomenología social. Fueron entrevistados 20 cuidadores registrados en la atención primaria a la salud de un municipio de Minas Gerais, Brasil. La recolección de datos fue realizada por medio de entrevista fenomenológica e interpretada a través de las fases de descripción, reducción y comprensión. En el análisis de los datos, se utilizó la modalidad temática categorial, con el auxilio del programa ATLAS TI 7. **Resultados:** fueron identificadas las categorías: Redes de apoyo al familiar cuidador; Dinámicas y rutinas diarias de cuidados prestados por el familiar; Sobrecargas físicas y mentales del cuidador familiar. **Conclusión:** los cuidadores vivieron importantes cambios en sus rutinas diarias, lo que acabó por ocasionar una sobrecarga física y mental a los mismos, llevando a la necesidad de redes de apoyo formales e informales para estos cuidados. Se observaron la inexistencia de una red de apoyo formal a los cuidadores y la falta de entrenamiento y orientación suficientes para realización del cuidado junto a su familiar. Se resalta la importancia de la actuación de los equipamientos de la APS, por medio del apoyo a las necesidades biopsicossociales de estos cuidadores. **Descriptor:** Atención Primaria a La Salud; Cuidados Paliativos; Cuidadores; Apoyo Social; Sistemas de Apoyo Psicossocial; Percepción.

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INTRODUCTION

It is known that the increase in the number of people affected by chronic non-communicable diseases (CNCDs) has taken place progressively by the population aging and improved life expectancy.¹ In this context, the need for assistance in palliative care (PC) associated with CNCDs and life-limiting conditions, emphasizing that all patients with serious, progressive and incurable diseases should receive this care since their diagnosis.²

There is a greater incentive to community strategies for CP around the world with a collective health approach. It is an approach of care provided not only by specialists but by generalists, with the help of providing quality care at home, in the course of illness and at the end of their life. However, it is necessary to train the primary health care professionals (PHC), with the collaboration of specialists and non-specialists, through an organized care network³, since PHC is the gateway for users in the health system and to communicating with the entire health care network.⁴

Health care networks (HCN) are considered as the solution to the problem of the fragmentation of care by levels of care. However, there are not yet many experiences of HCN for PCs in Brazil.⁵ The lack of training of health professionals has hindered the articulation of HCN since it is known that the curricula of undergraduate courses in health still address the theme of the PC in a fragmented way and with a focus on health recovery actions.⁶

In this context, the lack of an organized care network for PCs and a lack of PHC professionals trained to meet the needs of these patients in the home environment highlights the role of the caregiver.⁷⁻⁸ The role of the caregiver becomes fundamental. Therefore, they should be trained in this care, since they are involved in many activities for the maintenance of their family member's well-being.⁹ Also, through experiences of home care by family caregivers, PCs require a major change in the caregiver's family roles, involving the decline in sexual relationships between caregiver spouses and the high responsibility assigned by other family members to the caregiver. It is known that such experiences can cause stress, overload, and impacts on the quality of life of the family caregiver.⁶

In this sense, to study the experiences of family caregivers of patients eligible for PC in the context of PHC becomes relevant, to understand the demands of this population

and provide subsidies for the organization of a care network for the PCs that address the needs of caregivers.

OBJECTIVES

- ♦ To identify and understand the experiences by the family caregivers of patients eligible for PC assisted at the PHC.
- ♦ To identify the support networks available to family caregivers of patients eligible for PC assisted in the PHC.

METHOD

This is a descriptive and exploratory study with a qualitative approach. In the qualitative studies, the objective is to understand the meanings and experiences by the individuals to their actions, and for this understanding, it is necessary to insert them in a context.¹⁰ This study is based on the phenomenological approach, investigating the phenomenon based on the experiences lived by the participants. Social phenomenology was adopted as a theoretical reference, discussing the structure of reality highlighting the social relationship as a fundamental element in the interpretation of the meanings of the action of the individual in the everyday world.¹¹⁻¹²

The research was carried out in the city of Divinópolis, Minas Gerais, Brazil. The municipality of Divinópolis is divided into 12 health sectors and sector nº seven is the one with the highest number of patients eligible for PC, according to a previous survey. The participants were 687 eligible patients for early PC belonging to the health sector nº seven, who had the highest number of patients eligible for PC, identified from a previous study.¹³ The participants were selected through a draw, with each draw being checked by the patient care network if he had a constant family caregiver at his home, excluding those who did not. As a criterion for defining the sample the convenience¹⁴, that is, the collection of data was interrupted as soon as the corpus needed to analyze the reports was obtained, constituted by relevance of the speeches, discussed among all the researchers.

The sample had 20 family caregivers of patients eligible for PC enrolled in the city's PHC. The following selection criteria were adopted: being a caregiver, aged above 18 years old, being a family member of a patient eligible for PC, living in the same household as the patient classified as eligible for PC and with a score of <70% according to the Scale of Performance of Karnofsky (KPS), and belonging to sector nº 7 of the municipality.

There were no refusals to participate in the study.

For the data collection, the phenomenological interview was used, in which the participants described their experiences and the way they perceive the phenomenon of caring for a patient eligible for PC. A semi-structured interview was used as a collection tool, containing the following guiding questions: How is your experience of caring for your family member at home? What are your experiences with the health unit in your neighborhood?

The interviews were carried out by 3 undergraduate researchers from the last period of the nursing course, duly trained in 4-hour training by the researcher responsible, Ph.D. in nursing. The interviews took place from March to July 2015, in the interviewee's own residence, in a private place, lasting from 10 to 30 minutes. The interviews were scheduled previously, according to the participants' availability. Before the beginning of the research, the participants were clarified on the objectives and method of the study as well as the ethical aspects. Subsequently, they were invited to sign the Free and Informed Consent Term. Participants had no prior knowledge of the project and did not know the researchers.

The reports obtained in the interviews were recorded, transcribed in their entirety and analyzed according to the phenomenological framework. Afterward, contents were prioritized and analyzed using the ATLAS TI 7 computer program. For the comprehension of the discourses, it was proceeded: pre-analysis (floating reading of transcribed data); (interpretation of the subject) and treatment of the results (interpretation). Then, the categorization was started, where the information contained in the participants' statements formed the corpus of analysis that led to the elaboration of indicators which were submitted to the analytical procedures and subsequent inference, comparing with the literature data.¹⁰ For the discussion of the results, the phenomenological reference was adopted, where the data were examined in three phases: description, reduction, and comprehension.¹¹

The research project was sent to the Research Ethics Committee of the Federal University of São João del Rei, before the data collection, with approval number 965,622, CAAE: 41781414.8.0000.5545.

RESULTS

There were 20 (100%) family caregivers of patients eligible for PC participating in the study, 17 of them (85%) were female and 3 (15%) were male. As for marital status, 14 (70%) were married; 3 (15%) were single; 2 (10%) were widowers and 1 (5%) were divorced. As for the professional situation, 10 (50%) caregivers were housewives; 6 (30%) were retired; 3 (15%) were active in the labor market and 1 (5%) was unemployed. As for age, 6 (30%) were between 60 and 70 years old; 4 (20%) were 30 to 40 years old; 4 (20%) from 40 to 50 years old; 4 (20%) from 50 to 60 years old; 1 (5%) from 70 to 80 years old and 1 was more than 80 years old. Regarding the degree of kinship with the patient, 5 (25%) were mothers; 5 (25%) were wives; 5 (25%) were daughters; 1 (5%) was a son; 1 (5%) was a husband; 1 (5%) was a brother; 1 (5%) was a sister and 1 (5%) was a granddaughter. Regarding the time they were in care, 8 (40%) were from 1 to 5 years; 5 (25%) from 5 to 10 years; 3 (15%) from 10 to 15 years; 3 (15%) over 15 years and 1 (5%) less than 1 year.

After knowing the profile of the participants, the data from the interviews were analyzed. There were 3 categories emerged from these data: 1. Support networks for familiar caregivers; 2. Dynamics and daily routines of care provided by the relative; 3. Physical and mental overloads of the family caregiver.

DISCUSSION

♦ **Category 1.** Support networks for family caregivers

The family caregivers interviewed had some formal or informal support networks, which help them cope with the overloads related to home PCs. Below, there are some speeches that refer to these experiences with support networks:

[...] the staff, how do you say? From the church, the Catholic Church, the conference, the conference staff, the conference boys come to help me know" (E 17).

[...] the doctor came here once, once, now the health agent is there, she goes there once every 2 or 3 months to find out if she needs a medicine or a prescription" (E 19).

[...] my husband helps me, I take care of myself during the day, in the afternoon he helps me bathe, put her in the chair "(E15).

[...] to take him to the doctor, dentist, my daughters help me, there is one who lives here on the side, and my children are very good for me, they help me, you know" (E 05).

It is known that coping with a disease with no possibility of cure has a great impact on the life of the patient and their families, leading to changes in their structure and dynamics. In this context, the family caregivers often use support networks as a form of support and reference.¹⁵ The network is a social circle constituted by ties of affinity that unites people, which can be formal and informal¹⁶ and in this study, participants shared experiences with the collaboration of religious entities, relatives, and PHC health units. It is noteworthy that this collaboration gave the caregiver greater emotional support, providing moments of rest and leisure. However, from the reports, the incipience and lack of preparation of the formal PHC network to support the needs of the caregivers are observed, since they reported that they receive few visits from health professionals and they are only to see if they need any medicine or prescription.

Studies show that religious groups are important elements of social networks and help to deal with suffering in the face of illness through spiritual support.¹⁷ As important as informal support networks, the formal network offered by professionals is necessary and essential to support to PC patients at home, aiming at better care and avoiding the overload of caregivers. Well-prepared home care teams provide conditions for adequate support to caregiver demands and bring benefits to the patient, family, and health system.¹⁸

In this context, PHC plays a fundamental role in ensuring continuity of care for these patients, being the basis for the referral and counter-referral system, ensuring continuity of care in other levels of care. Thus, it is fundamental to structure care models that contemplate end-of-life care in a structured way and guarantee integrality through the organization of a Health Care Network (HCN) for these care.¹⁹

♦ Category 2. Dynamics and daily routines of care provided by the relative

Through this thematic category, the dynamics and routines that the family caregivers of patients in PC experience are observed. All caregivers reported experiences related to work dynamics and daily routines in PCs.

[...] at seven thirty I will give her another snack, I would even give her some soup if I could give her a dinner, we used to eat dinner, then I would pick up some soup(...)" (E 6).

As he says, I fight with him, what I can do, give medicine, medicine, (...) at the right time" (E 11).

[...] so I know the way she thinks about the bath, (...) raising her, the type of comfortable clothes, the way to lie down" (E 16).

"It's got to be kind of special care right, it's the bath, the diaper, the food, it totally depends on me, right?" (E 03).

[...] he depends on everything he knows, I give a bath, cut his hair, shave, cut the nail, toothbrush, do everything (...)" (E 05).

It is observed that when assuming the responsibility of taking care of the patient, the family caregiver has new experiences. A loved one, being affected by a disease out of therapeutical possibilities of healing, ends up generating great changes in the daily life of their families. Such context requires that family caregivers experience functions, most of which are previously unknown, such as medication administration, bed hygiene, feeding preparation, drainage handling, probes, and dressing, as well as dealing with the progression of symptoms and the possibility of impending death of the relative. This context where the family caregiver is inserted, especially in the advanced stage of an illness, favors the presence of physical, emotional, social and economic overload in them¹⁶, as identified from the reports of the participants of this study.

♦ Category 3. Physical and mental overloads of the family caregiver

From the reports presented in this category, it is seen how much the family caregivers of patients in PC are physically and mentally overloaded with the care provided, being this overload demonstrated through the reports of all (100%) the relatives interviewed.

[...] It's tiring, right. It's very tiring, that I even talked to my sisters, look a month ago they did not want to look right. Then she gets so tired of her head, she gets tired like that, wanting to rest, her body also gets very tired, she is taking her right" (E.3)

[...] Only I and her daughter give a hand, help a little, she looks at the medicines, buy the pills, diaper, everything she does because there's no way out for me "(E18)

[...] I do not 'mind' taking her, turning her around, turning her around, do you know?" (E 15)

It can be observed from the reports, the presence of a physical and mental overload among the patient's family caregivers. In literature, caring has the meaning of helping the other in what he cannot do for himself, by being present and offering an emotional response in support of the other.²⁰ Care is a relationship permeated by affectivity that demands responsibility, attention, concern, and involvement between the binomial, the caregiver, and the care.²¹

It is emphasized from the speeches that changes in the dynamics and daily routines of care provided by the caregiver family may be related to this overload. Feeding, medication administration, and bathing were cited as daily care routines.

Due to the diverse activities performed by the caregiver, the lack of adequate training to dispense with their care activities and the lack of clear knowledge of the patient's prognosis, it is noticed that the caregiver is overwhelmed both physically and emotionally.²² Overworked caregivers tend not to perform the care of appropriate form, so the support of a network becomes important, informal and/or formal, through the health professionals. This network will support both the physical and emotional needs of the caregiver and the patient, reducing physical and emotional exhaustion by providing a better quality of life for both.

CONCLUSION

From the results of this study, it was possible to understand the experiences by family caregivers of patients eligible for palliative care and to identify the support networks available to them. It was found that they experienced important changes in their daily routines, which eventually caused a physical and mental overload, leading to the need for formal and informal support networks for these care.

Corroborating with the hypotheses of this study, it was observed the inexistence of a structured support network to attend to the needs of the caregivers of patients in PC in the city studied. It is observed that these caregivers did not receive enough training and orientation of health professionals to perform care with their relative, demonstrating physical and emotional overload. Thus, it is observed the importance of the effective performance of PHC equipment, through the support of the biopsychosocial needs of these caregivers.

This study becomes relevant, as it provides subsidies for a better understanding of the phenomenon experienced, collaborating for the discussions about the structuring of the HCN for the PC and for the need of permanent education of the PHC professionals to attend the needs caregivers.

REFERENCES

1. Van Vliet LM, Harding R, Bausewein C, Payne S, Higginson IJ. How should we manage information needs, family anxiety, depression, and breathlessness for those affected by advanced disease: development of a Clinical Decision Support Tool using a Delphi design. *BMC Med* [Internet]. 2015 Oct [cited 2016 June 02];13(1):263. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/26464185>
2. Andrade CG, Costa SFG, Vasconcelos MF, Zaccara AAL, Duarte MCS, Evangelista CB. Bioética, cuidados paliativos e terminalidade: revisão integrativa da literatura. *Rev enferm UFPE* [Internet]. 2013 Mar [cited: 2016 June 06];7(spe):888-97. Available from: <https://periodicos.ufpe.br/revistas/revistaenfermagem/article/view/11554/13491>
3. Leysen B, Van Den Eynden B, Gielen B, Bastiaens H, Wens J. Implementation of a Care Pathway for Primary Palliative Care in 5 research clusters in Belgium: quasi-experimental study protocol and innovations in data collection (pro-SPINOZA). *BMC Palliat Care* [Internet]. 2015 [cited 2016 July 08]; 14: 46. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4585994/?tool=pubmed>
4. Brasil. Ministério da Saúde. Secretaria de Atenção à Saúde. Política Nacional de Atenção Básica. Brasília, 2012, 110p. Available from: <http://189.28.128.100/dab/docs/publicacoes/geral/pnab.pdf>
5. Paz CRP, Pessalacia JDR, Zoboli ELCP, Souza HL, Granja GF, Schweitzer MC. New demands for primary health care in Brazil: palliative care. *Invest educ enferm* [online]. 2016 Jan/Apr [cited 2017 Feb 15]; 34(1): 46-57. Available from: http://www.scielo.org.co/scielo.php?script=sci_arttext&pid=S0120-53072016000100006
6. Santos Junior AG dos, Santos FR dos, Pessalacia JDR. Desafios para os cuidados paliativos na atenção primária à saúde: revisão integrativa de literatura. *J Nurs UFPE on line*. 2016 July [cited 2017 Feb 15];10(7):2708-19. Available from: <https://periodicos.ufpe.br/revistas/revistaenfermagem/article/view/11332/13031>
7. Fratezi FR, Gutierrez BAO. O cuidador do idoso em cuidados paliativos: o processo de morrer no domicílio. *Ciênc saúde coletiva* [Internet]. 2011 [cited 2016 July 01];16(7):3241-8. Available from: <http://www.scielo.br/pdf/csc/v16n7/23.pdf>
8. Nunes MGS, Rodrigues BMRD. Tratamento paliativo: perspectiva da família. *Rev enferm UERJ*. 2012 jul/set [cited 2016 July 08];20(3):338-43. Available from: <http://www.facenf.uerj.br/v20n3/v20n3a10.pdf>
9. Delalibera M, Presa J, Barbosa A, Leal I. Burden of caregiving and its repercussions on caregivers of end-of-life patients: a systematic review of the literature. *Ciênc*

saúde coletiva [Internet]. 2015 Sep [cited 2016 July 12];20(9):2731-47. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-81232015000902731

10. Bardin L. Análise de conteúdo. São Paulo: Edições 70; 2011.

11. Jesus MCP, Capalbo C, Merighi MAB, Oliveira DM, Tocantins FR, Rodrigues BMRD, et al. A fenomenologia social de Alfred Schütz e sua contribuição para a enfermagem. Rev esc enferm USP [Internet]. 2013 jun [cited 2018 Apr 21];47(3):736-41. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0080-62342013000300736&lng=en

12. Capalbo C. Metodologia das ciências sociais: a fenomenologia de Alfred Schütz. 2nd ed. Londrina: Universidade Estadual de Londrina; 1998.

13. Azevedo C, Rates CMP, Pessalacia JDR, Da Mata LRF. Prospects for palliative care in primary healthcare: a descriptive study. Online braz j nurs [internet]. 2016 Dec [cited 2017 Feb 15]; 15 (4):683-93. Available from: <https://www.objnursing.uff.br/index.php/nursing/article/view/5370/pdf>

14. Patton MQ. Qualitative research and evaluation methods. 3rd ed. London: Sage; 2002.

15. Gomes IM, Lacerda MR, Mercês NNA. A vivência do apoio da rede social pelas pessoas envolvidas no cuidado domiciliário. Rev Esc Enferm USP [Internet]. 2014 [cited 2016 July 01];48(3):484-91. Available from: <http://www.revistas.usp.br/reeusp/article/view/84114/86986>

16. Duarte IV, Fernandes KF, Freitas SC. Cuidados Paliativos Domiciliares: considerações sobre o papel do cuidador familiar. Revista da SBPH [Internet]. 2013 dez [cited 2016 July 02];16(2):73-88. Available from:

http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S1516-08582013000200006

17. Brondani CM, Beuter M, Alvim NAT, Szareski C, Rocha LS. Cuidadores e estratégias no cuidado ao doente na internação domiciliar. Texto Contexto Enferm [Internet]. 2010 [cited 2016 July 05];19(3):504-10. Available from: <http://www.scielo.br/pdf/tce/v19n3/a12v19n3.pdf>

18. Queiroz AHAB, Pontes RJS, Souza AMA, Rodrigues TB. Percepção de familiares e profissionais de saúde sobre os cuidados no final da vida no âmbito da atenção primária à saúde. Ciênc saúde coletiva [Internet]. 2013 [cited 2016 July 10];18(9):2615-23. Available from:

<http://www.scielo.br/pdf/csc/v18n9/v18n9a16.pdf>

19. Paz CRP, Pessalacia JDR, Zoboli ELCP, Souza HL, Granja GF, Schveitzer MC. New demands for primary health care in Brazil: palliative care. Invest Educ Enferm [Internet]. 2016 [cited 2016 July 18]; 34(1): 46-57. Available from: <http://www.redalyc.org/articulo.oa?id=105244267005>

20. Pires MRGM, Duarte EC, Gottem LBD, Figueiredo NVF, Spagnol CA. Fatores Associados à Atenção Domiciliária: subsídios à gestão do cuidado no âmbito do SUS. Rev Esc Enferm USP [Internet]. 2013 jun [cited 2016 June 21];47(3):648-56. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0080-62342013000300648

21. Fernandes MA, Evangelista CB, Platel ICS, Agra G, Lopes MS, Rodrigues FA. Percepção dos enfermeiros sobre o significado dos cuidados paliativos em pacientes com câncer terminal. Ciênc saúde coletiva [Internet]. 2013 Sept [cited 2016 June 23];18(9): 2589-96. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-81232013000900013

22. Ignacio MG, Storti DC, Bennute GRG, Lucia MCS. Aspectos da sobrecarga em cuidadores de pacientes terminais por câncer: revisão de literatura. Psicol hosp (São Paulo) [online]. 2011 jan [cited 2016 July 20];9(1):24-46. Available from: http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S1677-74092011000100003

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