Original Article

Meaning of home care and the moments experienced by oncologic patients in palliative care

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ABSTRACT

This study aimed to understand the moment and the meaning of home care for oncologic patients in palliative care from the perspective of the Paterson and Zderad's Humanistic Theory. This is a descriptive, exploratory study, with qualitative approach, developed with five oncologic patients in palliative care in home care. Data collection was conducted through semi-structured interviews, from May to August 2013. Thematic content analysis was used to interpret the information. The results revealed that patients identified home care as a substitute to hospital care, allowing more freedom, comfort, autonomy and strengthening the relationship with the health team. Participants pointed out that unproductive feeling against the evolution of the disease was hard. The potential of this model of care is in accordance with the assistance that aims to encompass the principles of palliative care, such as well-being and being the best possible for these patients.

Descriptors: Home Nursing; Palliative Care; Chronic Disease; Oncology Nursing; Nursing Care.

INTRODUCTION

The progressive aging population, coupled with the prevalence of chronic, degenerative diseases of slowly evolving and growing and steady rise in cancer cases are a challenge in the health field. In this context, Palliative Care (PC) is considered a very necessary step in an approach that seeks to promote the quality of life, prevention and relief of suffering of these individuals and their family members(1).

Ideally, PC should be provided from the diagnosis of a disease with risk of death, being adapted to the growing needs of patients and their family members and becoming the main focus of the assistance as the curative therapeutic possibilities decrease(2).

The care interdisciplinary team aims to control pain and other common symptoms such as anorexia, anxiety, constipation, depression, delirium, dyspnea, nausea and fatigue and other psychological and spiritual symptoms, using communication skills and establishment of individual care goals(3).

Home care is regarded as an approach facilitator factor to PC because it is focused on the reorganization of the health teams working process in order to humanize care, increase the autonomy of individuals and seek deinstitutionalization(4). Continuously expanding in Brazil, it aims to enhance the social and family context of the users(5).

Not all patients in palliative care are able to be at home until their death. However, a study conducted in Montreal(6) points out that this is the desire of most terminally ill patients and that home care structure can enable this permanence.

This scenario requires a multidisciplinary team that understand the multiple dimensions involving home care, so that with their "looks" and specialized perceptions they can draft a comprehensive approach that meets the individual-family needs(1). The multidisciplinary perspective on home care allows to understand and assist the patient at home, a propitious place to greater interaction between the assisted person and the professional, where affection can be expressed, unlike a clinic or hospital in which relations are often more distant(7).

In this sense nursing theories have contributed to the planning of care based on assumptions, such as Paterson and Zderad, who state that care is a qualified meeting between humans in response to a need on the health/disease process, aiming at searching for the well-being and being the best possible(8). Assisting the people in the perspective of this theory presupposes attention to the health needs holistically, encompassing the physical, psychological, biological and spiritual features(9).

Therefore, Paterson and Zderad's theory, such as other nursing theories, are designed as an epistemological contribution to the construction of knowledge and practice, as they enable knowledge of the care reality, associated in the definition of performing nursing. The humanistic approach of Paterson and Zderad's theory values human experiences(10-11) and meets the care needs, unlike the biomedical model that still persists in the health scope and, in a way, limits the form of experiencing the health-disease process(10).

In this perspective, this study focused on oncologic patient's experience in PC at home, thus identifying the strengths and weaknesses of this model of care. Moreover, it also focuses on understanding how the terminal human being experiences this condition and which factors related to the quality of PC will enable the health teams' reflection in a way to promote actions that can increasingly meet the needs of this clientele.

Thus, this study aimed to understand the experienced moment and the meaning of home care for oncologic patient in PC according to the Paterson and Zderad's Humanistic Theory.

METHODS

This is an exploratory, descriptive research with qualitative approach, based on the assumptions of the Paterson and Zderad's Humanistic Theory(8), held in a city in southern Brazil. The participants were five oncologic patients in palliative care, assisted at their homes by the Home Care Interdisciplinary Program (PIDI, in Portuguese) of a teaching hospital. The PIDI was implemented in 2005; the structure of the program holds 20 concomitant patients, divided into two teams. The direct care team (physician, nurse, social worker, two nursing technicians and two drivers) visits the patient twice a day, and the matrix support team, consisting of a nutritionist, a psychologist and a chaplain, visits each patient two to three times per week(12).

To select subjects, the following inclusion criteria were adopted: age equal or higher than 18 years; understanding their diagnosis; being in stable clinical condition; being lucid and oriented, verbal communication; clinical conditions incompatible to perform an interview was considered as inclusion criteria. Data were collected from May to August 2013 through semi-structured interviews with voice recording system.

To maintain the anonymity of the participants, the statements were referenced by the letter E (interviewed), followed by the numbers of interview order from 1 to 5. The survey was conducted according to the provisions of Resolution No. 466/12 of the National Health Council of the Ministry of Health, on Human Research and Ethics Code of Nursing Professionals(13). The research project was registered in the Brazilian Platform and approved by the Ethics Committee of the Medical School of the Federal University of Pelotas, n. 263,909 on April 30 2013.

Data were analyzed according to the fundamentals of thematic content analysis, in steps as described by Minayo(14): the first was the triage of data including interview transcription, material reading and organization of data collected the second was data classification and theoretical basis. The final analysis consisted of reflection, understanding and interpretation of material, from the perspective of Paterson and Zderad's Nursing Humanistic Theory.

RESULTS AND DISCUSSION

After data analysis two thematic units occurred: home care from the perspective of oncologic patients in palliative care; and experienced moment and the health team performance.

Home care from the perspective of oncologic patients in palliative care

Health care provided in people's homes allows in-depth understanding of the context in which the patient, routine, culture and family are inserted, thus potentiating the actions aimed at the pursuit of completeness(15).

Home care in oncology context in relation to the PC means a potential qualification of health care. The following statements address the assistance provided to patients during home care.

For me it was very good, I think there is all type of assistance[...], I do not have to move from my house to have a blood test, a urinalysis, I do everything in my house, I do not have to go out, if I had to leave I would be unable to do so. (E3)

[...] the injections I had in the vein in the hospital, they do it right, I already have access. In here everything is pill, but there is pill and liquid, they prescribe a syrup. They gave me an oil to take with morphine, because it dries out too much, so the oil is for the intestine [...] but it is very good [...] I thought if you're admitted you will have it in the vein, if not, then it is all in pills. (E5)

We noted that patients perceive home care as a substitute to the hospital, where there are possibilities of examinations and administering medications without leaving their houses, which is a benefit for people in PC.

As a tool that leverages new forms of home care production, home care focuses on the health needs of the patients(15). It highlights the health teams' potential as facilitators of access to health technologies, by developing the ability to manage care, with the establishment of different forms of organization of the working process and the use of tools/technologies(2).

It is possible to observe the speech of patients on the team commitment and their recognition as the care they received.

[...] the girls (nurses) who come here are very thoughtful, very good, they care about us. I realize, if anything happens... The other day I got sick, we phoned them and they came. (E4)

[...] today, we perceive a person’s responsible, the attention, which is very important, I perceive it [...] they ask things, they want to know deeply, I find it very important [...]. (E5)

Patients understood professionals as exercising their knowledge guided by the dedication and concern facing their condition. In this context, the nursing profession is understood as a careful response from a person to the other, in a period of necessity aimed at the development of well-being and being better, and the humanistic nursing, according to Paterson and Zderad, it is a special type of dialogue, which requires nurse/client involvement, and care, it is essential character(11).

Patients find in nursing a reliable link for comfort at this difficult time, minimizing their fears and anxieties. Therefore, it is important to plan actions in order to control the cancer impacts and to be sensible to identify physical, psychological, social and spiritual disorders(16).

Regarding the oncologic patients' autonomy, it is known that the hospital promotes a distancing, since several routines "must" be followed, unlike home care, in which the patients are free to carry out their usual activities according to their condition; considerations that are in accordance to what has been disclosed and described by the participants of the study.

If I want to do something I start doing [...] I light the fireplace, I sat down, I made a porridge, a "big porridge" I sat there, putting wood on the fire [...] in the evening I had a shower, took an hour in the shower, it was the best thing being there in the warm. (E2)

For patients care in PC occurs properly, it is necessary that they keep their autonomy, or control over their bodies. Thus, professionals need to go hand in hand with them, collaborating in their decision-making, never judging or deciding for them(17). With this approach, home care offers more comfort and quality of life and a better social interaction(13). The patients are in a familiar environment while maintaining their privacy, being able to perform tasks of daily routine, keeping some habits, leisure activities and food is more varied with not so rigid schedules. It strengthens the patients' autonomy and completeness as individuals(2).

A patient candidly exemplified how being in his house gave him autonomy in the simplest day to day decisions, for example, at any given time be unwilling to talk or receiving visits, and having the freedom to decide about that.

Look, for me to be at home is good, I am at home with my children [...] be able to hear their voices, able to eat, receive my friends, to me is quite comfortable, to talk to them (health team), I have fun with them. But there are days we do not want to see anyone, do not want to talk to anyone, I tell them to say that I'm not home, that I'm in the shower, that I'm here, that I'm there, that I'm not willing to talk with anybody [...]. (E3)

With the evolution of the disease, patients also reported the emergence of difficulties in carrying out certain activities and often frustrations regarding the impossibilities that started happening. The patient, who was experiencing a "normal", productive life, gradually loses many functions, realizing limitations and becoming dependent(18).

Depression, I have a lot of depression, sometimes I wake up in the middle of the night. Sometimes I have a lot of sadness, it is going away ... Being as I've always been, an active person, always working, active, always working, I used to do everything, everything, I walked in the courtyard, I did everything through my hands (crying), but not now, I depend on others to do anything [...]. (E3)

I'm getting used to it because it is complicated, I've always worked, I'm getting used to it [...] I became ill working, but as I was saying I lost the strength, I have no strength. (E4)

One of the major disorders addressed by the patients was the feeling of inactivity and lack of productivity, which pervaded their thoughts, and sadness against this is inevitable. This finding is an important observation, which instigates reflection about the possibilities for intervention that can help people in this situation. Thus, it is understood that with the progression of the disease and the impairment of physical condition, the need for a systematic and ongoing evaluation is justified in order to identify early disabilities that may affect the exercise of autonomy(19).

Many patients lose the ability to perform some activities, but others are possible, and the health professionals, in an interdisciplinary action, try to find ways for activities that are plausible and sometimes it is necessary to seek cooperation with other networks, not only from the health services. Thus, quality of life would be better for these patients, contemplating the great goal of the PC.

The experienced moment and the health team's performance

The concept of health advocated by Paterson and Zderad considers improving (being better), by the relationships with each other in community, and that the disease or medical diagnosis little do to determine the ability of a person towards health and that this can be found in the will that a person has to be open to life experiences(11).

It is what reveals the following statements, in which one of them spoke about his contentment as to how he was experiencing his life, despite the diagnosis, and other patients' statement on the family's contribution support to his moment of happiness.

Well, I feel good, [...] in the mood, I go out, I take a walk, peaceful [...] I turn on my radio, someone comes by and sits quietly to talk to me, we have mate, I like to drink mate, it makes me want to go out, so I go out, my wife and I go out to see my mother-in-law, I come back, if I want take a nap, I take a nap, all is good [...] I get up the time I want, I eat the time I want. (E5)

I'm having a very good moment, I say it every day, you know, I'm in a moment of happiness. I talk to my sister every day, she is 73 years old, my brother is 72 [...] they support me by phone, they talk, so now when I get better, when I feel stronger I will go to Santa Catarina, spend a few days there [...] the family, they are very supportive, my siblings are very supportive. (E2)

What has been described by the patient (E2) reveals the importance for people to spend the last days at home, accompanied by their loved ones. Home care is a more humane alternative, allowing the patient greater comfort and proximity to family(16). Care actions such as aid, support, company, as well as feelings such as affection, appreciation and love from family members, friends, neighbors and people in their acquaintanceship result in trust and loyalty relationships, causing patients to feel more safe and secure(20).

Given these observations, the participants of the study showed how home care and team performance provided them support so that the moment was experienced with more happiness, comfort and safety.

[...] the assistance that I have here, I think too good for me because any need you have you call the girls and they come here, it is a good service to us, it's good, very good [...] it is so true, I got here and I could not believe I was going to stay a week, I was so bad, I felt so bad, I felt that I was going to die soon, I would not take much longer, then this overturn happened, I fought against that feeling, this bad thing, and I believed, and I was so well assisted [...] it helped me so much that I'm here laughing, it helped me a lot, I really appreciated it, very good, I found the service was amazing [...] I'm in a moment of happiness [...]. (E2)

[...] I feel well now, I'm fine, I have no pain [...]. (E4)

Patient satisfaction due to their and their families' well-being with home visits from a PC team was also identified in a study in southern Spain. However, the team being composed of physician and nurse was described as a limitation of attention because of the centrality of care in controlling symptoms(7). In contrast, the health service that composed this study had a multidisciplinary team, which aims to holistically meet the needs of patients.

There were also moments, during the interviews, that patients expressed their thoughts about what they were experiencing, related to diagnosis and future expectations. The following lines allow two interpretations, one of which would be that the healing impossibility had not been approached directly with the patients or, if approached, they were going through one of the five stages of death and dying described by Kübler-Ross, which was denial(21).

I can almost see it [...] I am cured from this cancer, that this does not bother me, I have no short of breath, I sleep well, I take a walk, I ride my bike, so if I had something maybe I could not do this type of exercise [...]. (E5) As I told you I am very positive, I deal with this, so I will get better, I will recover. (E3)

In this process, after approaching the matter with the patient, when they are aware of the diagnosis, they go through the five stages, denial is among them. This or at least partial denial is observed in almost all cases in the early stages of the disease, after confirmation of the diagnosis, or sometimes at a later stage. People can consider the possibility of their own death for a while, but they need to set aside the thought and fight for life, which is a healthy way to deal with the painful and unpleasant situation they are required to experience(21).

Patients rely on health team members to address spiritual concerns(3); the professionals need to plan ways to address the issue of death, both with patients and with their family members. At this point, which is taking care of the other, the Humanistic Nursing Theory guides the professional action, highlighting the construction of a trust relationship in a process of human interaction respecting the singularities(22).

In this process dialogue is extremely important. It is understood from a concept broader than just communication, being used in an existential context, referring to a living dialogue, in which the nurse and the patient relate creatively. Thus, one must be open, receptive and available to the other reciprocally, in order to assimilate the existential moment of the other(8). In humanistic theory, dialogue is a precondition for the effectiveness of home visits, constituting a way to establish a creative relationship, with real experience sharing(9).

Healthcare professionals need to be sensitive, to have communication skills, listen to the anxieties, doubts and fears with gestures of affection, and be directed to the well-being and being better, considering the context of each patient as unique.

FINAL REMARKS

This study made it possible to give voice to the human being who is in PC, hospitalized at home, allowing that important aspects of this experience were known and understood from the assumptions of the Humanistic Theory, which provides important tools when thinking about care.

Home care is shown as a space that allows freedom, comfort and autonomy. It also provides that the health team's performance can contemplate the principles of PC, the bonds are stronger and the work of professionals can transform the moment experienced by these patients, bringing visible benefits, aiming at quality of life. Also, it helped identify the difficulties faced, as the feeling of sadness against the sense of unproductiveness with the progression of the disease, a challenge for the service and the health team.

This research has some limitations, among them, the small number of participants due to the specific characteristics of the study population and the context in which the study was conducted. Still, it was difficult to met the comparative analysis of the data in greater depth due to the difficulty in finding similar studies, revealing the need for further research be undertaken in order to increase knowledge on the subject.

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