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## DIFFICULTIES OF CAREGIVERS PROVIDING PALLIATIVE CARE TO PATIENTS COVERED BY THE FAMILY HEALTH STRATEGY

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**ABSTRACT:** This study's aim was to identify the main difficulties faced by caregivers of patients receiving comfort care at home and how they perceive the support provided by the Family Health Strategy. Qualitative research involving 50 caregivers providing comfort care to patients cared for by the Family Health Strategy in a city in the State of São Paulo, Brazil. The interviews were transcribed and analyzed using the Collective Subject Discourse methodological strategy. The results show that countless difficulties are experienced, which are linked to a lack of support, of equipment and financial resources and a lack of preparation to deal with death in the context of terminal illness. The program actions are limited and sporadic. The difficulties caregivers experience reflect unpreparedness combined with social and economic instability experienced in the home context. Additionally, caregivers are confronted with restricted and discontinued care provided by the program.

**DESCRIPTORS:** Family health program. Palliative care. Primary health care. Caregivers.

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## DIFICULDADES DE CUIDADORES DE PACIENTES EM CUIDADOS PALIATIVOS NA ESTRATÉGIA DA SAÚDE DA FAMÍLIA

**RESUMO:** Objetivou-se desvelar as principais dificuldades enfrentadas pelos cuidadores de pacientes em cuidados paliativos no domicílio e compreender a percepção dos mesmos em relação ao suporte oferecido pela Estratégia da Saúde da Família. Pesquisa qualitativa realizado com 50 cuidadores de pacientes em cuidados paliativos, atendidos pela Estratégia da Saúde da Família em município do interior de São Paulo. As entrevistas foram transcritas e analisadas utilizando-se a estratégia metodológica do Discurso do Sujeito Coletivo. As dificuldades vivenciadas pelos cuidadores são inúmeras e atreladas à falta de rede de apoio, de recursos humanos, materiais, financeiros e ao despreparo para lidar com a morte no contexto da terminalidade. As ações desenvolvidas pela Estratégia da Saúde da Família são limitadas e pontuais. As dificuldades sentidas pelos cuidadores refletem o despreparo pessoal aliado à precariedade social e econômica vivenciadas no contexto domiciliar. Além disso, defrontam-se com a atenção restrita e descontinuada prestada pelo programa.

**DESCRIPTORIOS:** Programa saúde da família. Cuidados paliativos. Atenção primária à saúde. Cuidadores.

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## DIFICULTADES DE CUIDADORES DE PACIENTES EN CUIDADOS PALIATIVOS EN LA ESTRATEGIA DE SALUD DE LA FAMILIA

**RESUMEN:** Se intentó desvelar las principales dificultades enfrentadas por los cuidadores de pacientes en cuidados paliativos en domicilio y comprender su percepción del soporte ofrecido por la Estrategia de Salud de la Familia. Investigación cualitativa con 50 cuidadores de pacientes en cuidados paliativos, atendidos por la Estrategia de Salud de la Familia en un municipio del interior de São Paulo. Las entrevistas fueron transcritas y analizadas mediante la estrategia del Discurso del Sujeto Colectivo. Las dificultades vividas son innúmeras y vinculadas a la falta de red de apoyo, de recursos humanos, materiales, financieros y de preparación para lidiar con la muerte en el contexto de la terminalidad. Las acciones desarrolladas por el programa son limitadas y puntuales. Las dificultades sentidas reflejan la falta de preparación personal aliada a la precariedad social y económica vivida en el contexto domiciliario. Además, son confrontados con la atención restringida y descontinuada prestada por el programa.

**DESCRIPTORIOS:** Estrategia de salud familiar. Cuidados paliativos. Atención primaria de salud. Cuidadores.

## INTRODUCTION

Palliative care refers to an emergent modality of care provided to terminal patients, based on an integral, holistic and interdisciplinary care model intended to enable patients to live as actively as possible.<sup>1</sup> It was initially developed for cancer patients but, in recent decades, has been extended to patients with chronic, progressive, and degenerative diseases who do not respond to a curative treatment.

This context has compelled healthcare providers to rethink the way they provide care to these patients, because, despite the preference for home care, the difficulties experienced in this environment are numerous and often determine the need for an institutionalized death.<sup>2</sup> In this context, the Family Health Strategy (FHS), implemented to reorganize primary health care, plays an essential role, as it can establish a closer relationship and ties of trust with patients and family members, while providing humanized care in the death process.<sup>3</sup>

Nonetheless, studies show that healthcare providers feel unprepared to deliver this type of care at home.<sup>4,5</sup> The work process within the FHS takes place in an environment permeated by the challenge of delivering care to individuals experiencing extreme fragility, and often, in very poor working conditions.<sup>6</sup>

Additionally, we should consider the inability of professionals to deal with patients in a situation of imminent death. Even though health professionals experience death in their daily practice, it still arouses great fear, as the individuals do not receive proper training in their programs or after graduation to cope with it. Furthermore, one should consider that, in addition to being an eminently biological event, it is also part of a social construction influenced by meanings individuals attribute to it and, that directly influence care delivery.<sup>7</sup>

Palliative care always targets both patient and family since the family provides and receives care.<sup>2</sup> In this context, there is a primary caregiver, generally a close family member, who assumes the responsibility to care for a dependent patient without any financial compensation, and who often ends up relinquishing his/her own life.

In practice, however, as healthcare providers focus on the patient, who requires specialized care, the needs of caregivers may be overlooked or neglected. The literature has shown that caregivers experience significant physical, emotional, social, material, financial and existential burden, especially

when the care process is prolonged and the disease is in an advanced stage.<sup>2,7-8</sup>

This study is justified by the need for researchers to better understand this context through field research and to identify the specific care needs of this group within the sphere of palliative care, as well as the need for reflection upon the work developed by the FHS based on the integrality and interdisciplinary principles.

Given the previous discussion, this study's aim was to identify the main difficulties faced by the caregivers of patients receiving comfort care at home and understand their perceptions regarding the support provided by the Family Health Strategy.

## METHOD

This exploratory study with a qualitative approach was conducted with caregivers of patients receiving comfort care by the FHS in Botucatu, São Paulo, Southeast of Brazil.

The city has six primary health care (PHC) units and 11 FHS units supported by 14 family health teams. Each FHS is responsible for providing care to up to 4,000 inhabitants or 1,000 families within the unit's area of coverage. This team is composed of one nurse, one physician, four to six nursing technicians or auxiliaries, four to eight health community agents, one dentist, one dental assistant, one administrative assistant, and one general services assistant. All the units are supported by the NASF (Support Center for Family Health), which is composed of psychologists, social workers, occupational therapists, nutritionists, fitness trainers, physical therapists, pharmacists, acupuncturists, geriatricians, gynecologists and obstetricians, psychiatrists, pediatricians, and homeopathic physicians who provide care at the health unit or at the families' homes.

Initially, we consulted the nurses of the PHC units to identify caregivers. Inclusion criteria were: being the primary informal/formal caregiver, being available to respond to the questionnaire, and consenting to participate in the study. Those who did not meet the inclusion criteria or whose homes were not located, were excluded.

A semi-structured interview, composed of two parts, was used. The first part characterized the participants and the second was composed of four questions regarding the experience of providing comfort care to a patient at home: In your opinion,

are there difficulties caring for a patient requiring comfort care? If yes, which ones? What are the difficulties faced at home while providing care to this patient?; In your opinion, how it could be improved? What are the resources or services you utilize or have available when you need help at home?

The interviews were conducted in a single meeting in a private area within the home in order to ensure the participants' privacy. Interviews were fully audio-recorded and the researcher took the care necessary not to influence the interviewees.

Theoretical saturation determined the sample size; i.e., new participants ceased to be included when new data no longer significantly contributed to the study.<sup>9</sup>

A total of 62 caregivers were identified from May to November 2013. Of these, five were excluded because the patient died, two did not consent to participate, and five were not located, totaling 50 participants. This non-probabilistic sample was composed of 86% women, aged 52 years on average. Almost all the participants (92%) were informal primary caregivers.

The reports were transcribed after the interviews and analysis was initiated using the Collect Subject Discourse (CSD) technique.<sup>10</sup> The methodological steps from the interviews up to the synthesis included: (a) reading the set of reports collected during the interviews; (b) reading the responses to each specific question, highlighting key expressions; (c) identifying the core ideas of each response; (d) analyzing all key expressions and core ideas, grouping similarities in homogeneous groups; (e) identifying and naming the main idea of each homogeneous group, which is a synthesis of the core ideas of each discourse; (f) constructing the collective subject discourses after identifying the core ideas and key expressions that named the discourses of the collective subject.

This study was approved by the Institutional Review Board at the Medical School of Botucatu, UNESP (CAAE 12841813500005411).

## RESULTS

Based on the analysis of the interview transcriptions, the core ideas and key expressions were identified and the discourses of four themes that emerged from the guiding questions were organized. Below, we present the themes with the respective core ideas and the caregivers' CSDs.

### Theme 1 - Main difficulties faced in the context of comfort care listed by the caregivers

Core ideas - Anticipatory grief; caregiver emotional burden; unpreparedness to deal with suffering; pain management; financial hardship; and lack of support from within the city.

Collective Subject Discourse 1 (CSD 1) - *The most difficult thing for me is that the doctors gave no hope; you look at the person and know that soon, you'll be apart. It's always the same story: there is nothing else to do. And I think, how come? There's always something to do. I can't stand this situation, let alone talk about it. I'm emotional. I'm distressed. I can't deal with so much suffering; today she wanted to hug me and I couldn't face the situation, it's so sad. I have a hard time to sleep because when I close my eyes, I see her lying on the bed, by herself, nobody beside her, so I can't sleep thinking about the loneliness she lives with. There is nothing in the world that distresses me more than hearing her crying the whole night because of pain and we don't know what to do. On the other hand, sometimes, she gets very aggressive with me, belligerent, she fights, but I know she needs affection, help, and dedication. And there's also the financial hardship, which is our greatest difficulty at the moment. I make little money and half of it goes to buy what it is needed because we have many expenditures and because of it, we leave our needs aside. Another problem is what we face with the city's urgent services from which we ask for help and they say the ambulance has to come but we have to wait for hours.*

### Theme 2 - Difficulties faced in the process of providing care at home

Core ideas - Time spent to provide care to another person; domestic chores; unpreparedness to care for a bedridden patient; caregiver's physical burden; lack of proper equipment; lack of physical structures at home; lack of support on the part of the FHS team; relinquishing one's life for the sake of another person.

Collective Subject Discourse 2 (CSD 2) - *The time she demands is my greatest difficulty. It is a long period to provide care, because it takes time. I myself have no time to eat or to go to the doctor. Things have to be done in her schedule, not mine, so I leave my things aside to do hers. Also, it is complicated to keep the house tidy, drawers, clothes, the family's meals, you know, taking care of the house and keep everything organized. In addition, I'm having back problems, because my mother is very heavy, so there's great physical exertion while caring for her. With my pains, I feel I can't do much else*

*for her, I can't squat anymore, can't climb the stairs; so on top of everything, I have my own problems. But I'll take care of her as long as she needs. The bath has been really difficult for me because there is no one to help me. I do everything by myself, I have to lift her, carry her with an arm, and lift her with the other, change diapers, take care of the tracheostomy. Additionally, there are times the food probe comes out and I get desperate because I have no guidance on how to take care of it. Not to mention that it is adapted and we have to improvise everything at home. I don't have a wheelchair that could help and the bed... it is not like a hospital bed, so it requires more effort. A wheelchair would be useful, though it'd not pass through the bathroom's door. Finally, in our case, the greatest difficulty is having stairs at home, which prevents her from going outside, watching the street, seeing the sun.*

### **Theme 3 - Contributions to improve comfort care at home**

Core ideas - Support the family; adequate material; adequate structure; financial support; technical support; emotional support.

*Collected Subject Discourse (CSD 3) - Honestly, I don't know how it could be improved; sometimes I ask the help of my sisters or the family doctor, but it's difficult. My family says they can't stand seeing her in this situation, and for this reason, they won't help. But they could at least help with the house chores, so I could have some rest. If I could share the responsibility with the family, also financial responsibilities, the burden wouldn't be so heavy. There are no resources to buy a wheelchair, a shower chair, a homecare bed, you know, to adapt the house. It's very difficult because there's not even a nurse to supervise or at least give some guidance. It's complicated; we don't know what to do, I needed guidance on how to provide care, to know if I'm doing it right, I get very insecure. I've never experienced this in my life and never saw anybody pass away.*

### **Theme 4 - The city's support networks to which the caregivers turn when in need**

Core ideas - Public services; healthcare insurance plan; friends and neighbors.

*Collective Subject Discourse 4 (CSD 4) - What we really seek when we need help is the urgent medical service, which does not always respond promptly. We also seek the closest PHC unit, the municipal ER, UNESP, and the health care insurance plan. But those who help the most when we ask for help are our friends, family members, and neighbors.*

## **DISCUSSION**

This study's limitations are related to the fact it was developed in a single health service, with local particularities. On the other hand, the results allowed understanding the magnitude of the difficulties faced by the caregivers of patients receiving comfort care at home and the set of complex interfaces that permeate FHS actions.

The process of demographic and epidemiological transition, characterized by population aging and the increased prevalence of non-transmissible chronic diseases, especially cardiovascular diseases and neoplasms, have imposed the need for care provided at the end of life, demanding that healthcare services be reorganized.<sup>11</sup>

In this context, even though the premise of the FHS is health promotion, protection and recovery centered on the family, in the city where the study was conducted this role is restricted, limited and only occasionally followed when providing care to patients who have no possibility of a cure. One study, conducted in the interior of Minas Gerais, Brazil that assessed the satisfaction of professionals and the community with the work performed by the FHS, reports that a lack of access to services, a lack of training, and an insufficient number of health providers to meet the community needs, are limitations of the service.<sup>12</sup>

In addition to these limitations, there are also operationalization difficulties, both in regard to the identification and the referral of patients with this specific profile. Hospital facilities, at the time of discharge, do not always contact FHS teams to refer the patient. As a consequence, the family caregiver becomes responsible for the entire care process.<sup>3</sup> A lack of a culture to share care actions among healthcare providers in the different spheres of the healthcare network still presents a barrier to the optimization of palliative care, as it hinders mapping cases that demand this type of care.<sup>13</sup>

Even though the Relieving Pain and Palliative Care Brazilian Program was implemented more than ten years ago, a national policy is still needed to connect initiatives to provide care at the end of life within a mainly palliative and integrated model,<sup>11</sup> intending to improve quality of life by alleviating pain and controlling symptoms allied with psychosocial, spiritual, and multidisciplinary support provided both to patients and their family members.<sup>14</sup>

In this context, caregivers are often the only source of social and emotional support to patients

and play an important role in the management of the disease.<sup>15</sup> At home, however, the caregiver is obliged to play multiples roles and is the only person providing care, often relinquishing his/her own life, and only occasionally receiving the help of other family members.

There is also a moral obligation imposed on the family to assume care in a situation of terminal disease, while they do not have proper training or qualification for that function,<sup>11</sup> which exposes family caregivers to complex interfaces that permeate the dynamics of providing care to a terminal patient at home.<sup>16</sup> Such a role implies considerable personal costs for these individuals who need to have their own needs addressed.<sup>17</sup>

This qualitative study was conducted with caregivers of individuals with advanced diseases and shows they require physical, practical, and psychosocial support to persevere through the demands of homecare.<sup>18</sup>

This study shows that the the caregivers expressed many difficulties, which were linked to lack of support, human, material and financial resources, unpreparedness to deal with death in the context of terminality and social isolation. This study corroborates the findings of other studies addressing this topic.<sup>8,11-12,19</sup>

In this context, in which managerial, technical and psychosocial support is also absent, the burden of caregivers is intensified and aggravated when care involves cancer patients and financial hardship.<sup>20</sup> One study conducted with 1,271 caregivers of cancer patients in Italy reveals that, even though families are responsible for a small portion of all the costs accruing from homecare, the impact of the disease on daily activities and on the family's budget can still be substantial.<sup>21</sup>

Additionally, one should consider that the comfort care of a patient in their home, in its permanence, is not always peaceful, especially when the management of pain and other symptoms is inefficient and requires unexpected visits to a health facility, compounding the stress on the family. Researchers who interviewed 53 informal caregivers identified that stressors affect not only one's perception of care needs but also the disease and coping strategies.<sup>22</sup>

One study that addressed the experience of a caregiver of a patient who was an allogeneic hematopoietic stem cell transplant recipient reveals that, even though the effects of homecare stressors are

inevitable for the caregiver, the identification of risk factors is essential, as is assessing the extent to which the life and health of caregivers can be negatively affected, so that multidisciplinary interventions are devised, especially at a primary health care level.<sup>19</sup>

Social support has been indicated in the literature as being able to mediate the negative effects that compromise interpersonal relationships, while positive strategies enable coping strategies, which imply the provision of diverse information, emotional and technical support to caregivers through a continuous health education process.<sup>23</sup> One study revised sociodemographic risk factors and adverse events related to the overload of caregivers and reports that the assessment of interventions in the psychosocial and pharmacological spheres should be applied to the individual circumstances and the context to which they are linked.<sup>24</sup>

The caregivers addressed in this study did not mention any support directly provided by the FHS, even though it is supposed to provide such support, as FHS teams are capable of strong interventions in the complexity of problems these individuals experience. It is, however, imperative that these healthcare providers identify the caregivers requiring assistance, are sensitive in assessing the needs of each individual, and recognize their role within the health service in order to implement support actions provided through the establishment of bonds.<sup>18</sup>

Patients and families should be invited by healthcare providers to participate in decision-making concerning the treatment established and the implementation of care, in order to build a relationship based on trust. One Canadian study conducted with 17 caregivers cared for by the family medicine program verified that only 35% of the participants preferred care be provided to the patients within the hospital facility. Most (77%) reported being prepared to provide homecare and almost all (94%) the participants were comfortable with the management of care provided to the patient at home. The main reasons for such findings are related to the conditions and support offered by the program that allowed the patients to be comfortable and relaxed at home.<sup>25</sup>

Within the FHS sphere, communication is key to implementing health education, the purpose of which is to encourage and provide tools for self-care through reflection and actions that change the attitudes and behavior of those using the FHS service. The caregivers in this study, however, did

not report this as being a resource used to guide the homecare process.<sup>26</sup>

This reaffirms the assumption that healthcare providers do not acquire communication skills as they acquire more professional experience. Rather these skills are acquired with proper qualification and training in service. A randomized study assessing the effectiveness of a training program that focused on communication skills among nurses demonstrated the positive impact of this intervention on the patients' quality of life and greater satisfaction with the care provided by healthcare workers.<sup>27</sup>

On the other hand, it is apparent in the literature that health education is often not provided by the FHS professionals because they do not have a profile that conforms to the program guidelines, which leads to a lack of interest and commitment toward the community's health needs.<sup>28</sup>

And finally, in the attempt to bring the FHS into proximity with the community, it is essential that health workers disengage from the traditional concept of health and understand that the objective of interventions at home is not to unveil the secret to change the current healthcare model but to acknowledge the knowledge of the various individuals involved in the process and that can contribute to the daily construction of care.<sup>29</sup>

## CONCLUSION

The difficulties expressed by the caregivers reflect personal unpreparedness in combination with social and economic instability experienced within the home context. Additionally, they face restricted and discontinued care on the part of the FHS.

From the perspective of the interviewees, the actions to improve comfort care should include not only aspects that are inherent to the proper delivery of care at home, but also financial, technical and emotional support to the caregiver/family. Support networks acknowledged by the caregivers include public services, the companies of healthcare insurance/plans, friends and close neighbors.

In this context, it is important to note that one of the greatest challenges of the FHS is the need not only to qualify the staff working in the program to provide adequate care in the context of terminal diseases, but also to review the work processes in the context of care. Palliative homecare requires availability of time on the part of health providers,

strengthened bonds, and an available and flexible support network.

Finally, it is expected that this study's results will contribute to the reorganization and connection of actions within the FHS, as palliative care is an interdisciplinary care practice that is under construction and demands effort to be effectively implemented in the current Brazilian healthcare system.

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