



Perspective of the Family Caregiver in View of the Benefits of the Permanence of the Person with Advanced Chronic Illness at Home

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Abstract

Background: The technological advances and the improvement of health care verified in the last decades, combined with the current economic and health policies allow and guide for the provision of care to move more and more from the hospital environment to the home, even when we are facing more advanced stages of the disease. In this context, the family appears as a key element in the care process, since it assumes and plays a major role in the maintenance and continuity of care at home.

Objective: To analyze the perspective of the family caregiver in view of the benefits of staying with the person with advanced chronic illness at home.

Methodology: Qualitative study, case study. For data collection, semi-structured interviews were carried out with ten family caregivers of people with advanced chronic illness, admitted to surgery units of a Local Health Unit in the metropolitan area of Porto and discharged to their homes. Content analysis was carried out according to the Bardin. The study respected the ethical-moral principles.

Results: The family caregivers emphasize several benefits of the permanence of the person with advanced chronic illness at home, such as providing love, comfort and a accompanied end of life process.

Conclusion: Caring for a family member with advanced chronic illness at home allows the provision of care in the comfort of home and in the company of those who are most loved, surrounded by gestures of love and affection, providing the best possible well-being and quality of life.

Keywords: Emotional Experience; Family Caregiver; Person with Advanced Chronic Illness; Transition; Home

Abbreviations: HIV: Human Immunodeficiency Virus;
AIDS: Acquired Immunodeficiency Syndrome.

Introduction

The increase in average life expectancy, seen in the last decades, is reflected in the health status of communities, such as the significant increase in chronic diseases and the number of people with multiple comorbidities, resulting in a greater need and complexity of care [1,2]. Chronic disease is defined as a long-term disease, usually with a slow progression, and which covers a variable set of situations, such as cardiovascular disease, diabetes, asthma, chronic obstructive pulmonary disease, oncological disease, human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS), mental and psychiatric illness, as well as diseases of the musculoskeletal system, which often result in disability and require long periods of supervision, observation and/or care [3].

For this reason, they are often characterized as complex and multimorbidity situations, which imply multidimensional, integrated and continuous approaches at the various levels of care in the health system and that involve different sectors of society [4]. On the other hand, the management of chronic disease implies continuity of care since, being of slow progression and associated with an increase in the degree of dependence, it requires the existence of a caregiver who can assume the (co) responsibility for this management and maintenance of the sick person at home. In the face of an aging population, dependent and with advanced and progressive chronic diseases, it is a priority to implement and adapt strategies that allow responding to the global needs of patients and their families [5].

Once diagnosed, the disease becomes part of the person's life and the entire family system, so, given the inherent complexity of their experience, it is important to reflect on the impact that this condition may have on the quality of life of the sick person and family. Taking care of a family member at home, according to the wishes of both, allows them to live in their family environment with more individualized, personalized care, with greater comfort and proximity to those dearest to them [6]. Given the fundamental role of the family and the caregiver in the care process, in Portugal, Law No. 100/2019 [7] of 6 September is introduced, which approves the Informal Caregiver Statute, regulates the rights and duties of the caregiver and the person cared for, as well as establishing the respective support measures. In this research, the concept of family is specified in a systemic perspective where affective bonds predominate. It is a complex, evolving and context-dependent system, which gives it its own identity and allows for self-organization. According to Ordinance No. 64/2020 of March 10 (p. 6) [8], the informal caregiver is defined as "the spouse or unmarried partner, relative or similar up to the 4th degree of the straight line or line collateral of the person cared for, who accompanies

and takes care of them". The main informal caregiver in this research consists of the "informal caregiver who monitors and takes care of the person cared for permanently, who lives with them in a shared housing and who does not receive any remuneration for professional activity or for the care he provides to the person being cared for".

In this context, and in accordance with the assumptions above, the following research question arises: "What is the perspective of the family caregiver regarding the benefits of staying at home for a person with advanced chronic disease?", which lead to define as the general objective: To analyze the perspective of the family caregiver in view of the benefits of staying at home for a person with advanced chronic disease. This study aims to contribute to families continuing their life projects with quality and to develop intervention strategies that aim to preserve the well-being of families and the person cared for, through training and emotional support.

Theoretical Framework/Rationale

In the current demographic and socioeconomic context, the increase in average life expectancy and the prevalence of people with progressive and disabling chronic diseases, reflect a greater need and complexity of care, implying new ways of caring. The family plays a fundamental role in the care process, given that it assumes its continuity and the maintenance of its elements at home. However, the responsibility of providing care to the person with advanced chronic illness in the performance of their daily activities has been identified as one of the factors that can precipitate important emotional changes and influence the well-being of family caregivers.

Caring in the home context implies the transfer of a series of responsibilities to the family, which can be a source of tension and burden on the caregiver, as well as triggering needs arising from the exercise of their role, with repercussions on their health and well-being [9]. As the disease progresses, caring tends to be a more demanding task, as there is often an increase in dependence in carrying out activities of daily living and greater complexity of care. Providing care is time consuming, requires dedication and abdication, involves physical and mental effort and has an impact on the various areas of family life. Changes in rest and leisure activities, in the organization of day-to-day activities, in the marital and parental relationship, in the family's work and economic situation, are commonly reported, as well as the need to resort to formal and informal support [10-12].

Delalibera M, et al. [13] shows that caring is also related to states of anxiety, depression, tension, stress, feelings of helplessness, helplessness, social isolation, physical and mental fatigue, sleep deprivation, financial difficulties and

support as well as a decrease in the quality of life. However, families continue to keep their families at home, ensuring continuity of care. Studies carried out by Sapeta A [14] show that families prefer to take care of their family members at home and that they, in turn, prefer to be cared for by their family members. Caseiro A, et al. [5] corroborate this fact by stating that patients and families prefer to stay in their homes, even facing illness and even death processes, regardless of their personal, family, cultural and socioeconomic differences.

Taking care of a family member at home, according to the wishes of both, allows them to live in their family environment, with more individualized, personalized care, with greater convenience and proximity to those who are most dear to them [6]. Coleman E, et al. [15] state that recognizing the importance of caregivers in maintaining their family members at home involves knowing how to listen to them and integrating their preferences in care planning. The nurse thus plays a fundamental role through a global and holistic approach to the patient and family, taking into account their entire physical, psychological, social and spiritual dimension, in order to improve their well-being and quality of life.

In fact, scientific evidence has shown that family members, absorbed by the complex function of caring, start to live almost exclusively for the patient, in favor of their personal needs and desires, which can lead to the development of a series of consequences in the personal, social and emotional life of the caregiver. Shyu YI [16] developed a study to explore the needs of family caregivers in the transition from hospital to home. The results revealed that their needs relate to the three identified phases of adaptation to the role of caregiver:

- Role engaging - commitment phase, which occurs in a hospital context, in which the patient and family caregiver begin to raise awareness about the assumption of its role;
- Role negotiation - negotiation phase, which takes place immediately after returning home;
- Role settling-resolution phase, which concerns the adaptation and stabilization phase of the caregiver role.

The return to the home can also be explored according to Meleis A [17] Theory of Transitions. For the author, the concept of transition translates the passage from one stage of life, condition or state to another. It presents itself as a multidimensional concept, closely related to change, development, evolution and adaptation, which results from a complex interaction process between the person and the environment. The knowledge of the experiences and strategies and compensation mechanisms used by family caregivers becomes important for understanding family experiences and subsequent development of interventions.

The nurse thus plays a key role through a global and holistic approach to the patient and family, taking into account their entire physical, psychological, social and spiritual dimension, in order to improve their well-being and quality of life.

Methodology

According to the problem and objective of the study, this investigation is assumed as a qualitative study, since it is intended to know the reality of a certain phenomenon, based on the perceptions of individuals, in a search for meaning, interpretation and meaning of particular situation or context. Qualitative studies aim to discover, explore, deepen and describe the phenomena, understanding their essence [18]. As stated by Fortin M [19], it is in the “methodological phase that the researcher determines their way of proceeding to obtain answers to research questions or verifies hypotheses”, so the nature of the study design will depend on the purpose of it. Thus, researchers who use the qualitative approach are interested in how people give meaning to their life experiences, in which the process of conducting the research “reflects a kind of dialogue between researchers and their respective subjects”.

Type of study

The first stage of the methodological phase points to the choice of the study design, in which the researcher defines what type of study, will be used, taking into account the research questions and objectives, as well as the adopted approach, in this case, the qualitative one. Bogdan R, et al. [18] state that qualitative research is descriptive, as the data collected is translated into words and not numbers. On the other hand, the descriptive design seeks to obtain more information about the phenomena to be studied and it develops in its natural environment, without introducing or manipulating variables. Since we want to know the perception of family caregivers about the benefits of caring for a person with advanced chronic disease at home, our type of study focuses on a case study.

According to Fortin M [19] “The case study consists of the detailed and complete examination of a phenomenon linked to a social entity (individual, family or group)”, enabling the obtaining of in-depth information about a new phenomenon and in a specific context. The researcher is interested in the “signification of the experiences lived by the individuals themselves”. Coutinho C [20] states that the case study seeks to describe reality in a complete and profound way, highlighting the complexity of the situation and the multiplicity of facts that involve and determine it. In this sense, the use of qualitative methodology was an option taken by the researcher, as it allows her to approach social situations, to describe and understand them, based

on the knowledge and opinions of the people involved in the situations. We consider that these interact with other elements of the social context, based on the meaning and knowledge they have about themselves and reality.

The study was carried out in the surgery department of a Local Health Unit in the metropolitan area of Porto.

For the selection of study participants, a non-probabilistic sampling method was used for convenience, since the participants are elements of the population that are easily accessible at the location of the research and at a given time. The number of participants was determined by the principle of data saturation.

Inclusion criteria were defined as:

- Being a family member of the person with advanced chronic disease,
 - Being 18 years of age or older,
 - Accepting to belong to the study and
 - Assuming the responsibility of caring for the patient in the home after discharge from the surgery service.
- Exclusion criteria were all parameters that are not included in the inclusion criteria.

The study therefore counted on the participation of ten family caregivers of the person with advanced chronic illness admitted to the surgery service and discharged to the home, who will provide permanent care and who lives with the person with advanced chronic disease in a shared housing and who do not receive any remuneration for professional activity as a caregiver. It was considered as an advanced chronic disease, a disease with significant and disabling progression, with multidimensional suffering, regardless of the expected survival.

For data collection, a questionnaire was applied in order to obtain a brief sociodemographic characterization of family caregivers and the person cared for, followed by a semi-structured interview, composed of open questions, allowing participants to freely express their experiences. After obtaining the data, Bardin L [1] content analysis method was used. It should be noted that, in relation to the characterization of the person with advanced chronic disease, the assessment of their degree of dependence was carried out according to the Mahoney F, et al. [21], since it constitutes the instrument for the assessment of functional capacity of the person that is validated for the Portuguese population [22] and integrates the nursing practice support system. In order to ensure the matrix for conducting the interview, as well as the perception and interpretation of the narratives, they were always carried out by the researcher.

At the beginning of each interview, the objectives of the study were presented and explained, followed by the request for authorization to record the audio, safeguarding its confidentiality and anonymity. The family caregiver signed the Declaration of Informed Consent, Free and Informed (Declaration of Helsinki), clarified any doubts and was informed that, since their participation would be free and voluntary, they could interrupt or desist whenever they wanted to. Regarding the time horizon and physical space where the interviews took place, they were carried out between December 2019 and July 2020, in a service office, at an opportune date and time for the family caregiver, lasting an average of 30 minutes, having been interviewed only once. During the interviews, some notes were also made regarding behaviors related to non-verbal communication, since there are certain comments that are accompanied by emotions and facial expressions that cannot be recorded, but which are to be valued and interpreted, such as the smile, the sigh or the posture.

After data collection, it is necessary to analyze and systematize them for a better understanding. Data analysis “Involves working with the data, organizing it, dividing it into manageable units, synthesizing, looking for patterns, discovering the important aspects and what must be learned and deciding on what will be transmitted to others”.

To this end, the method of content analysis by Bardin L [1] was used, defined by the author as “A set of communication analysis techniques aimed at obtaining, through systematic procedures and objectives of description of the content of messages, indicators (quantitative or not) that allow the inference of knowledge regarding the conditions of production/reception of these messages”. The content analysis process was based on the four phases proposed by the author: organization, coding, categorization and inference, taking into account the three chronological polls: pre-analysis, material exploration and treatment of results, inference and interpretation. The data analysis performed thus allowed the construction of a final data matrix and the respective categories, subcategories and units of analysis, enabling a global view of the phenomenon under study.

In order to guarantee all ethical and legal procedures, a formal request was made to the institution's Ethics Committee for the implementation of the research study. After a favorable opinion, data collection was initiated, with informed, free and informed consent from all study participants, formalized through a written document. The commitment to confidentiality, anonymity, as well as the destruction of all information after data processing was safeguarded. The confidentiality of the sources of information was guaranteed throughout the process, through their identification in a coded form.

Results

We found that regarding the profile of the family caregivers who participated in the present study shows that the majority are female (with a male caregiver), married, aged between 37 and 70 years (average of 57.5 years) and cohabits with the sick person. Regarding the degree of kinship with the person being cared for, it appears that 70% are daughters and 30% spouses. Most of the family caregivers in the study do not work (40% are unemployed and 30% are retired) and about a third (30%) remain employed. As for educational qualifications, basic education (60%) prevails, followed by secondary education (40%). With regard to the number of household members, it appears that half of the households are composed of three members, with the remaining five households being composed of one, two, four, five and six members. It appears that the majority of family caregivers cohabit with the sick person.

Regarding the time of providing care, it appears that 20% of family members have assumed the task of caring for less than a year, 30% between one and three years, an equal percentage between four and six years and 20% are caregivers more than seven years ago. Regarding the profile of the person with advanced chronic disease, the majority is female, aged between 70 and 88 years old (average of 78.1 years old). There is a greater expression of oncological diseases (40%), followed by dementias (20%), kidney disease (20%), heart disease (10%) and liver disease (10%). According to the Mahoney F, et al. [21], all patients have some degree of dependence on self-care, with 50% being severely dependent, 30% moderately dependent and 20% slightly dependent.

After analyzing the narratives, the results of the study reveal that, from the perspective of family caregivers, the permanence of the person with an advanced chronic disease at home allows for love, comfort and accompanied end-of-life process. Being able to provide love is mentioned by the family caregiver of the person with advanced chronic disease at home as something very gratifying, as it can create emotional bonds, thus smoothing the negative effects of the care process. The more cohesive the family bond, the lesser the existing imbalances and disturbances. In this context, four family caregivers report that providing love is one of the benefits of staying at home for a person with advanced chronic disease, in addition to helping them to prevent complicated grief:

(...) Yes, in my case, it benefits a lot. Because... in the case of my mother, for example, they already wanted to take her to a rehabilitation center and I was unable to sign her to go there because I think she was better off with me. Because I ... in my case I think ... and love was so much that it gave them that I thought she deserved it, so ... it really had to be out of

love because I think she deserves it, she doesn't deserve to be abandoned or ... or anything (...) FC1

(...) The good part... of this part that she will live in is that we can give her quality time, affection, pampering... that when we do that, we are also pampering ourselves (...) FC5

(...) I speak for myself. I am well. For me, it is her being with me (...) people who like her (...) It's not out of obligation, it's out of love, that's all (...) FC10

In fact, the possibility of the family member being able to provide love, according to the testimonies, facilitates an environment of affective interaction, the demonstration of openness, interest, attention and availability, which facilitates the realization of mourning. Providing comfort to the person with advanced chronic disease is something urgent for the family caregiver, emphasizing the importance given to a respectable appearance, providing a private environment and guaranteeing confidentiality is for five caregiver's reasons for benefit:

(...) it is the best situation, the patient is at home. (...) So much so that I took care of everything for her to have maximum comfort at home (...) FC4

(...) Now more than ever, try to give her the greatest comfort and the best that she can have until the end, even. FC6

(...) I think ... it is ... it is ... it is the comfort of the person to know that he is going but that he is in the corner, it is not ... the corner he has, it is the visits he may have ... from the family ... Yes, I just think there are benefits. Being in our midst, not least because after being in a much more hospital environment, it is not, it ends up not ... visits are not when you can ... not be ... it is different. No ... I think there are only advantages ... with such a guaranteed technical component ... FC5

In fact, comfort is for the family caregiver a central value to preserve the person's dignity, that is, for them; it marked the difference and maintains the person's identity as a dignified social being. Providing an accompanied end-of-life process is one of the benefits that the family reports, however it is a very complex task for the family caregiver, often placing them in a position of great vulnerability. However, they state that primary care is their support, assistance and monitoring to be able to take care of their family member in order to maintain their dignity.

This monitoring of the patient and family caregiver implies a continuum of care, allowing for a greater possibility of integrating the physical, psychological, social, spiritual and economic dimensions, improving the relationship between recipients and caregivers, reducing the misuse of health care services with an eventual reduction in costs, a reduction in the fragmentation of care, information and guidelines, as well as an increase in the satisfaction of patients and families, as mentioned by four caregivers: It is important because we

know that one day they have to leave, as we also have ..., but we are with them until that time, it is not It is much more ... it is much more important than calling me from the health center or the palliative center ... to tell me that ... look at your mother passed away, isn't it ... it might happen one day down the stairs and my mother being ..., but it's different, it's with me. FC6

Yes, it is being in the family environment ... I think it is very important (...) FC7

(...) I think the patient always likes to be at home next to theirs, I think that... I think it's great. FC9

In summary, assuming the family caregiver as a subject of nursing care and not just as a partner, enhances health gains, both for the patient and for the caregiver. Thus, knowing the perspective of the family caregiver regarding the benefits of being able to care at home is essential for health professionals to contribute to a greater effectiveness of the care to be provided and, as such, more effective and efficient care.

Discussion of Results

Technological advances and the improvement of health care seen in the last decades, combined with the current economic and health policies, allow and guide for the provision of care to move more and more from the hospital to the home environment. Since this provision of care implies the existence of a caregiver, it is important to know more specifically, from the perspective of the family caregiver, what are the benefits of staying with the person with advanced chronic illness at home.

The family caregivers of the study consider that at home there is a greater availability of time to provide care, attention and allows maintaining the emotional bond between the family and the patient, in which the provision of care is involved in actions and gestures of respect and solidarity. Thus, the home seems to be the place where there is the greatest opportunity to pamper, give affection and provide love to your sick relative. Fernandes A [23] mentions that the permanence of the sick family member at home allows the continuation of a relationship of affections.

On the other hand, it allows the provision of care in the patient's space, according to their preferences and routines with greater convenience, tranquility and cosiness. The caregivers revealed to prepare the return of their relative, through changes and adaptations in the home structures and the purchase of support equipment adapted to the home and the patient's needs, in order to provide comfort.

A clear sense of protection and belonging can be seen in the reports of family caregivers, coupled with the family's affective bonds, which leads them to consider that providing a accompanied end-of-life process is also considered a

fundamental premise for the patient and family. They value the fact that their sick family members can stay with the family, increasing the importance of mutual presence until the end of life. Fernandes A [23] even states that "enabling the end of life at home accompanied by love is fundamental for a decent end of life".

These assumptions become evident in the verbal statements of family caregivers, considering that the permanence of the person with advanced chronic disease at home provides greater monitoring, comfort and affection, inferring that the care provided by the caregiver aims at well-being and the quality of life of the person being cared for. Also the studies by Cunha A, et al. [24] and Oliveira M, et al. [25] show that, in an advanced stage of the disease, family caregivers perceive that love, affection, attention, comfort, well-being, availability and companionship are fundamental aspects of the care process. According to Rocío L, et al. [26], caring for a family member is a way of expressing confidence, compassion, gratitude and protection.

In the study developed by Ponte A, et al. [27], which aimed to compare the perspective of the patient and the family about the well-being of the palliative patient, the authors concluded that the absence of pain and the presence of the family were considered by both to be overriding factors for your well-being. However, contrary to the findings of this study, dying at home was considered by both the patient and his family, the least important aspect for the well-being of the palliative patient, a fact that the authors consider may be associated with the family's perception of disability to care for the sick person at home. However, the authors also add that, when there is agreement between the patient and family on the place to face the end-of-life process, the levels of well-being are higher, and this choice will depend on several factors, such as needs, characteristics and will of both parties.

Considering that advanced chronic disease falls within the "set of clinical situations whose patients are included as a target population for palliative care" [28], we found that the benefits of the patient's stay in the home, according to the reports of family caregivers in this study, are based on some of the principles and objectives of providing the same care. Thus, taking care of a family member at home makes it possible to provide care in the company of those who are most dear to them, wrapped in gestures of love and affection, with the comfort of their home, aiming at their well-being and possible quality of life. Taking these assumptions into account, the implications of this research for clinical practice are based on the following aspects:

- The existence of social support and emotional support networks that guarantee the quality of life for family caregivers is important.

- Creating spaces for critical and reflective discussion within the health team in order to develop specific skills in the context of communication/information in order to enable the family caregiver to provide care and for their emotional self-management.
- Investing in more research in nursing that gives voice to other family members.
- The existence of elements of the nursing team with a specialty in Community Nursing will be preponderant for the dynamization of the implementation of interventions that promote the minimization of the suffering of people with advanced chronic disease and family caregivers.
- It is pertinent to extend this study to other care contexts.

Conclusion

From the results of the study, we can see that family caregivers recognize that the permanence of the person with advanced chronic disease at home provides greater monitoring, comfort, affection and, consequently, well-being and quality of life of the person being cared for. In turn, it also provides family members with intimate moments and sharing of feelings and emotions. However, they recognize that upon discharge from the hospital to the home, the nurse must ensure that the basic needs of the sick person will be met and, as such, it is their responsibility to support in an integrated manner, offer guidance, provide information necessary for care and provide health care to family caregivers, detecting their needs, difficulties, problems, among others.

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