Phenomenological study about the nurse's home care for families of terminally ill patients*

ESTUDO FENOMENOLÓGICO SOBRE A VISITA DOMICILIÁRIA DO ENFERMEIRO À FAMÍLIA NO PROCESSO DE TERMINALIDADE

ESTUDIO FENOMENOLÓGICO SOBRE LA VISITA A DOMICILIO DEL ENFERMERO A LA FAMILIA DURANTE UN PROCESO TERMINAL

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ABSTRACT

The present study is a qualitative and phenomenological research aimed to understand the phenomenon *Nurses working in the FHP (Family Health Program) and home care provided to the family living in a home where terminality of one of its members is being experienced*. The study was carried out with healthcare providers who work in the Southeastern Region of the city of Sao Paulo/SP, Brazil. Existential phenomenology was used as the theoretical background. This study made possible the comprehension of what this experience meant to healthcare providers in a moment of *being with the family* in an existential situation of loss and death, creating a home protection network in order to make this process of terminality of one of the family members as smooth as possible. Even though permeated by care giving filled with humane feelings, thus representing a unique and remarkable experience, it was also a weary and difficult event that triggered labor health problems.

KEY WORDS

Nursing.
Nursing care.
Hospice care.
Family health.
Home nursing.
Family Health Program.

RESUMO

Pesquisa qualitativa e fenomenológica que teve como proposta compreender o fenômeno: *Enfermeiros que atuam no PSF e o cuidado, em domicilio, à família que vivencia, nele, ao término de um dos seus membros*. O estudo foi realizado com enfermeiros que atuam na Região Sudeste do município de São Paulo, SP. Utilizou-se como referencial teórico a fenomenologia existencial. Com este estudo foi possível desvelar que essa vivência significou para os enfermeiros um momento para *estar-com-a-família* em uma situação existencial de perda e morte, construindo no domicílio uma rede de proteção para que o processo de terminalidade de um de seus membros fosse o mais ameno possível. Apesar de ter sido permeada por um cuidado de enfermagem repleto de humanidade, significando uma vivência única e singular, foi também uma experiência difícil, desgastante, representando situações geradoras de agravos a sua saúde enquanto trabalhador.

DESCRITORES

Enfermagem.
Cuidados de enfermagem.
Saúde da família.
Cuidados paliativos.
Assistência domiciliar.
Programa Saúde da Família.

RESUMEN

Investigación cualitativa y fenomenológica que tuvo como propuesta comprender el fenómeno: *Enfermeros que actúan en el PSF y el cuidado, a domicilio, a la familia que experimenta, en él, el término de uno de sus miembros.* El estudio fue realizado con enfermeros que actúan en la Región Sudeste del municipio de São Paulo, SP. Se utilizó como marco teórico la fenomenología existencial. Con este estudio fue posible revelar que esa vivencia significó, para los enfermeros, un momento para *estar con la familia* en una situación existencial de pérdida y muerte, construyendo en el domicilio, una red de protección para que el proceso terminal de uno de sus miembros fuese lo más ameno posible. A pesar de haber sido otorgado un cuidado de enfermería repleto de humanidad, significando una experiencia única y singular, fue también una experiencia difícil, desgastante, representando situaciones generadoras de agravios a su salud, en cuanto trabajador.

DESCRIPTORES

Enfermería.
Atención de enfermería.
Salud de la familia.
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Atención domiciliaria de salud.
Programa de Salud Familiar.

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INTRODUCTION

I have been interested in the subject of death, and especially in the work of health professionals in situations that involve human death, since my graduate studies in nursing. Nurses working with the Family Health Program (FHP) usually report that their daily routine involves weariness and suffering due to their taking care of families during the death and dying process of one of their loved ones at home. This caught my attention and raised many questions, which resulted in this study.

The strategy of the FHP, initiated in 1994, is to make the Unified Health System (UHS, referring to the Brazilian public health system – *Sistema Única de Saúde*) feasible and to reform primary care, and it has grown considerably over the last years. The program addresses the family, considered the main object of care. The family is understood based on the environment it lives in, since it is there that family relations are built both among family members and with others outside the family. It is also in that environment that the family strives for better life conditions. This permits a broader view of the health/disease process, and, therefore, of the need for interventions with greater impact and social meaning[1].

Nurses, with the family health team, are responsible for making the FPH work. One of the many roles of nurses is to make home visits (HV), which can be viewed as one kind of collective health nursing technology used for intervention in the family's health-disease process[1-2].

HV is one of the tools that help nurses to identify how families are structured in terms of the forms of work and life of the family members, how these forms are socialized among them, what pattern of solidarity developed in this universe, and how the family can contribute to the process of care, cure, or recovery of one of its members. HV is an activity that should be based on previous planning and should be supported by a process of systemized work that starts before the visit and continues after it; otherwise it would be considered mere social work[2-3] .

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Considering HV in families with a terminally patient at home, it can be inferred, based on the precepts of palliative care, that the patient's home is the best place for care because the patient's quality of life can benefit from living with family members and friends in his or her own environment[4-6].

HV in palliative care, in the FHP context, is a type of technology that demands nurses to be prepared to work with families inside their homes, be capable of articulating their technical knowledge with the reality experienced by the family, and be able to understand the meaning of disease, death, and dying in the nuclear family. These subjects are not well studied and are not often discussed in nursing practice[7-8].

Although HV is described as a modern nursing activity, it currently poses challenges to nursing schools because nurses must receive an education that provides them with deep knowledge and skills to deal with human relations in the context of family life. Studies about families, as a care unit, have shown that it is an emergent area for nursing and has achieved considerable theoretical advancement; nevertheless, in nursing practice, this movement remains timid. Furthermore, nurses often lack the skills to deal with human death due to poor health area curricula on this subject[2,7-10].

In this sense, the present study seeks to understand the phenomenon: *Nurses working with the FMP and the families with a terminally ill member at home*, by asking: how do those professionals feel about taking care of these families? How do they experience these situations? Therefore, the purpose of the present study was to learn, from the statements of those professionals, the meaning of their experience.

I believe that this study will contribute to FHP nurses by expanding their understanding about taking care of families experiencing a situation of illness and death in their homes, and by promoting discussions about the practice, teaching and research related to this subject.

THE THEORETICAL-PHILOSOPHICAL FRAMEWORK

To answer the questions of the present study, I chose to use a qualitative and phenomenological approach to research using Martin Heidegger's concepts of existential ontology.

Heidegger's phenomenology questions man's way of existing, which can only be revealed by unveiling the world. It seeks to recover the strangeness of things, or, better speaking, man's wonder over things, to try to show that everyday ordinary life, with its seeming monotony, hides the mystery of being. Heideggerian ontology may be a pathway to clarify the meaning of thoughts, feelings, perceptions, and behaviors, helping to understand the other as a human being, which is the center of this study[11-12].

Taking these concepts into consideration, from the phenomenological perspective there is an opportunity to understand some aspects of the *being-there-nurse living with the family* and *sharing* terminal situations at home, in their existential condition of *being-in-the-world.*

METHOD

This study was performed at Family Health Units located in the city of São Paulo. This study complied with the recommendations of Resolution 196/96 regarding the rules and

guidelines to be followed in studies involving human subjects (Bioethics register number 024/2006).

Study subjects were nurses who were working in the Family Health Units during the data collection period and who were experiencing or had experienced providing home care to families with a terminally ill member. All participants provided written consent.

I scheduled the interviews with the nurses using the following guiding question: *What is it like for you to take care of a family with a terminally ill member at home?*

The interviews were recorded, and the interviews were terminated when the discourses became repetitive to unveil the phenomenon. Seventeen interviews were performed, but four of them were excluded because, after careful review, it was noticed that they did not answer the guiding question. Each discourse was labeled with the capital letter *D* followed by a roman numeral, according to the order in which the interviews were collected.

The analysis framework used in this study was the Situated-Phenomenon Structure[13], in which the discourses were analyzed in two stages: ideographic, in which the researcher searches for the most relevant and essential information in the statements to unveil the phenomenon; and nomothetic, in which the discourses are analyzed as a group, with the objective of revealing the general structure of the phenomenon. Finally, the thematic categories were further developed and discussed in the light of Martin Heidegger's philosophy.

BUILDING THE RESULTS

During the search for the phenomenon, five thematic categories emerged. Below, I present and elaborate on the categories.

Being-nurse-with-the-family

The nurse, *launched* into the FHP reality, working in the outskirts of São Paulo, faces the fact that his or her routine involves taking care of families with a terminally ill member at home. In this *specialty*, nurses end up *coexisting* in that world and living with these people's feelings of *sadness*, *pain*, *hopelessness*, *fear,* and *hope* towards death, poverty and social exclusion.

> What really makes me miserable is this restriction. It's pragmatic, really... working in a place with so much deprivation, poverty, criminality, and negligence (DII).

The nurse, by entering these families' worlds, authentically experiences this situation and, by living this reality, initiates a sharing relationship with these people:

> The FHP, in the outskirts of São Paulo, [...] only has old people, children who dropped out of school, and the adults there are only home because they are unemployed. It is great affliction, utter abandonment, there are many types of abandonment. But then we arrive, and we are with them! We sit beside them, at first we don't know exactly what to do, but we start building in that direction (DI).

> So we bond and become part of the family. Family! We take care of those people, not only of the patient, everyone in that family builds a very strong relationship with us (DIII).

In some statements, I realized that the attachment of that professional with the family involves suffering, because when they become involved with the family problem, the nurses are no longer able to set limits to that relationship:

> You become attached to the family, and, in the end, you … it is like they are part of your life, you feel sorry for the person,... you become very empathetic. I remember it was close to Mother's Day and I was hoping... oh, my God, that he wouldn't pass away on Mother's Day, because... picture that mother, what would she feel? Her day would be... It's complicated, you end up seeing that family... you put yourself in the place of others a little, I guess. Sometimes, I think we exaggerate. And you... it's like that saying: you have your professional side, but also your human side, which is also very powerful, because you are attached (DXI).

Other statements reveal that some professionals, in spite of the sadness shared with the family, see that the attachment is important and positive for providing the care that is needed:

> I really like it, it is positive, there is a positive response, although the end product is the patient's death, and there is nothing we can do about it. It is good because you build a very strong attachment with the family. The family comes to you more often, they also come to cry because of the delay in getting the pension, they also come to laugh and invite you for a small party they are having, or bring you something different (DVIII).

The discourses show that, in this ontological unification, that *co-existing* with the family, in their existential world, permits nurses to share, live together with, and build with these people a pathway permeated with care. However, the way that professionals experience that unification is defined based on the many possibilities of *being-in-the-world-with-others.* Perhaps the fact of seeing the attachment experienced during the HV as something negative is centered in the social context of nursing that aims at meeting capitalist productivity, which focuses on accomplishing tasks and performing procedures. When the nurses face the opportunity to develop care that is centered in humanism, inherent to the FHP philosophy, they do not know how to manage their care practice and thus suffer with the feeling of sadness that permeates the relationship they have with the family[11-12,14].

Building a network for family protection

Based on their living with the family's *world-and-life*, nurses and their team organize the home space in which care takes place. Nurses often use their creativity to improvise environments within the house, using any material re-

sources available to build a space where the family is protected to live through the terminal situation:

> In the end, this patient passed away at home. We had obtained all the strongest medications to alleviate his pain. We improvised the gastrointestinal tube feeding with a nail on the wall, you know? We really shook the place! (DIII).

The technological resources found in hospitals are not available at Family Health Units. When nurses at HV realize a terminal patient is pain, they experience the suffering of the patient and the family that is caused by that situation. This often results in the nurse searching for medication at other levels of health care service, breaching rules determined by the same Health Care system.

> I like it, I do. I used to work in the ICU, I also had a lot of terminal patients there, who needed Dolantina, which is not easy to get out of the hospital; we literally stole it, I did it all the time (DVIII).

According to the Hedeggerian philosophy, man truly exists, establishes relations with the world and, being open to it, learns about it and reveals it. The human *being-here* leads us to place man in the space and as a *being-in-the-world,* man participates in it, organizing, relating things and assigning meanings to those nearby. Hence, the *FHP being-in-the-world nurse* gathers objects from the world and brings them closer, building a network to protect the family of the terminally ill patient[11-12].

In building the family protection network, the nurse, despite having technological knowledge in palliative care, faces the reality of FHP work. By visiting homes filled with deprivation and poverty, nurses realize the richness of their human technology as support and resource:

> There are places, like hospices, where people move from the process of pain to rest, the family will participate in this hospitalization and the person will rest a little, use devices that are better controlled in the hospital [...]. This reality is completely different from ours. But what can we do? If that's how they work there, what can we do within the limits of our situation? How can we do our best and leave with the feeling of having worked well? By giving support, holding someone's hand, listening to someone cry, and if we can't hold it inside, we cry with them (DI).

It should be noted that this nurse, in his discourse, described his experience as an intern at a *hospice* in Paris during his graduation studies. In his speech, he presents his knowledge about palliative care. When he recalls his previous experience at a high-technology center at both medical and human levels, he is able to overlap it with the current situation, using his knowledge and his story, providing quality humanized care, in a situation of deprivation and poverty. In the Heideggerian perspective, the *presence*, that is, the *being-there* has its history and can have it because the being comprises historicity being the happening in the story, being the happening of the *being-in-the-world*. Therefore, this nurse's historicity, marked by the experience of palliative care in a first-world situation, has an influence on his view of the world, giving uniqueness to the care he provides to the family with a terminally ill member at home, in the FHP situation. Comparing this discourse with the others, it is possible to understand that particularity[11-12].

Seeing care as unique

Nurses recognize the uniqueness of the care they provide in the HV and, later, they interpret it by describing the aspects that make it unique. One of the factors that emerged in the interviews as something particular to this nursing activity in the FHP, is the place where the care takes place, in addition to how the nurse becomes physically and emotionally close to the family:

> It is different from the hospital, which you leave knowing that a colleague will continue the care; there is a whole structure to support that family. The situation in public health, for those working with the FHP, is very different, you are a reference for that family: they stop following the recommendations they received at the hospital and really trust our professionals at the Health Center (DIII).

The home, a place rich with social and cultural meanings, provides nurses with the chance to approach the humanity in which the family is immersed, making it possible for them to provide more than technical-biological care.

> I know that our administration professors would kill us if they heard us say that. Because you are a nurse, and a nurse doesn't cry, doesn't get involved. The professional must set limits on the relationship with the patient. But in the FHP, these limits are beyond our imagination! For that reason, we are very happy and sometimes we suffer. We have to be mature to deal with these limits. Reality is in our face, you can't go by untouched, like the walls in a hospital. The hospital rules fill us with paper and bureaucracy. I have worked in a hospital before. For patients to reach you, they first have to go through a number of people: security, receptionists, you-name-it. It's not like that here. They knock on your door and call you by your name: *Mr. So-and-so is crying with pain, he's calling out for you* (DI).

By analyzing these speeches, I understand that nurses experience the possibility of *being-for,* that is, of *caring-with, worry-for,* going beyond the technical limits that the nursing profession often implies in the everyday practice. The possibilities of using the human resources of the profession are strong in the FHP because the nurses become very close to the patient and family's life situation. This favors the *being-with-others-in-the-world* and the *being-there-for-others-in-the-world*. Man, through different forms of solicitude, not only becomes known as a *being-in-the-world,* but also seeks to know other? individuals into? the world[11-12,14].

Experiencing difficulty being-with-the-family

The FHP nurse, as a being launched in the world of a family experiencing the death of one of its members at home, and *co-existing* with it, faces unexpected situations of abuse, carelessness and negligence:

And the fact that sometimes, during the visit, the family itself refuses to cooperate and they stay isolated. This makes me suffer a lot as a nurse, because it is negligence (DII).

Family negligence and carelessness toward the patient is a negative experience for nurses. These situations make nurses feel sad, surprised, powerless, and angry; and, during the visit to this family, they end up providing merely technical care to the patient and no longer offer the family the opportunity to be cared for.

This attitude is the nurse's choice, because becoming subjectively involved in these situations requires this professional to become involved withthe family's history, which is often marked with deep scars between its members. This requires the professional to have had specific training to deal with the families and to work, within the multidisciplinary team, with other professionals that could help in this situation[7].

Another factor experienced by the study subjects that makes the nurse/family relationship difficult refers to the family members asking for care that goes beyond primary health care, that is, beyond the ability of the family health team:

As for Maria, I think it was a relief. However, she thought that it was somewhat our fault, of the team, because we didn't provide enough care. She wanted us to visit the patient on a daily basis, you know? (DIV).

The paradigm of modernity, founded on the view of the rational individualized man and on technique as a synonym of progress for the future of humanity, remains predominant in our society and is intensely disseminated in the education of health professionals. FHP nurses, away from the technologies usually available in hospitals, feel their work is restricted and insufficient when providing care to families at home. Such a paradigmatic conception, centered on individualism and on intervention/cure, is focused on an unauthentic *way-of-being-in-the-world* frof nurses in their existential experience with the families. This makes is impossible to provide any care beyond scientific knowledge and blocks possibilities of thinking the unthought-of, of creating and caring for families not only through knowledge and technical resources, but through themselves, in their ontological condition of being taken care of[15].

Feeling physical and mental weariness

In certain home visits, nurses have an inauthentic existential experience and end up focusing the care on a technical-biological view. Furthermore, nurses realize the difficulties they are dealing with related to controlling the physical symptoms caused by a disease that is serious and difficult to take care of at home. With the purpose of obtaining support from the health care network, at both secondary and tertiary levels, these professionals realize the deficiencies of the Health System when there is a need to refer the terminally ill patient to a hospital. The nurses and their team suffer with a feeling of loneliness when providing primary health care to that family:

The hospitals didn't offer much support, so we ended up taking care of him until the last minute (DIII).

When nurses feel they are part of a health care network that does not offer any support to the family, they feel frustrated because they understand that, within primary care, they are unable to provide care with the same technical quality that is available in hospitals:

I think the technical part is limited by a few things, you don't have that many resources to take care of that patient (DIX).

These speeches show that nurses are centered on the technical-scientific dimension of care to the detriment of the existential view of man as a whole. Since they are also away from technologies, nurses feel weary when dealing with families in this specific situation, because the families often expect that their relative, who is terminally ill, will be cured. In other words, families often ask for technical care that is beyond the capacity of the family health team and of primary care:

Anguishing. Because you know you are going to take care of a patient. The anguish is not because of taking care of him, it's because you know you'll have to deal with his family. The patient is there, you take care, do everything you should, but the way the family demands things from you ... For you, it is about the patient getting better or not, the hard thing was that Ana wasn't a very understanding person. Sometimes she wanted us to be inside her house 24 hours a day, which is something we cannot do (DX).

In some discourses, the nurses report that, to protect themselves from the weariness inherent to home visits, they assume a technical posture as a way to deny the existential situation of terminality:

And sometimes we end up becoming a little cold and rational to deal with this more easily. Because, if you act on emotions, you end up 'putting your foot in your mouth'. I think that it would be even more complicated if that were to happen (DIX).

In discourse XII, the nurse realized that he held his feelings inside when he thought about the feelings he had experienced while taking care of a family living the process of losing one of its members:

I stop now to talk about something I experienced the whole time, but I find it hard to talk about it: what do I feel exactly, what is it? Do I feel, do I still feel anything? Sometimes we are so conditioned to take what you cannot solve and put it away behind that little locked door, that we even forget about it, and it gets difficult to open the door and see what's inside: *What is in there for me to talk about with her, what bothers me?* What I do remember is this anxiety, I think we suffer (DII).

These nurses'statements show that there is little space in their everyday work routine to talk about the feelings they have during their existential experience. Such difficulty in talking about death and dying can result in nurses hiding their feelings of sadness and powerlessness, making them more susceptible to work-associated psychopathologies.

Therefore, it is necessary to open more spaces in the nurses' work context to promote discussion about the negative feelings that emerge during this work activity [9].

FINAL CONSIDERATIONS

Performing this study allowed me to unveil some aspects of home visits by FHP nurses to families who are experiencing the process of losing one of its members at home.

This study allowed me to better understand that FHP nurses have specific characteristics, which makes their practice unique. Their ability to build an attachment by becoming close to the people they are taking care of is characteristic of their work with these families.

Another aspect that should be considered characteristic of these nurses is their creativity when facing the diversity inherent to their practice. Though the nurses suffer in many situations because of being thrust into a social and cultural situation filled with poverty, deprivation, and social exclusion, they overcome the situation using their creativity of *being-with-the-family* and they build a protective network for the terminality process.

The nurses' perception about the uniqueness of the care they provide usually occurs only after having a positive experience with a family. That is, the nurse only realizes the importance of *being-with-the-family* when the family members actually feel that the nurse is taking care of them: they value the nurse's presence in their home, and thank and thank the nurse for the care filled with humanity. Because the nurses become close to the family, they realize there are other forms of care and learn new ways to provide health care from their own practice.

Some very meaningful aspects of caring for terminally ill patients for these nurses are their feelings of anger, sadness, and powerlessness that emerge when facing family conflicts and because of some negligent attitudes. These feelings affect the way that nurses take care of the family, because the nurses end up creating an emotional distancefrom these people they now consider undesirable and awkward. The nurses' difficulty in working with such nuclear families is perhaps a sign of their inability to take care of families.

Despite their strong potential to provide the family with holistic care, the nurses' closeness to the family's life situation, in some cases, makes them shift from humane care to technical-scientific care, aiming at curing the patient who is facing death. This paradigm is strongly disseminated during the nurses' professional development. Nurses suffer with the distance between their practice and the high technology available in other levels of health care, which could mask the terminality situation they experience during the HV. Since they may not find a place to share these feelings, they become more susceptible to occupational health hazards.

The FHP is expanding rapidly in Brazil and its philosophy is becoming sounder as years go by. Studying specific topics such as taking care of families in a death and dying situation, which are complex and of broad practice, can contribute to improving the FHP and favor the humanization it recommends. Based on the experiences reported by the nurses in this study, it is possible to have different views about how this form of health care has been practiced. This allows for creating new strategies to overcome the difficulties that nurses have to deal with, by means of discussions and training programs.

Investing in studies that address the experiences of nurses in situations involving families and disease, death and dying and HV can promote new discussions about these issues, thus permitting the construction of a more humane nursing that is better prepared for situations inherent to nursing care. In addition, further studies on this topic can expand knowledge of palliative care, which is currently centered in the hospital environment.

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