




Satisfying needs and expectations of terminal cancer patients: Organizational challenges to social workers

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Abstract

Despite medical and scientific advances, numerous clinical essays, and research to fight cancer, endless concerns associated with this pathology continue to persist in the twenty-first century, with a strong impact on individuals' lives particularly at the economic, social, emotional, relational, behavioural, and spiritual levels. However, metamorphosing this into reality still seems to be a distant event because this pathology is still considered one of the leading causes of death in different countries worldwide, and Portugal is no exception. This study aims to study the motivations expressed by terminally ill cancer patients and their caregivers, whose main differences are characterized. The results show that the clinical, social, spiritual, economic, and emotional issues associated with the end-of-life context are numerous, therefore patients and their caregivers may have a number of circumstances to face. The presentation of the patients' and their caregivers' needs, expression of motivations, requests for social work, and emotions experienced at the end of life are some of the core features of the study. We show disparities between patients and their caregivers, including different motivations, needs, requests, and different manifestations related to the place of death that constitute a major challenge for social work in the context of palliative care and care at the end of life. The paper identifies a number of organizational issues relevant to healthcare management contexts. Such issues recognize the importance of integrating innovative social work procedures and protocols into internal medicine departments, planning hospital discharges, making psychosocial and complicated

grief risk screening at patients' admission, promoting social work palliative care education and training for hospital social workers, and the creation and development of more hospital palliative care teams in acute care hospitals. Also the relation between cost and quality of healthcare seems to place social workers in a very relevant healthcare management position.

Keywords: Social work, Terminal cancer disease, Patient and families' expectations, Caregivers, End-of-life, Palliative care, Hospital management

Introduction

Health is far from being an exclusive area of biomedicine; it has always been assumed to be a social phenomenon of a psychosocial, cultural, and spiritual nature. Social work has always had a deep and broad look at the concept of existential human suffering, and the promotion of social advocacy in order to achieve rights and social justice. The international definition of social work according to the IFSW¹ is understood as:

Social work is a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledge, social work engages

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people and structures to address life challenges and enhance wellbeing.¹

This setting accepts a wider dimension of the role of social work and its impact on the relationship with the individual and the population (group and community), making it clear that it is not just a profession, but also a growing field of knowledge (science) that is based on its own theories, and on social and human science. Since this is a discipline of social science, the truth is that social work has always absorbed the area of health, being completely integrated into the delivery of psychosocial care. Internal medical services are characterized by a predominantly elderly population with most disabling and chronic diseases, often in a terminal stage. Hospital admissions for malignant neoplasms in the terminal stage have a very significant percentage and the intervention of the social worker should be aimed at promoting improved quality of life, being a strong contribute to the decreasing stress, anxiety, anger, fear and suffering of the patients and caregivers during hospitalization and after discharge, and in community monitoring. When studying needs, we cannot disaggregate them from a conceptually associated notion – the motivation. Studies show that there are various theories regarding this concept, many of them linked to psycho-sociology of the organizations. We begin by noting the pulses theory by Thomdike² and by Hull³, specially directed to the explanation of the reasons for occurrences that have already happened, and go through the expectation theories to the theory of Vroom.⁴ In fact, one of the most significant issues associated with the concept of motivation gives emphasis to the different variables related to human behaviour (p. 41–42).⁵ Notably, what we aim while studying the motivations of patients and their caregivers, in the context of our research, are the particular needs of this process, that is, the content of what moves and motivates the individuals. One of the most recognized models is the Maslow hierarchy of needs.⁶ His model is based on deductive reasoning and it is conceptually very simple. It proposes a hierarchical structure that begins by physiological needs; as soon as these are satisfied, we move to the next level, security needs, followed by social needs, the self-esteem/ego, and finally the needs related to the realization of one's own success. It was later expanded by Alderfer⁷ to the ERC theory. The latter points to the existence of three levels of needs: basic (related to survival); the relationship (concerning social interaction and

recognition by others); and growth needs (associated with success and autonomy of the individual). It should also make reference to the theory of socially acquired needs (achievements, power, and affiliation) of McClelland.⁸ The theory of Herzberg, Mausner, and Snyderman⁹ links hygiene factors with the motivators among others (pp. 41–42).⁵ It is not easy to define the concept of motivation. This differs from individual to individual and we argue that it can be seen as an 'umbrella' of energies and potentials that lead persons to achieve something that satisfies themselves as an answer to their needs. The social work in health care and in the end-of-life care has a different look from other disciplines, its objective being focused on the promotion of social justice and on solving social problems through empowerment aiming to improve well-being (p. 69).¹⁰ According to this author, in addition to promoting social cohesion and the empowerment of patients, families, and community groups, the social worker plays an essential role in managing the various stages of the disease course and the subsequent different circumstances of life. He helps the patients and families to reflect on the changes brought about by the disease process and the approaching end of life by assisting in redefining projects, planning hospital discharge, managing losses, and providing support in bereavement. He intensifies the delivery of skills related to the practical and emotional issues (p. 73).¹⁰ We cannot fail to mention that the care at the end of life is different from palliative care. The latter is specialized care provided by multidisciplinary teams of healthcare and social services to people with advanced disease that usually leads to death. End-of-life care is that provided to people whose life is coming to an end (p. 19).¹¹ Oncologic pathology is a chronic disease and the evolution of this leads to multiple needs of clinical, social, and emotional order. Palliative care is fundamental to controlling symptoms and total pain, delivery of quality-of-life during complex and progressive diseases, and the promotion of a more dignified death and with less suffering.

Aims

We analyse the motivations expressed by terminally ill cancer patients and their caregivers. To achieve this goal, we outlined the following as specific objectives: to identify and compare the reasons expressed by terminal cancer patients and their caregivers; to characterize patients and their caregivers; to identify the situation that leads caregivers to ask for support from the social work; and to identify and characterize the main obstacles and difficulties faced.

¹Available in: <http://ifsw.org/get-involved/global-definition-of-social-work/>

Methodology

Study design

This is a qualitative study following an inductive procedure. For data collection we used the semi-direct variant interview. The determination of the sample was performed by saturation of the medium field to ensure the validity of the elements obtained (see¹²). Data were collected in a university hospital, in an internal medicine department, for a period of 5 months. The interviews were conducted separately and were initially held with patients, and subsequently with their caregivers. The average time of each interview was 40 minutes.

Study participants

An empirical objective was to define specific characteristics or indicators for the pre-analysis; therefore the study participants included patients with their perspective of hospital discharge, with the ability to define their life project and answer the questions set during the interview, with a clinical diagnosis of malignancy and the end-of-life issues (defined by the attending physician and the respective caregivers). Empirical saturation was reached with the completion of the 14 interviews. Of these, seven were terminally ill cancer patients, and the remaining seven, the respective caregivers.

Data analysis

Regarding the interviews, we carried out a transcription of them fulfilling the principle of truth. After transcription, we proceeded to the reading, where we listened to the recordings again to clarify some contents. For data analysis, we used the content of the research analysis technique designed by Bardin. According to Berelson,¹³ this should be understood as 'a technique of research that through an objective, systematic and quantitative description of the manifest content of the communications has the purpose of interpretation of these same communications' (cited by Bardin, 2004: p. 31).¹³

Ethical consideration

We have respected all ethical imperatives inherent in any process of investigation, and the application of informed consent to all participants (see¹⁴) and institutional approval. This authorization includes the interview and audio recording. Confidentiality and anonymity are fully secured. The purpose of the study and that participation is completely voluntary was similarly explained to the participants.

Results

Data analysis allowed us to select the first dimensions of the analysis related to the fields of analysis. Thus, taking into account the objectives of the study, in the case of terminal cancer patients, the selected analysis dimensions are: the perception of the disease; the daily life of the patients; the trajectory of their motivations. For caregivers (namely family and informal caregivers) the selected dimensions are: perception of the disease; daily life of the caregivers; trajectory of their motivations. After the completion of the comparable units and initiation of horizontal readings, the following categories of analysis for patients are thus defined: illness; dependence on others; conformism; belief; avoidance strategies; revolt; expression of emotions; desire; expectation. For the caregivers the following categories of analysis are considered: disease; organization; strength; belief; conformism; denial; impotence; avoidance strategies; perception of loneliness; revolt; anguish; expression of emotions; desire; expectancy. Following the coding of the categories, we found the subcategories that guide the interpretation of the data, both for patients and for caregivers. However, not in all categories, subcategories are found. So, we proceed to the description of the data collected through the interviews. Through Tables 1 and 2 shown below, we characterize through six indicators (age, sex, role in the household, housing situation, professional situation, and household) the participants in the study.

(A) Perception of the disease dimension – terminal cancer patients

From the analysis it was possible to recognize that the terminal cancer patients are actually aware of their clinical situation and dependence on others. From the analysis of the data, we can conclude that patients have a clear awareness of the disease.

I asked the doctor how much time I would have, I mean, how long I would be alive, and it was some time ago, I think last year. The doctor told me: technically you weren't supposed to be here yet ... (Silence) ...

... The severity of melanoma is from 1 to 4 and I already was at 4 ...

The category – 'dependence on others' – includes two subcategories; the first has the intention to know if the participants have contact with different types of institutional network support, and the second aims to acknowledge the patients' aid relationships, such as people or family members

Table 1 Characterization of terminal cancer patients

Patient	Age	Sex	Role in the household	Housing situation	Professional situation	Household
P1	68	F	Wife	Own house	Retired	Husband, one son, two grandchildren
P2	69	M	Husband	Own house	Active	Wife
P3	75	M	Husband and father	Own house	Retired	Wife and daughter
P4	59	F	Lives alone	Own house	Active	Lives alone
P5	67	M	Husband	Own house	Retired	Wife
P6	49	F	Mother	Rent	Active	Under age son
P7	78	F	Wife	Rent	Retired	Husband

Source: (Self elaboration).

with more direct influence on patient support care. Regarding the institutional network support, we find that only one patient has support from the Health Centre of his area of residence. Until hospital admission no patient benefited from home support service from any local social institution. The identified reasons are the absence of need, not wanting to have (one patient), or lack of knowledge about this type of community support.

... No, I have never had that, support from an institution, to say the truth, I didn't even know it ...

No, I have never had support from any institution ...

As for the subcategory 'aid relationships' we found that all the participants have, at least, one family member or friend with a direct influence on them. From the seven interviews, two have as caregivers their husbands, two, their wives, two patients have two friends, and one had his daughter as the caregiver.

(B) Daily life dimension – terminal cancer patients

In this dimension 'daily life' we aimed to gather all the elements that refer to the way patients manage their

day-to-day lives. After analysing the interviews, four categories were found: conformism, belief, avoidance strategies, and revolt. Conformism emerges as one of the categories found, perhaps because all the patients participating in the study are aware of their diagnosis and prognosis. Thus, from the total of the patients interviewed, five transmit resignation when faced with their illness.

.... I guess I have no choice but wait ... (Silence) ...

.... My life has to continue although I'm ill

To hope and believe in something naturally arises in the final course of the disease process, where physical and emotional instability is present in a moment of such vulnerability.

In the category 'belief' and after the analysis, we found that a patient manifests feelings closer to the spiritual dimension, to faith and the supernatural, and sought supernatural practices; a patient expresses feeling being in the hands of someone and another reveals a hope that science advances in order that they be healed.

... My life is in the hands of someone I don't know who ...

Table 2 Characterization of caregivers

Caregivers	Age	Sex	Role in the household	Housing situation	Professional situation	Household
C1	65	M	Husband	Own house	Active	Patient; one son; two grandchildren
C2	66	F	Wife	Own house	Retired	Patient
C3	30	F	Daughter	Own house	unemployed	Patient; mother; daughter
C4	52	F	Friend	Own house	Housekeeper	Lives alone
C5	61	F	Wife	Own house	Housekeeper	Patient
C6	51	F	Friend	Rent	Active	Patient and son
C7	84	M	Husband	Rent	Retired	Patient

Source: (Self -elaboration).

I know I'll die, you know? (Cried) ... but sometimes I hope that science will advance and I'll be healed ...

We also note that four patients use avoidance strategies toward their families and toward themselves. We consider the category 'avoidance strategies' in situations where the patients are aware of their terminal situations, but avoid thinking about the disease (two patients) or convey the idea that their health status is not so severe (three patients); we can deduce that their aim is to protect their family.

... Look, as I said, I've been living the day-to-day. I try not to think too much ...

... I try to pretend I'm strong and I have nothing ... I must avoid crying near them ...

From the seven patients participating in the study, four express revolt about their disease, However, we also found some conformism associated with the clinical situation (two patients); however, persisting in them simultaneously was a state of revolt related not only to disease but also to suffering. For two patients the feeling of revolt exceeds the conformity (two patients).

... so much suffering for what? ... cried ...coughed ...

... But I feel a lot of revolt ... cried ... it is such a revolt ... cried ... that's ok, everything will finish Oh Doctor! I'm so sorry for my son ... he'll be alone ...

(C) Trajectory of the motivation dimension – terminal cancer patients

With the analysis of an additional dimension 'trajectory of the motivations' we seek to identify expressions of emotions related to fear, loss, and pain. Simultaneously, we intend to recognize their desires and expectations, in particular, the preferential expressions of the place of death. In the category 'expression of emotions' we find three subcategories: fear, loss, and pain. As for fear, from the seven patients, five state feeling fear. The fear is associated with multiple factors, namely: suffering (two patients); dying in pain (one patient); symptomatic uncontrolled (pain) (two patients); hospitalization (one patient); dying alone in hospital (five patients); and fear of night and dark (three patients).

... My biggest fear is leaving my daughter and wife alone ... they both will be alone ... we don't have any family here ...

... When I'm here, without him, It's night, I'm afraid of the dark, fear of being alone ... cried... I often spend the nights sleepless and I'm always thinking of him ...

As for the subcategory 'loss' we see that this is related to the patients' concern about leaving their families in loneliness and themselves losing their families (1 patient).

... We have always got along very well, never got angry ... I'm afraid of losing her forever ...

Also, regarding the subcategory 'pain' we found that all participants feel pain; this is manifested in the physical, social, emotional, and spiritual dimensions.

I have suffered a lot, only me to know what I have felt, I don't know well how to explain, it's an anguish to know that I have ...

I just want my child to have a good life ... I want to die in peace ... I don't want to have pain ... silence ...

The category 'desires' has the intention to detect to which post-hospital discharge destination patients prefer to go as requested to social workers. Thus, from the seven participants, six express the desire to return to home and only one for reasons of social, emotional, logistical, family, and financial order asks for integration into an institution – nursery home for continuity of care post-hospital discharge. The main wishes expressed by the patients are: no pain (two patients); absence of fatigue (one patient); return to a normal or partially normal life (three patients); acquisition of a support product – articulated bed – (two patients); referral to local home support service – personal hygiene (two patients); return to domicile to be with family (five patients); being with family regardless of the local (one patient); review or meet demographically distant relatives (one patient); supply of goods (two patients); admission in an institution (one patient) of a minor son in the care of a friend after death (one patient); die in peace (one patient); go home before his death (one patient); brighter future for the children (two patients); continuing of

support for dependent relative (one patient); and finally the desire to accomplish unfinished projects.

... My greatest need, you know, is the pain relief, if I could do a few little things, until God wants me to go ...

I need help from the retired centre near my home ... I also wanted to talk to you about the articulated bed, the nurses told me that I was better in a bed like that ... I think it would be better ...

The purpose for the category 'expectation' is to identify the preferential manifestation concerning the place of death. We found that, except for a patient who expresses a particularly strong desire to die in an institution, perhaps knowing that there are no conditions to be at home due to lack of caregivers and adequate support structures, the remaining study participants refer home as the preferred place of death.

... I do what they tell me. When I'm discharged from hospital I go home with my wife. I'd better to die at home ...

... I have no expectations, the only thing I don't want is to die in suffering, no one deserves that. I would like to go to an institution, my home is now in a mess, without conditions, but I would like to see my home before dying ... then I could die there, in the institution ...

(D) Perception of the disease dimension – caregivers

From the dimension 'perception of the disease' we intend to recognize whether the caregiver is aware about the disease of the patient (category) and organizational dynamic of these (category), that's to say, the available time they have to support the patient and the third-party help that complements this support. Through this analysis, we can conclude that all caregivers are aware of the medical conditions of the patients.

... I know he is very ill, in a situation of end of life and very dependent on all ...

Even today the doctor told me when he saw me with my husband ... you must comply, madam, he is very ill, he is in the finals ... silence ...

The category 'organization' involves two subcategories, one that aims to know the availability of caregivers to support the patient, and a second with the goal to identify the help from a third person to

complement this support, particularly institutional support or from other people or other family members. Regarding the availability of caregivers to support patients, we find that one caregiver is at home most of the night and all morning with the patient (one patient), four caregivers are permanently at home to support the patient, and two caregivers are available at some specific times of the day. As for the subcategory 'third party assistance' we find that from the seven caregivers, five reveal not to receive help from any local institution, one reveals receiving aid from the health centre (nursing), and two caregivers claim they only have contact with the family doctor and very occasionally. Regarding third-party assistance provided by other family members or friends who help and complement the support of caregivers, one turns out to have the support of a sister-in-law, one of his children, one of his/her mother, one of his/her nieces; one is unsupported; one caregiver says she has the support of her husband and son; and finally, one claims to occasionally have the help of the concierge.

... I am always at home when he is there ... I give all possible support ... I do everything I can ... but I'm getting tired ... more direct family, I'm the only one ... he has no one else ... as I have already said, my daughter is far away, in France and she can't, poor thing, being always coming here ... life is very difficult and money is very much needed ... mainly now she'll have a daughter ...

I've been taking care of her for long, she has been ill for several years, but so ill as she is, only now. Walking was already difficult for her. I had to support her and sometimes I had to ask the concierge of the building for help ... she is very helpful ...

(E) Daily routine dimension – caregivers

In the dimension 'the daily life of caregivers' we aim to bring together all the elements that refer to the way caregivers manage the day-to-day life. Thus, we find nine categories: strength, belief, conformism, denial, helplessness, avoidance strategies, perception of loneliness, anger, and anguish.

From the total participants, four express the feeling of strength that allows them to manage their day-to-day lives.

... Look ... my grandchildren are those who give me joy. It's with them I have tried to survivecried

... I keep on living I keep on living with the support of my dear children and grandchildren ...

From the seven caregivers, three express the belief/hope that the patient will get better.

The doctor has said he is very ill, very ill ... let's see ... it will be the God's will ...

... It seems as if I couldn't believe it ... cried ... I don't know what will become of me without her ... silence ... but we must have some hope, belief ...

Only one of the seven participants reveals conformism concerning the clinical situation of his family member. In the testimony of this caregiver we can deduce that this feeling is possibly due to the fact that the patient had expressed a lot of suffering, pain, and fatigue throughout the process, being fully aware of the proximity of death.

... Only there in my home locality, people know what I have suffered, everyone knows me ... but it's like that, we are keeping on living ... silence ...

Another category found was denial. From the total number of participants, three transmit a feeling of denial when confronted with the situation of terminal illness. In the specific case of a caregiver, we find that although she has conveyed conformism toward the clinical situation, she expresses denial when faced with the approaching of death of her family member. The denial comes here as a normal reaction to the disease state, as a defense against the approach of death.

... But even today, I see him, here in the hospital bed, rolling from one side to the other, and I still don't believe he will die ...

... And I think that I am not willing to accept that she is in a terminal phase ... that's what I say ... I mean ... she seems to have phases, some days she is very ill and some days she looks better. However, I don't have any hope ... I wouldn't say she'll live, no, I wouldn't ...

Concerning the category 'impotence' from the seven caregivers, four manifested a feeling of powerlessness in the face of the terminal situations of the patients. This later is considered as an opportunity

to restore something that cannot be recovered, such as, the impossibility to put an end to the irreversibility of the disease.

I can't do anything else for him, but give him love and much affection ...

Management of the day-to-day lives has been here considered as a great distress accompanied of oppression and sadness.

... My main anguish was, at home, early in the morning, for her to open the door ... silence ... cried ... she never gave me the keys ... she came crawling ... cried ... crawling ...

My life has been very difficult, I even don't know how I have endured so much pressure and heartbreak ... my wife is so ill that I feel powerless to help, I don't know how to help ... I don't know if it is impotence ... I don't know ... I'm desperate, sad, anguished ... cried ...

(F) Trajectory of the motivations dimension – caregivers

With the dimension 'Trajectory of the motivations' we intend to identify emotional expressions associated with fear, worry, and pain. We also intend to meet the wishes and expectations of the caregivers concerning the place of death of the patients. In the category 'expression of emotions' we found three subcategories: fear, worry, and pain. As for fear, six of seven interviewed caregivers report feeling fear. This was related to multiple factors, including fear of a worsening in the health status of the patient (one caregiver); hospital discharge (three caregivers); be close to the patient (two caregivers); death at home (one caregiver); death (two caregivers); pain (one caregiver) on confrontation with the news of the death (two caregivers); and loneliness (one caregiver).

I fear that if he is – as the doctors say – in a terminal phase – he is given hospital discharge ... I don't know Silence ... my biggest fear is that I don't want him to die at home ... silence ... this is the truth ... I don't want him to die at home

... cried ... my biggest fear was morning ... cried ... I was very afraid ...

As for the subcategory 'concern' we note that all caregivers have numerous concerns directly linked

to anxieties, restlessness, and unpleasant foreboding. The concerns are related, in particular, to different concerns regarding the care of grandchildren (one caregiver); grandchildren having the grandmother at home at this stage of evolution of the disease (one caregiver); lack of capacity to receive the patient at home after hospital discharge (four caregivers); sharing of goods (one caregiver); symptomatic control – pain – (one caregiver); financial and bureaucratic problems after the patient's death (one caregiver); know his granddaughter (one caregiver); underage son and his reaction to his mother's loss (one caregiver); end of life with dignity is essential (one caregiver); underage son in the charge of a friend – the patient's caregiver – according to her desire (one caregiver); fear of not finding the patient alive, during the hospitalization (one caregiver)

... What is worrying me much are my grandchildren, we have already talked to the other grandmother of them, asking her to give them some support ... The kids aren't prepared to have their grandmother at home, as she is now ...

He was so fond of seeing his granddaughter to be born ... it's a very great sorrow he has, not seeing his granddaughter ... my daughter wants to come to Portugal when my granddaughter will be born ... as soon as possible ... cried ... maybe he won't even see her granddaughter

Regarding the subcategory 'pain' we find that the patients are not the only ones who manifest pain; also the caregivers express it related to patients' suffering and sadness (two caregivers).

My life has been very difficult ... I don't know how I have endured so much pressure and heartbreak My wife is so sick and she feels so bad and I feel so powerless to help ... I don't know if it's impotence. Or whatever ... I'm desperate of my life ... cried ...

From the analysis of the data, we also found that from the seven caregivers, two use avoidance strategies concerning the patients and themselves.

I try to have a lot of strength, a lot of strength ... I happen to live near her with great courage, great courage, but behind ...

I try not to think too much ... but then I don't sleep at all. I'm there alone I have no one else but him ... I even don't feel like eating. I'm on the phone with my daughter ... I've tried to think of my granddaughter's birth, I wish at least she is perfect and she comes with good health ...

With regard to the category 'perception of loneliness' this is manifested in three caregivers. These reveal to be aware of the diagnosis and prognosis of the disease, allowing them to reflect on how their days will be after the patients' death and how they will miss them.

I'll miss her a lot, she will be greatly missed, and it represents forty years of marriage. Life doesn't end, but in this sense it will end ...

... What I ask to God is ... I'm being selfish, I'm being very selfish But I would like her to stay even more 10 years in a hospital bed, or so, it would be better than leaving her son like that ... even she, herself, would prefer it, doctor, ask her ...

The category 'revolt' was hardly referred; only one caregiver expresses it.

... But a person feels some revolt ... she was always seeing the doctor, how is it possible? Her sister died of cancer but I have never thought that it would happen with my wife ... life surprises us with such horrible things ... cried ... I don't know what to say, what to do ...

I'd like to visit her every day, but I would like she went to a place where she could be assisted, I can't bear so much suffering any more ...

My luck is that I'm medicated ... I feel sorrow, but I've been feeling it since I started to have the perception of my father's illness and what is going on ... that this is not a disease supposed to be solved ... since then ... silence ...

The category 'desires' aims to detect what the caregivers need or wish and what they ask of social workers, taking into account the stage of the evolution of the disease and a possible hospital discharge. Thus, we highlight the following: need for symptomatic control – pain (one caregiver); institutionalization in the palliative care unit (one caregiver); stay in hospital until death (one caregiver);

stay with the patient 24 hours/day in the hospital (one caregiver); be with the patient at the time of death (two caregivers); be sent to domicile after hospital discharge (one caregiver); reconciliation with his/her mother before death (one caregiver); be sent to the nephews' home after discharge (one caregiver); referral to a local institution – home support service (two caregivers); custody of the patient's son after her death (one caregiver); payments/debts (one caregiver); institutionalization in a nursing home (one caregiver); return home after hospital discharge (one caregiver); patient have a talk about death with an expert in the field (one caregiver); stay as long as possible in the hospital (one caregiver).

She is always telling me that she knows she won't be here for long, so she asks, at least, for some pain relief and that is my perspective of help ...

He can't go home like this ... I don't know ... If he has hospital discharge, I'll need home care for personal hygiene from the Day Care Centre ...

With regard to the category 'expectation' we intend to identify which is the preferential expression of the caregivers concerning the patients' place of death. From the data analysis, we note the following main findings: hospitalization in the palliative care unit (one caregiver); death in hospital (two caregivers); death at home (two caregivers); death with relatives (one caregiver); death in a nursing home (one caregiver).

I would like you to refer her, after hospital discharge, to a specific unit in the cares she needs ... because she can't go home. I know there are some of these units, she can't die at home ...

I would like her to stay here as long as possible, I hope they don't give her hospital discharge ... if they say she is going to die, then let her stay here ...

Discussion

Categories of analysis were defined both for patients and for caregivers. With regard to patients we selected three dimensions: (a) Perception of the disease; (b) The patients' daily lives; (c) Trajectory of motivations; as for the caregivers, we selected also three dimensions: (a) Perception of the disease; (b) Daily life of the caregivers; (c)

Trajectory of the motivations for further study. Regarding the dimension 'perception of the disease' both patients and caregivers have perception and awareness of the clinical situation and its fast evolution. Even with regard to the perception of the disease, we can find two categories: (a) If patients either have or not contact with the existing institutional support resources; (b) Recognition of helpful relationships with the patient; more specifically, we intend to analyse which people or family members have greater influence in the care, thus identifying the caregiver. It is essential to have sensitivity to recognize who are the most important people for the patient. With regard to the category 'institutional support' we can conclude that among the patients interviewed, support at home previous to hospital admission as part of a continuum of care project is almost nonexistent. The category 'aid relationships' is critical in supporting terminal cancer patients. All participants have, at least, one family member or friend with more direct influence on them. As for the category 'disease', for caregivers, similar to patients, we find that all are aware of the severity of the situation and of the stage of evolution. Another category found 'perception of the disease dimension' was the organization of care in relation to the act of providing care to the patient. Within this category, we can find two subcategories: (a) willingness to support the patient; (b) assistance from third parties to supplement the support. We emphasize that all caregivers make an effort to keep the needed support to the patient and, whenever they have the opportunity, they ask others for help in order to support them, trying to provide the best possible comfort to the patients. The feelings conveyed in the dimension 'every day routine of terminal cancer patients' are: strength, belief, conformism, denial, helplessness, avoidance strategies, perception of loneliness, anger, and anguish. The involvement of the familiar members and/or caregivers is critical in providing supporting care at the end of life. The experiences associated with the support and care at the end of life from the social, emotional, and assistance perspective are deeply stressful and affect everyone involved. Generally, we can identify that resignation, belief, avoidance strategies, and anger are common feelings transmitted by patients and their caregivers. On the dimension 'trajectory of the motivations of patients' we found several categories, such as, expression of emotions (fear, loss, and pain – subcategories), desires, and expectations – preferred manifestations about the place of death. Also in caregivers and in the same field of analysis, we found three categories: emotion expression (fear, worry, and pain –

subcategories), desires, and expectations – preferred manifestations concerning the place of death. With regard to the category ‘expression of emotions’ we identified two expressions of emotions common to patients and their caregivers: fear and pain. When faced with the preferred place of death, the study reveals that six patients have their home as the preferred place of death. In contrast, compared to the manifestations of caregivers concerning this subject, we can highlight the following: (a) integration in the palliative care unit; (b) hospital; (c) home; (d) family home; and (e) institution – nursery home.

New organizational challenges for social workers in internal medicine departments facing these results, include the need for:

- (a) Integration of innovative social work procedures and protocols into internal medicine departments (such as effective application of social work assessment scales, preventive interventions, planning hospital discharges, making psychosocial and complicate grief risks screening at patients’ admission)
- (b) Development of therapeutic social work (patients and caregivers)
- (c) Promotion of social work with palliative care education and training for hospital social workers
- (d) Development of hospital palliative care teams in acute care hospitals
- (e) The relation between cost and quality of healthcare seems to place social workers in a very relevant healthcare management position.

Conclusion

The study contributes to the identification and understanding of the main needs expressed by cancer patients in the terminal stage, in an internal medicine department, and their caregivers. Qualitative analysis was considered the most suitable methodology to meet the objectives of the study. Regarding the patients at the end of life, the caregivers may have a varying degree of relationship, for example, friends, family, and neighbours, among others. The incidence of patients at the end-of -life stage and in need of palliative care is growing. The involvement of families is fundamental, as well as the continuity of care by trained professionals appropriate to care needed at the end of life. Given the result presented, we can see that the problems associated with terminal illnesses are of different orders, and emotional vulnerability is a

constant issue, as is the fear of lack of institutional support resources such as home support. For the social worker who works daily with such fragile life circumstances, moments of great tension, and responsibility in making ethical decisions, it is increasingly important to emphasize the importance of training in palliative care, at different levels (basic, intermediate, and advanced), wherever training in palliative care is lacking or insufficient, as the palliative actions as well as teamwork and family support are crucial to the reduction of suffering. The different manifestations regarding the place of death, for example, require on the part of social workers – who are integrated into teams directly involved in discharge planning – a self-reflexive practice, creativity, specific communication skills, and a deep scientific rigour in decision-making involving emotional, social, moral, ethical, spiritual, and financial issues.

Concerning new challenges for social workers in internal medicine departments, the study suggests the need for reconfiguring procedures, protocols, social work palliative care education and training, and more hospital palliative care teams, with management of healthcare to include social workers’ perspectives at micro, meso, and macro levels to improve best practices and promote quality in healthcare delivery; healthcare planning is to consider the practice, knowledge, and mixed (health and social policies) approaches of social workers.

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