

Perceptions of the caregivers of terminal patients

Percepções dos acompanhantes de pacientes em estado de terminalidade

Percepciones de los cuidadores de pacientes en el estado terminal de la enfermedad

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This study aimed at describing and analyzing the perceptions of the caregivers of terminal patients in a public hospital. It was conducted through a quantitative approach, with 104 subjects, all of which were caregivers of terminal patients hospitalized in the Emergency Room or in the Intensive Care Unit. Data collection was conducted through interviews with a semi-structured questionnaire. The results have shown that 36.54% of the caregivers did not recognize that there was no possibility of cure, while 16.35% were uncertain, adding up to a total of 52.89% of people who did not know the prognostic of the patients. 58.65% of the participants believe that measures to extend the life of the patient with an incurable condition should be taken. The caregivers for terminal patients need to receive more information regarding the irreversibility of the clinical condition of the patients. Health services aimed at dealing with terminal patients should include the caregivers and family members in their plans of attention and care.

Descriptors: Hospice care; Family; Humanization of assistance.

Este estudo teve como objetivo descrever e analisar as percepções dos acompanhantes de pacientes em estado de terminalidade num hospital público. Foi utilizada a abordagem quantitativa, tendo como sujeitos 104 acompanhantes de pacientes terminais internados no Pronto Socorro e Unidade de Terapia Intensiva. A coleta de dados realizou-se através de entrevistas com um roteiro semiestruturado. Os resultados demonstraram que 36,54% dos acompanhantes não reconheciam o quadro de impossibilidade de cura, seguidos de 16,35% indecisos, totalizando cerca de 52,89% sem conhecimento do prognóstico do paciente. O prolongamento da vida do paciente incurável é apoiado por 58,65% dos pesquisados. Os acompanhantes de pacientes terminais necessitam de maiores esclarecimentos sobre a irreversibilidade do quadro clínico. Os serviços de saúde direcionados aos pacientes terminais devem incluir os acompanhantes e familiares em seus planos de atenção e cuidado.

Descritores: Cuidados paliativos na terminalidade da vida; Família; Humanização da assistência.

Este estudio tuvo como objetivo describir y analizar las percepciones de los acompañantes de pacientes en estado terminal en un hospital público. Fue utilizado el abordaje cuantitativo, teniendo como sujetos 104 acompañantes de pacientes terminales internados en la Guardia y Unidad de Terapia Intensiva. La colecta de datos se realizó a través de entrevistas con un guión semiestructurado. Los resultados demostraron que 36,54% de los acompañantes no reconocían el cuadro de imposibilidad de cura, seguidos de 16,35% de indecisos, totalizando cerca de 52,89% sin conocimiento del diagnóstico del paciente. La prolongación de la vida del paciente sin cura es apoyada por 58,65% de los investigados. Los acompañantes de pacientes terminales necesitan mayores aclaraciones sobre la irreversibilidad del cuadro clínico. Los servicios de salud dirigidos a los pacientes terminales deben incluir los acompañantes y familiares en sus planes de atención y cuidado.

Descriptores: Cuidados paliativos al final de la vida; Familia; Humanización de la atención.

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INTRODUCTION

The proximity to death, its imminence, inevitability and irreversibility directly influence the relationship of patients, their family members and health professionals, impacting the entire health system. To the achievement of quality care, patient-family relationships should be well supported by the professional team¹.

The terminal stage is considered to be one of the most difficult for the health team, and the main difficulties it generates for patients involve: pain administration, respiratory insufficiency and mental confusion, followed by states of anxiety and depression².

Although the needs of these patients are classified as a priority, the attention dedicated to their caregivers and family members should also be highlighted, due to the high emotional impact they go through. The family is responsible for providing psychosocial protection to the patient, and thus become the main support system for them during the illness process³.

The vulnerability of family members and caregivers of terminal patients is associated to the appearance of certain psychic manifestations, such as: a negative view of the disease, relationship difficulties with the patient, absence of a support network, among others⁴.

It is worth highlighting that the caregivers are fundamental in the last stages of the disease, and are exposed to many different types of feelings, including fear, anguish and impotence when facing how close is the death of the person they care for⁵.

The World Health Organization (WHO) prioritizes the attention to the needs of the caregivers and family members of terminal patients, highlighting how important a support system is during the process of disease and grief⁶.

The satisfaction of the family regarding the care provided in the last stages of the patients' life is frequently used as a measure to evaluate the palliative care, as it is an important index of the quality of the health service. Thus, hospital organizations should recognize the importance of offering

care for the caregivers and family members of these patients⁷.

In view of the complexity of the team and of the importance it has for the health system, this study aimed at describing and analyzing the perceptions of caregivers of terminal patients in a public hospital.

METHOD

This is a quantitative study, conducted in the University Hospital of the University of São Paulo (USP), which is a teaching hospital of medium complexity in the city of São Paulo.

The research was conducted from July, 2013, to August, 2014, with 104 caregivers of both genders, who cared for patients who were considered to be severely ill, after their records were analyzed, and following the recommendation of the head nurse in each ward.

To be included in the study, patients had to: be over 65 years of age, and have a severe clinical condition, with no therapeutic possibility. Data collection was carried out through the use of a semi-structured questionnaire, directed to the caregivers of patients hospitalized in the Emergency Room and in the Intensive Care Unit (ICU).

The questionnaire included the following questions: (1) Do you recognize that there is no possibility of cure for the patient?; (2) Do you think that the patient feels hopeful for a recovery?; (3) Does the patient present pain or suffering?; (4) Do you think that treatments are valid even if there are no chances of improvement?; (5) Would you agree with comfort and relief measures?

The answers could be "Yes", "No", or "Do not know", except for the question regarding pain and suffering, for which the possible answers were "No presence of pain", "Moderate pain" and "Intense pain".

Data analysis was conducted with the use of the softwares Epidata and Excel 2003 (Microsoft Corp., USA).

The research project was authorized by the Research Committee and by the Committee for Ethics in Researches with Human Beings, from the Committee of the University Hospital at the USP (CEP-HU/USP). The participants were instructed

that the confidentiality of their information and was guarantee, as well as their anonymity. It was also mentioned that they could choose a fictional name. It is important to remark that all subjects in the research signed the Free Informed Consent Form, according to the Resolution CNS 466/12.

RESULTS

Caregiver characterization

Most caregivers were those with a closest family tie: sons, spouses and brothers (Figure

1).

Regarding the gender of the caregivers, 61% were women (Figure 2).

Caregivers and the terminal state

The perceptions of the subjects selected were considered, regarding the clinical framework of the patients in the Intensive Care Unit and in the Emergency Room (Table 1).

The perception of the situation of the patient, of the need for care and pain relief, was recognized by the caregivers, as Table 1 indicates.

Figure 1. Family relationship degree of the caregivers. University Hospital of the USP, 2014.

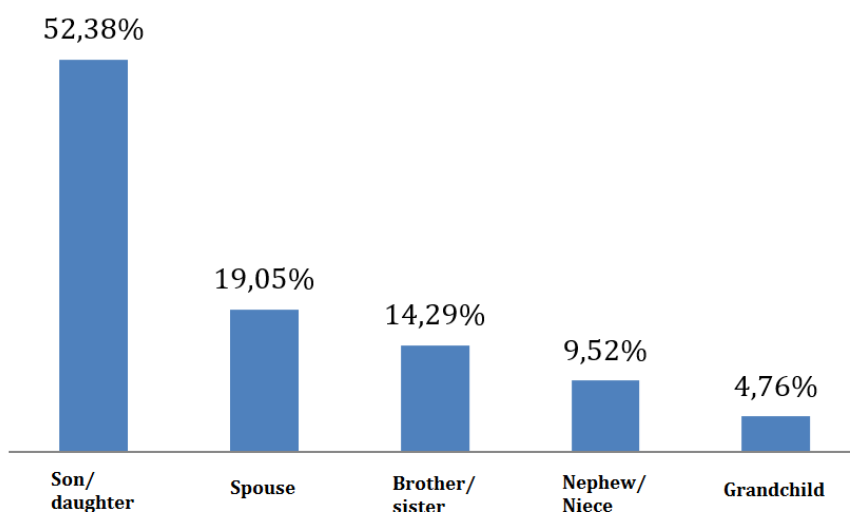


Figure 2. Gender of the caregivers. University Hospital of the USP, 2014.

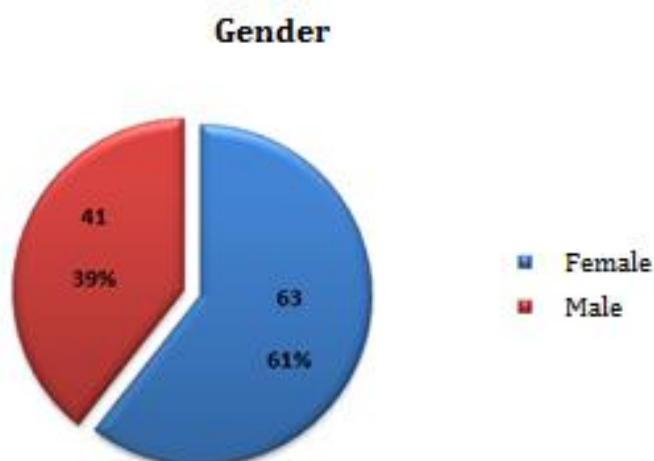


Table 1. Caregivers of terminal patients, according to their own perceptions. University Hospital of the USP, 2014.

Questions	N (%)
Do you recognize that there is no possibility of cure for the patient?	
Yes	49(47.12%)
No	38(36.54%)
Does not know	17(16.35%)
Do you think that the patient feels hopeful for a recovery?	
Yes	46(41.35%)
No	48(46.15%)
Does not know	13(12.50%)
Does the patient present pain or suffering?	
Intense	7 (15.91%)
Moderate	17(43.18%)
No/little	16(40.91%)
Do you think that treatments are valid even if there are no chances of improvement?	
Yes	61(58.65%)
No	38(36.54%)
Does not know	5 (4.81%)
Would you agree with comfort and relief measures?	
Yes	93(89,42%)
No	5 (4.81%)
Does not know	6 (5.77%)

DISCUSSION

In this study, the caregiver was capable of reflecting on the impossibility of cure and on the consequences of such a condition.

In the studied sample, 47.12% of the answers indicated that the situation of no possible cure was accepted. However, 36.54% did not recognize that the state of the patient was irreversible, not to mention 16.35% of patients who were undecided about the possibility of a cure. This a communication failure between the health team and the family members of the patient, that can result in a painful process of grief and non-acceptance of death.

When confronted with a situation of impossibility of cure, many family members

cling to religion to face the difficulties, seeking comfort and calm. Even in cases of long lasting chronic diseases the patient often disregards the real characteristics of the disease, and believes in the possibility of a cure, of overcoming that state.

When the caregiver was asked if the patient felt hopeful for their recovery, 46.15% of the individuals answered that they did not, while 41.35% of the individuals were hopeful for recovery. Since none of the patients had any possibility of cure, the health professionals might have been unprepared to explain the prognosis of the patient, leading the caregiver to doubt that there could be no cure.

The questions about the pain and

suffering of the terminal patients included relevant data, according to which 43.18% of caregivers reported the patient to feel moderate pain, while 15.91% reported that they felt intense pain. The remaining 40.91% of participants did not report that the patients were feeling pain, claiming that they were not presenting any signs or symptoms of pain.

The perception of the pain felt by others is oftentimes subjective, and hard to measure. It takes into account analysis of the behavior of the patient, including complaints, contractions indicative of pain, depression signs, among others.

When asked about whether or not treatments should be attempted in a situation with no possibility of improvement, 58.65% of caregivers stated that it should, as opposed to the 36.54% who disagreed.

In view of the importance of caring, and concerned about the comfort of the patient, 89.42% of caregivers stated that they agree to comfort and relief measures for terminal patients.

The role of caregiver during the treatment of terminal patients is important, mostly in the understanding of information that improves communication⁸.

Companions and caregivers are, mostly, related to the patients, live in the same residence and are females⁹. In another study, conducted in a hospital at Rio de Janeiro, 83.3% of companions of hospitalized elders were female¹⁰.

Companions who are present everyday can have a better point of view regarding the improvement or worsening of the patients' situation. When the visits are less frequent and there is no daily presence of companions, family members might have doubts regarding the possibility of cure, and frequently refuse to believe that the situation is irreversible - as in this study, in which, when asked if they recognized that there was no possibility of cure, 36.54% stated that they did not, while 16.35% were unsure.

In many cases, the patients themselves, when lucid and responsive, do not accept that their situation is irreversible. The patients act as if they did not know their

disease, but they notice, through the observation of their surroundings, the severeness of their case. They see changes in the behavior of family members and doctors, low volume speaking, looks of compassion towards them, and actions that are merciful towards them¹¹.

There are cases in which family members require physicians not to say anything to the patients regarding their situation, even when they are lucid, not to mention situations in which the physician does not tell the patients nor their family members that the state is irreversible. The code of ethics of health professionals aims at providing an adequate therapeutic environment that can potentially increase the quality of care through the development of self-knowledge and assertiveness¹².

When it comes to the role of the doctor, a study with oncologists has found that the main factors responsible for the difficulty in communicating bad news are: the infrequent approach of communication abilities in the medicine school curricula; the social representations; the symbolism of the disease; and the difficulties to deal with the finiteness of life¹³.

The lack of clear communication makes the process of grief and acceptance more difficult. Families need more support to accept the imminence of death than the patients themselves, in view of the feelings of guilt and sadness caused by grief. A study with caretakers of elders with cancer has found that difficulties in caring lead to changes in family and social relationships around the caretakers, compromising physical, emotional and social aspects of their lives¹⁴.

When the physician says that there is no possibility of cure, family members often resort to spirituality and religion as forms of coping, and these are relevant factors in the well-being of the patients and their families¹⁵.

Regarding palliative care, it is worth to highlight that caring and treating are different concepts. Health professionals should not care only with treating the disease and giving relief to its signs and symptoms; they should also value caring, that is, seeing

the patient as a whole, having their focus on a view of the person as a biopsychosocial being. When there is no more possibility of treatment, caring becomes paramount¹⁶.

Interventions during the death process aim at promoting the autonomy of the patient, offering a process of illness in which suffering and pain are reduced, comfort is offered in the form of symptom relief, and the participation of the family is promoted and encouraged¹⁷.

A study with 100 patients found that most (90%) of the companions, not only offered emotional support, but also took significant part in any decision making. Approximately 57% of the participants stated that the role of their companion was to make it easier for them to state their concerns, 51% of companions helped the patients to remember advices given by doctors, and 49% helped in decision making during consultations¹⁸.

A broad range of actions can be offered to the patients and their families, aiming at the relief of pain, the diminishing of discomfort, and the possibility of facing the last moments of their lives accompanied by someone who can hear them.

The companions and family members should recognize, whenever possible, the active decision of the patients, their autonomy and their choices, thus avoiding a delay of the moment of death due to abandonment and isolation¹⁵.

CONCLUSION

This study analyzed the perception of caregivers of terminal patients regarding their expectations and the perspectives of the clinical state of these patients.

It was found that the companions of terminal patients are not completely aware of the clinical state of the patients who have no possibility of cure, since the sum of individuals who do not recognize that a cure is impossible and of those who are unsure of that possibility results in 52.89%.

There was a tendency to be favorable to treatments that aim at prolonging life, even without any possibility of cure (58.65%). Palliative treatments that aim at offering

comfort and diminish the suffering of patients were also accepted by most companions (89.42%).

These results may be reflections of certain limitations of the study, such as the possible selection bias generated by the restriction of access by the heads of each department, and the sample bias, due to the fact that the research was conducted at a medium complexity hospital, which means that the magnitude of the clinical cases is different than that of big hospitals.

The emotional turmoil caused by the approach of such a personal theme in an emergency room is also a limitation, as it may generate responses that are not in accordance to the reality of the companion.

The perceptions of the caregivers reflect the need to include them in attention and care plans, as to make possible a humanized health management. The attention offered to a companion in the hospital setting allows for an authentic care, turning the patients and their companions in the central figures of the treatment.

The choices and preferences of care can be answered, promoting an interpersonal relationship capable of diminishing the depersonalization process of the hospitalized being. Thus, the practice of an integral care evaluates the human being as a biopsychosocial being, and not only as a being who has fragmented functional systems.

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CONTRIBUTIONS

Both authors contributed equally in the data collection for the study. **Suelen Cristina Batista da Silva** was responsible for the writing and **Mariana Rodrigues Guedes** for the final review of the article.

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