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Human relationships in patients' end-of-life: a qualitative study in a hospice ward

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Abstract

Living in a hospice department is an intense experience for patients, caregivers, and healthcare professionals. End-of-life care aims to conduct vulnerable dying patients towards a painless and peaceful death. The importance of a strong staff-patient relationship and the perspective of pain and suffering from patients has already been studied. This study aimed to explore patients' inner needs living in hospice through a qualitative research approach. A descriptive qualitative study was conducted in the hospice department at ARNAS Civico in Palermo, Italy. From a qualitative research point of view, a significant sample of ten dying patients was interviewed. Data were collected until saturation by in-depth interview using a semi-structured interview guide, and Colaizzi's method was used. Five themes emerged: experiencing hospice, hospice staff, family role, coping with the disease, and death. Human relationships seem to represent a fundamental key in patients' end-of-life, especially in their family fondness. Predictably, terminally ill patients seem to fear pain and incoming death. Even though patients had everything they needed in the hospice, their main thoughts were always focused on human relationships. End-of-life medicine should improve the quality of time that each patient could spend with significant others to improve end-of-life care.

Keywords Hospice care · Hospice and palliative care nursing · Needs assessment · Qualitative research · Terminal care

Introduction

Worldwide, over 20.4 million people need palliative care at the end-of-life, every year [1], and the largest share of this population, 69%, corresponds to older adults [1]. Older people include the fastest-growing segment of the European population and by 2060 persons aged 65 and older will be 28% [2]. The highest rates for people in need of palliative care at the end-of-life were in Europe and the West Pacific Region [1]. The most people who need palliative care died from cardiovascular diseases (38.5%), cancer (34%), and chronic respiratory diseases (10.3%) [1] that represent the most common diseases affecting hospitalized elderly patients [3, 4]. Hospice represents a model of care that provides relief from suffering, offering psychological, physical, and spiritual support in the end-of-life. Patients and their caregivers' needs are being recognized and satisfied by nurses because each of them has got a unique background of emotions, culture, and values. Also, nurses improve patients' symptoms control, quality of nutrition, sleeping, and personal care [5]. Peaceful end-of-life theory by Ruland and Moore [6] defines five major nursing outcomes for patients as not being in pain,

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being at peace, experience of comfort, the experience of dignity/respect, and closeness to significant others. Palliative care studies highlighted patient perceptions of pain, palliative care or dignity, and the nurse-patient relationship was studied from different points of view [5, 7, 8]. In hospice, some patients wished to live, and some others desired to die as soon as possible [9]. Cure and care acceptance in hospice could differ from hour to hour, and gravity of symptoms was underrating by physicians but overrating by caregivers [10, 11].

In the beginning, different emotional questions were asked to us by our patients—“why is this happening to me?”, “why should I leave my family?”. Most of the time, patients need to share their emotions with the staff or with their loved ones to better accept the condition.

This study aimed to explore inpatients’ inner needs by investigating the experience of living in a palliative care unit through a qualitative research approach to improve end-of-life care.

Methods

According to the qualitative research design [12] a significant sample of ten patients (five men and five women), admitted to the Hospice Department at “Civico e Benfratelli” Hospital, in Palermo, Italy, was interviewed on October 2016. Ms. G. and Ms. Ri. were affected by cerebral metastasis, Ms. S. was affected by recurrent uterine cancer, Mr. Pi. had pulmonary cancer and bone metastasis, Mr. G. was affected by prostate cancer, Ms. MC. had recurrent breast cancer, Ms. Ro. had bone cancer and diffuses metastasis, Mr. Pa. was affected by bone cancer, Mr. M. was affected by bone marrow metastasis, Mr. R. was admitted in hospice with a diagnosis of colon cancer. All of them had a poor prognosis. Exclusion criteria were cognitive impairment and sedation status. A descriptive qualitative research approach was adopted. Using a semi-structured interview guide (Table 1), through face-to-face in-depth interviews, data were collected until saturation. A pilot interview was not included in the analysis. According to Lincoln and Guba’s recommendations [13], conformability was given by T.B., a nurse that patients have never met. Before the interviews, an introspective analysis of her preconceptions, beliefs, values, and positions was taken on a reflexing diary. A single voice recorder was used to achieve credibility and dependability. Interviews took place in patients’ rooms when they were alone and in the mood of chatting, a whole meeting lasted about 40 min; meanwhile, T.B. reported non-verbal communication in a notebook. Interviews were conducted in Italian, recorded, and transcribed verbatim by the interviewer. An external audit, to compare data, conclusions, comments, and notes to the raw data was carried out. Colaizzi’s seven steps method was used to analyze transcriptions [14]. Each transcription was read several times. The researches extracted significant statements from the transcriptions, meanings were formulated and aggregated into themes. Because of patients’ health conditions, member checking was not developed. The Ethics Committee “Palermo 2” in Sicily approved the study with protocol number 79CIVICO. The study was conducted according to the Good Clinical Practice, and each patient signed informed consent before the interview. The authors were careful in interviews’ translation to maintain the original meanings.

Table 1 Qualitative interview guide questions

1	How do you feel here in hospice?
2	Where would you like to be right now?
3	Do you think someone is more important than anybody else?
4	Is someone supporting you in this period?
5	How are you dealing with the disease?
6	Did you accept your condition?
7	What makes you feel better?

Results

Five main themes (experiencing hospice, hospice’s staff, family role, coping with the disease, and death) were identified. Figure 1 shows the formulated meanings aggregated according to the themes.

Experiencing hospice

In hospice, like home, patients felt safe and protected surrounded by trained and friendly staff. Patients trusted in the purpose of the hospice. Staying at the ward, gave them the possibility to avoid suffering. It was one of their inner needs as Ms. Ro. said: “I prefer to stay here, all this is done for us not? So why not use what we have, here I feel safe, I trust them”. The opportunity to have the family very close was essential to them. Ms. Ri. said: “I’d like to let you know that I feel right at home. The environment is warm and welcoming. When I arrived in this department, it seemed like a beautiful place. My room seems like a hotel room and allows whoever wants to stay with me to feel comfortable. I have a single room, so if my husband and children want to stay, they could, it is not a problem. I have everything that I need”. Ms. S. also said: “I have the possibility and the luck to be able to face all this in a quiet environment, surrounded by my family and friends, to be followed by physicians and nurses as I could not be in another department. Honestly, I prefer to stay here”. Mr. G., a patient who had a bad family relationship, preferred to stay at the hospice ward: “From

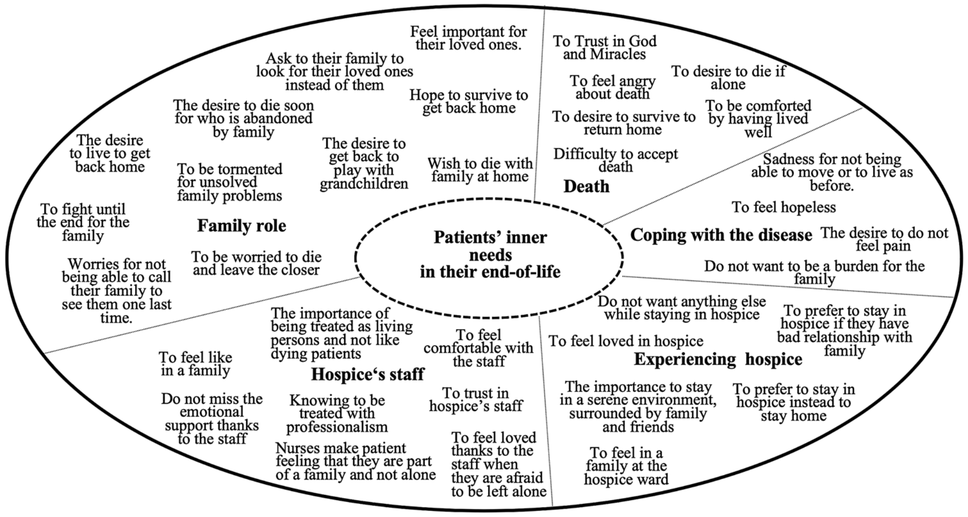

Fig. 1 Formulated meanings from significant informers' statements aggregated according to the main themes

the relief demonstrated from my wife and the behavior of my children, I prefer to stay here with you instead of staying at home". Someone instead preferred hospice to do not be a burden for the family like Mr. M.: "At home, we have a complicated situation. I feel better here with people that take care of me".

Hospice's staff

Hospice's staff improve quality-of-care treating pain and symptoms. Patients are treated according to a holistic approach. Ms. Ri. said: "People outside think that after a while, the sick person will be seen only as a patient or a job that needs to be done […]. I understood that we are treated with professionalism and that my family, as well as the rest, is welcomed and helped in every aspect as needed". People in their end-of-life needed to be treated as a human being and not as a disease to cure. Ms. M.C. said: "What makes me feel good is to be loved, surrounded by affection and carefully followed by the staff". Mr. Pa. expressed his feelings saying: "I thank you all, and pray that God blesses you all always […] I am very grateful for all the support that you all give me. I'm afraid of being left alone. You make me feel loved". Ms. Ri. emphasized the difficult role of the staff: "They are extraordinary people. I think that doing this work in this environment so sad and full of suffering is not easy. It takes strength and much courage. I admire you very much". Patients trusted in the skills of the hospice's staff". Ms. G. said: "Whenever I feel epilepsy tremors, I call for my angels. They know what to do and how to calm me down". A strong relationship with the staff could help patients to modify behavior and the interviews focused on this aspect. Mr. M. said: "Staff has transformed my anger into acceptance". Psychological support from the staff was important. According to Mr. G.: "Sometimes I feel desperate, I often cry but in their way they try to raise my spirits by making some joke and keeping me company". Mr. Pi. said: "Staff is fantastic, always ready to joke and make me smile". Ms. M.C. also said: "Everyone is always ready to reassure me and talk to me. They help me to deal with all this with sweetness and professionalism".

It was asked which member of the staff was the most important for them. Physicians and nurses had the same importance for all the interviewed. To someone, as Mr. M. nurses were more present than others: "I feel comfortable with the personnel. I have an excellent relationship with the physicians, and with the nurses, I have an even better relationship […]. They are very friendly, and they are always available. They understand me, and treat me like a living person not a walking dead". According to Ms. S. nurses had a central role in care management: "The hospice belongs to nurses and everything is handled by them. Yes, the physicians have their role, and they are important, but without the nurses, to whom I have created a relationship of trust and friendship, it would not the same. One thing I love is the nurse's yogurt granita. I am crazy about it". Ms. G said: "Physicians and nurses are on the same level. Let's say that in reality, I am a bit 'part … cheering for nurses".

Family role

In hospice, patients felt like in a family environment, and this gave them a chance to pass away peacefully. Also, to some of them, there was the opportunity to be with their beloved.

Mr. Pa. was left alone: "You are my family, are not you? I am a widower. I have an adopted son who never comes to visit me […] (with tears in his eyes) My son has left me after all that I have done for him. Do I deserve this?".

Different thoughts explained the family's role: to get worried about being a burden for them, the will of dying if the family will not be close and the desire to live to get back in the family. Mr. M. preferred not to have the family close for not being a burden: “My children often come to visit me, but I do not want them to stay. I prefer that they take care of my wife instead of me”. Mr. Pi. was grateful for having his family close, but he explained: “My family is always here. I must be such a burden to my brothers because I cannot walk anymore”.

Some patients with healthy human relationships were less anxious about dying, and some of them wanted to survive for re-joining their loved ones. Ms. S. was thankful to the hospice ward for giving her the possibility to live with joy in her last days surrounded by the family. Mr. M said: “The fact that I have lived a good life consoles me. I am 70 years old. I lived a wonderful life, and I had an incredible family. At the same time, I am sad and fearful because I know that I will die and I have to leave the people that I love”.

Coming back home was one of the patient’s inner needs. Mr. M. said: “The only thing that I truly want is to be healthy so that I can play with my grandchildren again”. As Ms. G.: “Knowing to be important for someone makes you feel good […], I want to get back home for cooking like I used to do, and having a beautiful party amongst family. I love to bake cakes. I promised my grandchildren I will bake as many cakes as they like”.

Patients with complicated family relationships, on the other hand, showed feelings of anger and loneliness. Mr. G. said some of the most touching sentences: “I feel more alone than ever […] my children don’t come to visit me. I’m worried. I have my son’s phone number, but he doesn’t answer either. I tried to call him again today but to no avail […]. I’ve sacrificed a lot for my family […] My wife breathed a sigh of relief when I left the house to come here. I miss my grandchildren. They have shown me true affection”.

Coping with the disease

Anger, resignation, hope, and fear of pain were patients’ feelings for facing their end-of-life. Mr. M. had a very dark moment when he discovered everything: “At first my children didn’t want to tell me anything, but I found it on my own. I know that I’m not going to leave here with my legs. I don’t want to make them worry. I’ve accepted it”. Ms. S also said: “At the beginning, I was admitted to this department with hope and faith, but now I know that it was all useless. I’ve accepted my condition. I am resigned. I’m 57 years old, and hypothetically, I should have a future ahead of me, but obviously, this is not my destiny”. Ms. MC. clarified the same resignation: “I accept what is happening to me because I cannot do anything else. Unfortunately, I cannot push a button and return in time”. Family love allowed patients to face up to the disease with courage, strength and the desire to heal as it was for Mr. R.: “I have to say that I have not yet resigned […] for my family. I don’t want to give up while I still have the strength”. Ms. S. said: “I try to live what is left with joy, for myself, but especially for my family”. Ms. G. also said: “I want to get out from here healed so that I can return to my sons and grandchildren”. People in their end-of-life needed to believe in something to find the strength to peacefully deal with the disease, either a loving family or God. Ms. G. explained how religion gave her hope: “This thing has been difficult to accept […]. There’s always faith in miracles, and I trust in you and God. This disease is a terrible beast to defeat, but I feel sure that together we can do it”.

Death

Some patients were resigned to death. Others instead wanted to fight until the end, and the forgotten ones wished to die as soon as possible. What Mr. G. told us was very touching: “I was born alone, and I will die alone […] abandoned in theory by the ones who should take care of me like I’ve taken care of them in the past. I want to die, die soon. This way, I won’t disturb anyone anymore”. Mr. Pa. was tormented by the thought of dying without knowing why his beloved son has abandoned him: “I’m afraid, afraid of death, afraid of loneliness. I want to see my son one last time to ask him why…why did he behave this way…with me, that I offered him a new life and the possibility of starting over […]. There are times that I desire death more than anything else”.

Mr. M. had his family closer and felt more serene but sad for abandoning them: “I am now resigned; I am 70 years old. I have had a good life and a wonderful family. I’m afraid of death. I don’t know what to expect […] I’m sad and fearful at the same time because I know that I will die and leave the people that I love. Death is a shadow behind me, I’m not depressed, but afraid of the pain, I would like to die peacefully. I trust the Lord and His mercy”.

Many patients felt impotent. Some patients had faith in physicians’ job. Ms. Ri. said: “I talked to the physician asking if it was possible to be sedated because the pain is hard to bear now. They reassured me saying that if I agree, I will be sedated so I can leave this world in serenity, as I wish”. Also, again: “I have accepted my condition, I am not afraid of death […] My fear is related to pain, but with drugs and sedation I don’t think I’ll have problems”.

Discussion

In this qualitative research study, the inner-needs of terminally ill patients admitted to the hospice ward were explored. Specifically, a descriptive qualitative research approach was used to identify the patient’s main issues. Five recurrent themes emerged. The first issue concerned the experience of hospice. Our patients affected by terminal illness generally associated hospice with a range of positive feelings such as motivation, protection, and a better state of mind. These findings were in line with a previous study [15] that reported the importance of hospice in improving the quality of life and patient's perception creating an environment where the thought of potential uncontrolled pain does not exist. In our study, the fundamental role of hospice staff was highlighted. The importance of nurse and physician personnel as the expert of end-of-life care [15] and the creation of a positive environment [16] were emphasized by our patients as Mr. M. said: "I feel comfortable with the personnel. I have an excellent relationship with the physicians, and with the nurses, I have an even better relationship […]. They are very friendly, and they are always available. They understand me, and treat me like a living person not a walking dead". This is consistent with other qualitative analysis that outlined that the nurse and physician's expertise involved pain management, dealing with family, and educating family members on what to expect [15]. Along with hospice staff, the family's role represents another key finding in this study. Family members play a vital service in end-of-life care by providing reassurance and love and by sharing everyday life and activities [16]. In this regard, it must be outlined what Ms. G. said: "Knowing to be important for someone makes you feel good […], I want to get back home for cooking like I used to do, and having a beautiful party amongst family. I love to bake cakes. I promised my grandchildren I will bake as many cakes as they like" [16]. In addition, family members must have the ability to face patients' emotional problems such as fear, anxiety, sadness and depression [16]. In fact, the main thought of our patients was the family in their ending life. Persons with good human relationships were less anxious to die, because, in our opinion, they were surrounded by family love and support therefore they faced death with more peace of mind. On the other hand, subjects who felt to be a weight for their family or in conflict with their relatives wished to die as soon as possible because they felt alone against everyone and everything and burden of suffering became unsustainable.

The individual coping of the disease characterized by multiple emotions and internal conflicts is congruent with the previous study which described the individual's emotional experience [17]. Finally, the theme of death becomes clear. The acceptance of death, the will to live, the strive to maintain the role inside the society and their family align with another research that investigated the dying process [17, 18]. Dying cannot be understood completely, and the individual's context influences experience. Terminal illness diagnosis produce emotions like anxiety, fear of death, melancholy and uncertainty. This study reveals that during their end-of-life, patients think more about human relationships, especially to their family. End-of-life medicine should improve the quality of time that each patient could spend with significant others. In particular, nursing staff should be trained to face patients' needs. Despite the small number of patients does not allow conclusion to be drawn that can be generalized to other subjects, ten patients are a sufficient number to explore human emotions and realities of subjects admitted to the hospice ward.

Further studies are necessary to better explore the emotional burden in terminally ill patients and to ameliorate end-of-life care.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Statement of human and animal rights This study was approved by the Ethics committee "Palermo 2" with protocol number 79CIVICO.

Informed consent Each patient supplied informed consent.

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