

# Ethical issues related to patient preferences in palliative care

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## Abstract

The respect for patient's autonomy is an ethical principle recognized in many areas of health care including palliative care, but not always the patient's preferences are respected. A better understanding of ethical issues related to the exercise of patient's autonomy in Palliative Care is an important step to support ethical judgments in daily practice. Therefore, this study aimed to identify and analyze ethical issues related to patient preferences recognized by professionals in the daily life of a Palliative Care team under the framework of Casuistry. Eleven practitioners were interviewed. The main ethical issues identified are: respect for patient autonomy, veracity and right to information, communication skills, conspiracy of silence, participation in the deliberation process, choice of place of treatment and death.

**Key words:** Palliative care. Personal autonomy. Patient preference.

## Resumo

### Questões éticas referentes às preferências do paciente em cuidados paliativos

O respeito à autonomia do paciente é um princípio ético reconhecido em diversas áreas da assistência à saúde, incluindo os cuidados paliativos, porém nem sempre as preferências do paciente são respeitadas. Uma melhor compreensão das questões éticas relacionadas ao exercício da autonomia do paciente em cuidados paliativos é importante passo para embasar juízos éticos ponderados no cotidiano da assistência. Tendo isso em vista, este trabalho objetivou identificar e analisar questões éticas relacionadas às preferências do paciente e reconhecidas por profissionais no cotidiano de uma equipe de cuidados paliativos à luz do referencial bioético da casuística. Foram entrevistados onze profissionais de nível superior. As principais questões éticas identificadas foram: respeito à autonomia do paciente; veracidade e direito à informação; habilidades de comunicação; cerco do silêncio; participação no processo de deliberação; escolha do local de tratamento e morte.

**Palavras-chave:** Cuidados paliativos. Autonomia pessoal. Preferência do paciente.

## Resumen

### Las cuestiones éticas relacionadas con las preferencias del paciente en los cuidados paliativos

El respeto a la autonomía del paciente es un principio ético reconocido en muchas áreas de la salud, incluyendo los Cuidados Paliativos, pero no siempre se respetan las preferencias del paciente. Una mejor comprensión de las cuestiones éticas relacionadas con el ejercicio de la autonomía del paciente en los Cuidados Paliativos es un paso importante para apoyar los juicios éticos ponderados en la práctica diaria de la asistencia. Teniendo esto en cuenta, este estudio tuvo como objetivo identificar y analizar las cuestiones éticas relacionadas con las preferencias del paciente y reconocidas por los profesionales en el día a día de un equipo de cuidados paliativos en el marco bioético de la casuística. Se entrevistó a once profesionales de nivel superior. Se identificaron las principales cuestiones éticas: el respeto a la autonomía del paciente, veracidad y el derecho a la información, habilidades de comunicación, asedio del silencio, participación en el proceso de deliberación, elección del lugar de tratamiento y muerte.

**Palabras-clave:** Cuidados paliativos. Autonomía personal. Prioridad del paciente.

## Aprovação Coep 181/11

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The author(s) declare(s) that there is no conflict of interest.

Jonsen, Siegler and Winslade first understand patient preferences in the context of clinical ethics as the choices one makes when faced with decisions about their health and treatments, from their experiences, beliefs and values. Thus represent the ethical and legal core of the clinical relationship, from which the patient must be respected in their decisions after reviewing the medical recommendation.

The underlying moral principle is autonomy. The therapeutic relationship and the professional autonomy of the patient must be respected. The professional should have respected your best judgment and conscientious objection. The patient, in turn, should be encouraged to express their preferences or to propose alternatives to the proposals made by the professional.

Respect for patient autonomy has clinical, legal and psychological significance. From a clinical standpoint, favors trust in the therapeutic relationship, greater patient compliance and satisfaction with treatment. In legal terms, supports individual rights over their own bodies. From the psychological point of view, offers the patient a sense of control over their own lives and personal<sup>1</sup> value.

Being ethical principle recognized in many areas of health care, respect for patient autonomy includes palliative care. Interestingly, even the changes in the doctor-patient relationship, which went from strong paternalism to respect for patient autonomy, was one of the factors that led to changes in the face of approaching death today, reinforcing the need to recognize the finitude of human life, prevent its conservation unconditionally apply all necessary and available steps to improve its quality, not its quantity, keeping the patient (and his representative) duly informed and respect your criteria so you can participate in the deliberation and decide, within the current laws on the treatment and some aspects related to the circumstances of his death<sup>2</sup>.

In parallel, Tapiero<sup>2</sup> highlights that despite the growing trend of respecting patient autonomy, in practice it is not usual to decide on the circumstances of his death, even as it is often to hide the condition of dying and therefore not it is common that the manner of death depends on your criteria, values and beliefs. Bélanger, Rodríguez and Groleau<sup>3</sup> also conclude that most patients in palliative care want to exercise autonomy, preferring to participate in decision making about treatment to some degree, while only a minority prefers to delegate this role.

These authors note, however, that in practice, some patients are not much encouraged to partici-

pate in the deliberation, the options are rarely discussed and the consent is only implicit, due to barriers relating to how the options are presented to the attempt of maintaining unrealistic expectations by the patient and family, and also the tendency to postpone deliberation. Then it is concluded that there are several obstacles to the exercise of autonomy and the patient's preferences to be in fact respected.

In general, the difficulties may be in professional training, in skills of communication, understanding and discussion between those involved in the therapeutic relationship for the decision making and the mechanisms that enable their achievement. In palliative care, the fact of dealing with people with diagnoses of life-threatening diseases, in a progressive and disabling course, makes frequent the problems listed above.

A better understanding of the ethical issues related to the exercise of patient autonomy in palliative care is therefore an important step for the further consideration necessary to support weighted ethical judgments in everyday care.

## Objectives

To identify and analyze ethical issues related to the patient's autonomy and recognized by professionals in the daily life of a palliative care team, under the bioethical framework of casuistry.

## Methodological procedures

This is an exploratory research, of qualitative approach in which all top level professionals acting for at least one year in the palliative care team in a general hospital in the city of São Paulo/SP, except the coordinator of the team, were invited to participate.

The interviews were administered in August 2011, during the hours of workers, with an average duration of 30 minutes. Except for a telephone interview, the others were applied in the workplace. The anonymity of the subjects who agreed to participate, being presented in numerical form, was maintained.

Semi-structured interviews were applied, whose script was developed by the researchers and validated by means of pre-test. The thematic analysis adopted as a theoretical sample. The guiding questions were: *"Please comment on how is the work of*

*the the palliative care team and what are the main difficulties”; “With the ethical problems you face to act in this service?”; “What facilitates discussion and decision making in these situations?”; “What kind of support would be interesting to help dealing with these ethical issues?”*

The study was approved by the Ethics Committee of the Faculty of Public Health, University of São Paulo (Office 181/11) and respondents were informed about the nature of the research, objectives, procedures and ability to refuse at any time, manifesting the consent by signing the term of free and informed consent (TFIC).

## Results and discussion

Three nurses, five doctors, one nutritionist, one physiotherapist and one social worker: eleven professionals were interviewed. The average age of respondents is 41.3 years, ranging from 28 to 51 years old. The average time of general professional practice was 14.5 years, ranging 5-25 years. Respondents are working 5.6 years on average in the field of palliative care there, ranging from one and a half to 12 years. With regard to religious belief, three said they were Catholic, three Protestant of various denominations, one spiritualist and one Jew, and three said they have no defined religion. Some participants had experience in palliative care prior to joining the team studied. The average time dedicated specifically to work in team studied is 3.77 years, ranging from 1-4 years.

Throughout the interviews the following ethical issues related to patient preferences were observed: respect for patient autonomy; truthfulness and right to information; communication and respect when receiving bad news; silence; participation in the deliberation and decision making: patient, staff and family; Preferences as to the treatment site and death.

### Respect for the patient autonomy

When the patient is able to judge, the team clarifies the situation and takes into account his opinion. When there is the denial of any intervention, the documentation in medical records is necessary to support the team, *“If the patient has the possibility of judgment we come very patient and asks, talk explains. What the patient does not want, we try to make everything very well documented in the medical records for that this does not cause problems”* (E4).

The existence of limits on respect for patient autonomy when he refuses an intervention in which the practitioner has security that would be useful is, therefore, questioned: *“When I get to a patient who needs exercise, a patient who would benefit much of a workout anyway ... And he tells me he does not want to do (...). When, as far as respecting the patient’s wishes if I know as professional that it would make a difference to him? Until what point to respect? Until when you let him exercise its autonomy?”* (E2).

In the following discourse we found that over time he works with palliative care, E2 has matured with regard the respect for patient autonomy: *“And I was realizing that not always my will was sovereign here.”* The interviewee acknowledges that vocational training directs and creates expectations regarding the professional proactivity to promote substantial changes from the therapeutic resources available.

However, the experience gained working in palliative care added awareness that sometimes the action is restricted to what she calls “surveillance,” and refers to the care given to patients who do not want the specific action you are offering: *“my background is this: I have to promote some change. So it took me until today .. and this is one thing that bothers me when I think ... Just ... Just watch ... ”* (E2).

In this example we can notice a conflict between the principles of beneficence and respect for autonomy. This posture can be paternalistic if contradicts the patient’s preferences and is justified by the goal of benefiting the patient or to avoid suffering damage<sup>4</sup>. Concrete circumstances of each case must be examined to see if it is a justifiable paternalistic attitude.

There are situations in which, contrary to the above reported, the patient elects the aggressive intervention despite of professionals’ evaluation that it would be futile or that it would bring more discomfort that it would benefit<sup>5</sup>. According to Macauley<sup>5</sup>, often the consensus is reached after certain clarification, but there are cases where the patient’s decision is more emotional than rational, and giving up from curative interventions would challenge the sense of hope, imposing heightened perception of failure, weakness or cowardice<sup>5</sup>.

The author argues that palliativists consider the complexity of human suffering, expressing inclusive the concept of “total pain” proposed by Cicely Saunders, but paradoxically resist to accept the possibility that the emotional distress of a patient who accept-

ed palliative treatment be more severe than the expected physical suffering as a result of an aggressive treatment. Then concludes that palliative care also have their evaluative bases, which sometimes generates conflicts by themselves for proposing to, at the same time, a customer-centric approach and that prioritizes the respect for autonomy<sup>5</sup>.

We also note the value of the opinion of the family in decisions about the patient and the consequent commitment to share with family all the necessary information: *"Because in palliative care usually we do not hide, especially from a family member"* (E1).

This reality reflects the fact that often the patient in palliative care is unable to deliberate and decide, and thus to exercise autonomy, becoming crucial, then, the participation of the family in order to represent their values and interests, or the use of advance directives (TFIC), whenever the patient has expressed.

According to Kovács, *an important part of care at end of life is to facilitate the exercise of autonomy and decisions of sick people, who bring their biography*<sup>6</sup>.

### Veracity and the right to information

The idea that the veracity between patient and health professional is (including, often, the patient's relatives also) essential for the exercise of autonomy and the construction or maintenance of a relation of trust was explicit:

*"Only the truth. Between doctor, staff, family and patient. I have some buzzwords: 'we can only fight known enemies'. I can not expect that the family helps in a decision - can not understand - if I tell half truths. Then sharing 100% with the family because the family does not feel safe and accepted will not work"* (E6).

The right to information is widely recognized by the studied team: *"If the patient has a desire to know, as is the case here, that the patient is fully informed and she led her team to tell her everything and the reasons of symptoms. Then the patient often leads the team, and is also a right that the patient has"* (E1).

The information about the clinical state are necessary, also, for the patient to plan his life and take action towards the closeness of the end: *"I think he has a right to know what he has left and to plan upon the time he still has to do his things. So if*

*he thinks it's alright, he might even die thinking it's alright"* (E2).

The communication was recognized also as a key to solve ethical problems between professionals and patient/family: *"Good communication. I think that is the main instrument between staff and must be extended to the relatives of the patient"* (E6). By communication, respect to diversity of opinions and the consensus must be reached, starting between the team members themselves:

*"I think it's just a matter of all speak the same language, you know, you have an open mind and you have the discernment to be able to discuss them. Even discuss them not only within team, but within the family, right? Before the rest of the multidisciplinary team. (...) Each one respects your opinion, but I think deep down everyone managed to reach a common point. I think this greatly minimizes the issue of medical dilemmas, as the question of butting heads against the same team"* (E4).

### Communication and respect on giving bad news

The understanding of information depends on the success of the communication process. In the case of communication between health professional and patient and/or family, many communication difficulties may be imposed.

Patients may have threatened or decreased their ability to comprehend as a result of mood states such as anxiety and depression, he decrease in the level of consciousness, cognitive impairment, sensory or by physical pain and other intense symptoms. The participation of family or legal representative of the patient in relation to decisions about the management of the case becomes greater.

In addition, health professionals may have difficulties to undertake an effective interaction with the patient/family by lack of ability to communicate in a simple, affordable manner, according to the characteristics of the interlocutors, or by the fear of emotionally burdening the patient with bad news or mitigate their hope.

It is worth considering that as well as access to information is identified as an important ethical element in the therapeutic relationship, the quality of communication also brings ethical implications, since it should benefit the patient and avoid the emotional damage that bad news can bring.

Many professionals and sometimes family members question whether the patient really wants

to know the truth, if it can harm you if it would be better to omit the truth or be truthful to preserve hope. This concern was presented: *"How far are we going? (...) So it is lawful us to expose the patient towards a truth that sometimes he does not want to see?"* (E9). This statement refers to an exception to the rule of the informed consent recognized in the context of health care. It's called *therapeutic privilege*, characterized by the omission of information about the health status of the patient, *based on the fundamented argument of the physician that to disclose the information would potentially be harmful to a patient who is depressed, exhausted or emotionally unstable* <sup>4</sup>.

It is thus understood that the information should be offered to patients with caution, while also respecting the right of "not knowing". A cultural difference between Brazil and countries of the Anglo-Saxon culture was recognized, allowing that, in Brazil, the information is given more cautiously: *"We have the fortune ethics ... a human fortune of not being in an Anglo-Saxon culture, within a still not as litigious culture that I need to say to the patient: lifetime; prospects; chances, etc. We have the possibility to tell what the Latin can stand to hear, at the speed we can stand to listen, to offer silence and wait ..."* (E7).

In this sense, Pessini <sup>7</sup> agrees that *the Anglo-Saxon attitude regarding the communication diagnostic/prognostic goes towards the objective of the truth facts, which contrasts with our Latin culture, which makes an emotional reading of medical truth with the concern to protect the patient from the truth*. It also recognizes that having access to information does not deprive the patient of suffering, but respectful communication brings benefits:

*"When the patient knows, we play it in the language that he can stand, the way he wants to hear. It's very nice. Usually those who lived well will die well. Who can have transparency at this time, does not mean it does not suffer, not anguish"* (E7).

While lying and omitting isolate the patient, the opportunity to share the fears, anxieties and concerns can promote a therapeutic benefit, considering the caution about *what, how, when, how much and to whom should be reported* <sup>7</sup>. Thus, reference was made to the way in which the information should be offered to the patient: *"of course the truth does not need to be 'thrown' but gently ..."* (E6).

Fallowfield et al. <sup>8</sup> underscore to be frequent that health professionals claim that most patients do

not want to know the truth, because they would lose hope, would be oppressed and depressed, thus becoming unable to enjoy the time they have left. However, there is a little evidence of this process. In contrary, the omission of important information about the reality of the health state of the patient does not protect the psychological suffering. The most common result of this evasive attitude of the professional is, to the patient, greater anxiety, difficulty and slowness in the required adjustment process.

Oliveira et al. <sup>9</sup> found that 90% of physician respondents affirmed to provide emotional support to the patient, but 20% did not talk about the illness or communicate the true diagnosis to the terminal patient. Furthermore, although 70% of physicians agree that open discussion about life and death issues does not harm the patient, 80% of them prefer not to clarify the estimated lifespan for patients.

The communication of physicians participating in the study mentioned above with the relatives of the patients is also restricted. 80% percent of respondents said they only answer questions from relatives and 30% reported not support nor talk openly with them about the patient's illness <sup>9</sup>. In a review of literature on communication between health professional and patients in palliative care, Slort et al. <sup>10</sup> found that the most frequently cited barriers to communication were: the lack of professional time; ambivalence or lack of desire of patient to know about his prognosis; and the fact that the professional does not speak honestly about diagnosis or prognosis.

In contrast, the most cited communication facilitators were: the availability of the professional; lasting relationships between patient and professional; professional who expresses commitment, openness and liberty to discuss any subject, being honest and friendly, listening actively and taking the patient seriously; to take initiative in touching topics related to finitude, without omitting information; negotiating treatment options, and willing to talk about diagnosis and prognosis, preparation for death, psychological, social and spiritual issues of the patient and their preferences.

Ambivalence was identified on the part of patient and professional about the prognosis. Many patients express to want complete information but are sometimes reluctant to hear a negative prognosis. In turn, professionals refer to be aware of the impact of such information on the hope of the patient and find it difficult to judge the right time to begin the discussion on these issues <sup>10</sup>.

Comparing their search with the literature on communication between professionals and patients in general contexts, Slort et al.<sup>10</sup> concluded that communication in palliative care is not so different. What could be understood as specific issues are: the difficulty in predicting the clinical course of the disease, which leads to greater uncertainty about the prognosis; ambivalence about dealing with information related to a negative prognosis; the importance of continually reassessing the needs of patients and family regarding the provision of information, since ideas and patient preferences may change over time.

In addition, professionals must distinguish between problems of the patient and their perceived needs, because the patient may not want to address certain issues. With regard to the issues of communication, more specific questions of palliative care are the explanation on the final stage of the disease, preferences and emotions concerning the end of life, spiritual issues, therapeutic futility, treatment options that prolong life, decisions concerning the end of life and beliefs about what is beyond life<sup>10</sup>.

The authors suggest that palliative care professionals to be available to the patient, have an open and committed approach, actively listen, take the initiative to talk about issues related to finitude, recognize their own ambivalence and the patients' about certain subjects, continually reassess the needs and preferences of the patient and have high level of communication skills to discuss, additionally, emotional and spiritual issues with patients<sup>10</sup>.

### Siege of silence

The difficulty of talking about the disease process and the expectation of the brevity of life is common among health professionals and also for the patients themselves and their families. It is common to observe the so-called "siege", "conspiracy" or "pact" of silence, identified by respondents as ethical problem: "From an ethical perspective, what draws my attention is still the siege of silence" (E7).

The siege of silence is defined as the implicit or explicit agreement from family, friends and/or professionals, to alter the information given to the patient in order to hide the diagnosis and/or prognosis and/or severity of the situation<sup>11</sup>. E7 states that the siege of silence: "is a diagnosis in palliative care where you realize that the patient is not actively participating in choices about himself because they do not know what's going on."

When someone detains the information, it is the family; it has the power to decide about the

patient: "Families take account of decisions, choices, and the diagnosis that belongs to the patient" (E7). The reason for imposing the siege of silence is to avoid the suffering of others: "He will not stand knowing"; "He will suffer too much" (E7). However, according to the interviewee, despite not excluding the suffering of the siege of silence, it deprives from the ability to exercise autonomy: "In fact, these people are suffering ... depriving the patient of choosing (...) greatly prejudices the family and also us, once the patients do not know what's going on" (E7).

Scene was described in the siege of silence permeating relations: "There in the house, at the gate, a family member asks me not to talk about it, about the diagnosis, the prognosis, over lifetime, just about anything, right? Most of the time, we know that the patient already knows and there is such a conspiracy of silence" (E10). By highlighting the dialectic of the siege of silence between patient and family, the interviewee states that often the opposite of the situations reported also occurs, and the patient who owns the information, does not want the family to know:

"The patient does not speak for the family, I imagine that is for the family not to suffer ... more ... And the family says nothing to the patient, also with the same goal. And everything is very ... stands a silent and painful situation" (E10).

In addition to causing distress to the family and the patient, the siege of silence poses a dilemma for professionals: "Who will I follow? And we go groping and ... huh? And leaving the ... thing flowing a bit slowly. And just ... in the end I think it all ends up working out. But it is a dilemma" (E10); "This issue of the siege of silence is one thing that has always vexed me because I do not know which side I'm ... So I'd rather stay in my own. I prefer to be very quiet" (E2).

Fallowfield, Jenkins and Beveridge<sup>8</sup> claim that although the motivation behind the siege of silence is well intentioned, results in a high state of anxiety, fear and confusion, not serenity and security. Furthermore, denies to the subject the opportunity to reorganize and adapt their lives to make more plausible goals, guided by realistic hopes and aspirations. In the case of palliative care, patients need clear information to plan and make decisions about facing the care and death, put pending issues in order, say goodbye, make amends and protect themselves from futile therapies. The authors conclude that providing honest information to the patient is an ethical imperative<sup>8</sup>.

**Participation in the deliberation and decision making: patient, team and family**

One interviewee considered as an important ethical problem taking unilateral decision by the medical staff on issues relating to the therapeutic investment: *“What makes me absolutely shocked, horrified, is the unilateral decision of a medical team of no longer investing in patient or not. And the term is ‘investing’, as if the patient were a purse, a stock market, right? So, in general, doctors warn that more will not do ... yet ... maybe warn ...”* (E7).

In the speech quoted above we find the hassle for the medical staff did not allow patients and families to participate in such important decision and also with respect to a term that is often used to “invest” which, in his opinion, is ambiguous and allows a derogatory and utilitarian view of the patient.

Jonsen, Siegler and Winslade<sup>1</sup> advise to never plead futility to justify unilateral decisions, thus avoiding difficult conversations with the patient or family, and that you avoid using the term futility with family, given its negative connotation. Suggest, instead, to direct efforts to provide comfort and palliate to the patient, because the losses in a more aggressive intervention may outweigh possible benefits.

Patient autonomy (exercised by himself or his representative) has been recognized as an important element for the definition of the action, while the team legitimizes their participation in the deliberative process: *“How did the idea of the ducts has a lot to do with respect for the autonomy of a patient (...) it is a matter of legitimating this patient, this family”* (E7).

The issue of family involvement in decision making is also brought with another focus. Respondents expressed concern about the assignment, to lay people, of the function to decide on technical issues over which they have jurisdiction:

*“I see it happening in the medical clinic, geriatrics, not with us ... Giving to families and patients the dilemmas that is for the team to decide. For example, if the patient has an indication of a procedure and that procedure is very specific, you need training to discern on that procedure. Often what, he’s thrown the responsibility for the family (...) I do not think it is ethical to discuss this with a lay person”* (E5).

E6 agrees, stating that: *“It is something that is medical conduct. Hence there is no ‘what do you want?’ Because medical management is not something that the family can choose”*. Faced with such findings, interviewees refer to the discussion on

what issues and how the family should participate in the deliberative process in palliative care:

*“It is ok (family participate in decisions) on issues such as analgesia, probe not to vomit ... help choose between sleepiness or some pain ... But operating or not, go to ICU or not, is another thing, are decisions of medical conduct”* (E6).

The discourses express, therefore, that it would be up to the team discern which issues related to treating the patient’s family can opine, and under what circumstances should be clarified in order to understand the behavior determined by the team: *“Many things the family does not have to decide but understand the decision, because the conduct is medical. The professional must have this clear for himself of until where the family can opine”* (E6). To delegate to the patient’s family the responsibility for decisions in medical conduct was identified as a problem, especially when there are disagreements between family members or between family and staff.

The cases cited by respondents, where such conflicts arise, ranging from referral to palliative care, including an indication of less invasive procedures and the contraindication of disproportionate measures, to the dilemma, especially between resuscitate or not the patient. In this sense, it was mentioned as a problem the fact that often the medical staff which directs the patient or referral asks not consider for the family prior clarification:

*“We often touch in the no speak of the medical team that is, shall we say, managing the patient’s case. The fact that they do not speak of the conditions that he really is ... The cure that no longer exists, control of symptoms”* (E4).

According to one respondent, the lack of family information occurs more due to limitations of the own family than due to unavailability of staff: *“What if there was a misinformation or no information, sometimes it is much more of a family that was not present because the patient did not leave, or because he could not be present, and we end up having to tell the whole story and the end ... Telling what is the best treatment for that patient. And induce this family to believe on us. We have an ethical problem, which is the problem of communication”* (E7).

As an ethical issue, E10 indicates the rejection of the family towards the proximity to losing of a relative, making it difficult to understand the idea of palliative care, as well as how much is safe to keep some procedures: *“The question of ... specially the family,*

not accepting the palliative care. It's not accepting to speak about unnecessary procedures ... futile. Too often, too. (...) It is very difficult to accept that people do not do more procedures, which do not invest in measures that will go nowhere". Guided by the same difficulties, the interviews also refer to problems at the moment of death: "The medical record was written, but we knew there was a dispute between medical staff and family. So what to do?" (E6).

The concern of respondents who spoke about family participation in decision making comes from the risk of possible legal implications against the team or certain professional. The next state well represents this position: "Legally, no matter what the family chooses. The decision of the family has no value. Incidentally, always have a family that comes from 'Titirica da Serra' and gets tired, put wrong thought in their minds and go to the judge. If you cling to the fact that the family chose it, you will certainly pay compensation. But if it was the conduct, it is bound" (E6).

This observation draws attention to the need for integration and coherence within team members and between them and the family, to avoid legal problems: "It is imperative that all steps are coldly rhythmic, and also differentiate what is medical conduct and in what the family can interfere" (E9). It is worth noting that: "Is it over reaching an agreement, but always with much wear, sometimes with a very ... high wear, right. There are some even violent people ..." (E10).

Kovács <sup>6</sup> relates the difficulty of the participation of lay people in the discussions and decision making about care at the end of life related to cultural attitudes of death denial. The author suggests discussions and clarifications to the population as strategies that enable the preservation of the dignity and quality of the dying process.

### Preferences regarding the local of treatment and death

It is common the inpatient wish to be treated at home. In these cases the team must then strive for that goal to be accomplished. The fact that the studied palliative care service offers home care favors this possibility: "The patient wants to go home. So the team strives even more to try to send that person home" (E2).

Often the patient wishes to die at home, but it has important legal implications: "And this is an ethical question that is not well accepted, understood? And we have many barriers in the event of death

at home. Not by the side of the family, but by the bureaucratic side, the system. When a person dies at home what are the current procedures? Police ... IML ... " (E1).

Besides the previously mentioned legal reasons, the difficulty of the patient to die at home even when they so desire is, according to respondents, related to the inability of the family to follow the process to the end: "Because the family has no structure to support this. The death at home ..." (E10). Respondents also allude to the lack of resources on the part of the team so that they can support the patient and family in this situation:

"One thing that would be, maybe it would fall into issue of the ethical principle of justice in palliative care, that sometimes does not have as many features as I would like ... to a patient who wants to be home and we cannot offer a daily curative, or we have no guarantee of immediate transportation, or we do not realize a demand which could be weekly medical visit, because we have the same team limit" (E7).

As a result, a very frequent ethical problem is the non-fulfillment of what was agreed between patient, family and staff with respect to the location and context of death, when you die at home is manifest desire of the patient: "Then it was right, the patient expressed a desire to died at home, the family agrees for a moment and when the moment comes they do not support and the patient sometimes dies in the ambulance, in route, or in an emergency room in a very bad way. Away from his family, away from his environment" (E10).

For all these questions the choice of location of care and death is seen as something challenging from the perspective of ethics <sup>12</sup>. Sometimes the patient prefers a particular location to be assisted and die, but this may not be feasible or ethical. The authors suggest that the planning for hospital discharge of patients with life-threatening disease consider whether he has mental condition to make that decision. It also should be analyzed risks that home care can mean for caregivers, their opinions, sources of necessary resources and the quality of the relationship between patient and family <sup>12</sup>.

The choice of the patient should be facilitated whenever possible, thus respecting their autonomy, but should avoid harm when home care is not plausible, using as criteria the best interest of the patient and the welfare of those involved in the care. It is also the role of the healthcare team to explain to the patient why their preferences can not be attended <sup>12</sup>.



## Final Considerations

The survey results helped to identify important issues regarding patient autonomy in palliative care, under the paradigm of bioethical issues, case by case. The duty to respect the patient's autonomy was recognized, however conflicts were identified between this principle and the beneficence, especially when the patient refuses intervention. Experience in palliative care was identified as a stimulus to act with greater respect to the preferences of the patient. It was also discussed the morality of the patient / family to participate in decisions about medical conduct.

The duty of truthfulness was recognized and communication identified as necessary for the therapeutic relationship, being an elementary condition for the patient to exercise his autonomy. In parallel, the respect for the patient's emotional boundaries regarding bad news was observed as necessary. To meet these demands, it was emphasize the importance of developing professional communication skills.

The siege of silence was placed as an important obstacle to autonomy and to the resolution of disputes by the patient who would still be able to decide and act socially. In addition, health professionals may face an ethical dilemma choosing the posture to adopt towards this siege.

The choice of place for the treatment and death was cited as an important aspect among the preferences of the patient, although the difficulty of enabling adequate assistance when the choice is the patient's home. In this case, it is necessary to evaluate the needs and preferences of the patient along with the availability of formal and informal home care.

The study highlighted the prominence of the theme of communication. The fact that communication in palliative care often include issues of strong emotional content makes it challenging for everyone involved, which often results in the omission of certain information and paternalistic attitudes towards the patient. In parallel, the recognition of his role as a tool to deal with ethical problems, and still as a prerogative to exercise autonomy, for the therapeutic relationship, psychological adjustment, and resolution of disputes.

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### Participation of authors

This manuscript is part of the results of the thesis of Carolina Becker, supervised by prof. dr. Paulo Antonio de Carvalho Fortes. Both have contributed in the conduction of research and in drafting the article, sharing its authorship.

