

Autonomy in palliative care: concepts and perceptions of a health teamwork*

Autonomia em cuidados paliativos: conceitos e percepções de uma equipe de saúde

Autonomía en cuidados paliativos: conceptos y percepciones de un equipo de salud

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ABSTRACT

Objectives: To analyze the concept that a health teamwork, acting on the field of palliative care, has about the terminal patient's autonomy and to identify the attitude of professionals facing the manifestation of that autonomy. **Methods:** Exploratory and descriptive study with a qualitative approach. 22 members of a palliative care team were interviewed. The data was analyzed using the content analysis methodology. **Results:** Three different categories were obtained from each professional group (Groups I and II): understanding the autonomy of terminal patients in a palliative care context, reactions of professionals on the daily assistance services, and, limitations of the relationship (autonomy vs. palliative care). **Conclusion:** Autonomy is an essential component in the palliative care philosophy; it must be able of creating ethical sustainability, applicable to therapeutic projects of terminal patients.

Keywords: Palliative care; Multiprofessional team; Communication; Bio-ethics

RESUMO

Objetivos: Analisar o conceito que a equipe de saúde inserida no contexto de cuidados paliativos tem da autonomia do doente sem possibilidades de cura e identificar qual é a atitude desses profissionais diante da manifestação dessa autonomia. **Métodos:** Trata-se de um estudo exploratório descritivo com abordagem qualitativa. Foram entrevistados 22 membros de uma equipe de saúde de cuidados paliativos. Os dados foram analisados segundo a metodologia de análise de conteúdo. **Resultados:** Foram obtidas três categorias distintas para cada grupo de profissionais (Grupos I e II). Elas evidenciaram a compreensão da autonomia dos doentes sem possibilidades de cura no contexto dos cuidados paliativos, as reações desses profissionais no cotidiano assistencial e suas limitações nessa relação (autonomia vs cuidados paliativos). **Conclusão:** A autonomia é um elemento essencial à filosofia dos cuidados paliativos e capaz de conferir sustentabilidade ética ao projeto terapêutico desses doentes.

Descritores: Cuidados paliativos; Equipe multiprofissional; Comunicação; Bioética

RESUMEN

Objetivos: Analizar el concepto que el equipo de salud que actúa en el contexto de cuidados paliativos tiene de la autonomía del enfermo sin posibilidades de cura e identificar cual es la actitud de esos profesionales delante de la manifestación de esa autonomía. **Métodos:** Se trata de un estudio exploratorio descriptivo con abordaje cualitativo. Fueron entrevistados 22 miembros de un equipo de salud de cuidados paliativos. Los datos fueron analizados según la metodología de análisis de contenido. **Resultados:** Fueron obtenidas tres categorías distintas para cada grupo de profesionales (Grupos I y II); ellas evidenciaron la comprensión de la autonomía de los enfermos sin posibilidades de cura en el contexto de los cuidados paliativos, las reacciones de esos profesionales en lo cotidiano asistencial, y, las limitaciones en esa relación (autonomía vs cuidados paliativos). **Conclusión:** La autonomía es un elemento esencial en la filosofía del cuidado paliativo, capaz de conferir sustentabilidad ética al proyecto terapéutico de esos enfermos.

Descriptorios: Cuidados paliativos; Equipo multiprofesional; Comunicación; Bioética

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INTRODUCTION

Palliative care as a philosophy of care, is designed to assist patients with no possibility of healing and seeking to consolidate a model of care that considers the process of dying as inherent to life. This philosophy is founded on the development of therapeutic projects capable to offer such patients a therapeutic, rationally oriented-care, increasing life quality, minimizing the symptoms, recognizing and respecting individual's rights. It is important to mention that family is an element that can strengthen the construction and consolidation of these projects, and which should also be assisted⁽¹⁻⁶⁾.

In 2002, the World Health Organization presented the latest definition on palliative care, and regarded them as:

"An approach that promotes quality of life of patients and families, facing conditions that threaten the continuity of life through prevention and relief of suffering. Requires early identification, impeccable assessment and treatment of pain and other problems of physical, psychosocial and spiritual nature"⁽⁷⁾.

Considering these aspects, it can be stated that palliative care depends on a multidisciplinary approach to produce a harmonious and convergent support to the individual without the possibility of healing, and family members. Thus, it is clear that the focus of attention is no longer the disease to be cured but it returns to the individual who is viewed as a biographical being, with complex physical, psycho and spiritual dimensions, active and entitled with the right of information and full autonomy over own decisions regarding therapy options, in addition to the individualized attention to family members and the pursuit of excellence to achieve symptoms control⁽⁸⁾.

The structure of such care model establishes intimate relation with the bioethical principles considered in the shed of principles: the beneficence or nonmaleficence, justice and autonomy. They are capable of supporting the opposition against the futility or therapeutic pace inherent in modern medical practice⁽⁹⁻¹¹⁾.

Given this proposition of care that seeks to uncover ethical values and human rights, individual autonomy stands as one of the core values in the search for the basis and excellence in palliative care.

For major Western societies autonomy is a core value that gives expression to a basic set of legal and political ideals which are recognized by the name of liberalism. In what concerns to the political-legal sphere is translated as independence, and implicitly to that concept the significance of self-confidence, critical thinking, understanding of self interests, qualities related, indefinitely, to concepts of action, beliefs, and reasons to act. From this perspective, individuals are free from external or social interferences and the State assumes a neutral positioning on this right. Within this context, individuals have not considered their social, economic and/or physical limitations, and the State protects itself in its posture of neutrality and noninterference⁽¹⁰⁾.

The political-legal domain is not coextensive with human life and certainly does not exhaust the domain of ethics as it relates to the relationship between the individual and the state

disregarding the interfaces with social relationships⁽¹²⁾.

Autonomy is a much more complex phenomenon when approached daily, it is built up in the midst of social and human relations, which do not release considerations relating to human development and relationships, to which the autonomy effectively operates in this particular case, the context of palliative care⁽¹¹⁻¹²⁾.

It is founded in the conceptual and political bases of palliative care presented by the World Health Organization in 2002, on the perspective of Beuchamp & Childress as the guide for key principles of bioethical, and Agich that considers autonomy a multi-dimensional concept related to the interstices of everyday life, allowing to be validated in the fragility and commitment through the rehabilitation of the individual residual autonomy, through the action of caregivers trained and able to recognize it and maximize it. Under these prospects this study sought to identify amidst the health team involved with the philosophy of palliative care, the relationship with the autonomy of patients without the possibility of cure^(7,12).

OBJECTIVE

Analyse the concept the health team applies relating to autonomy of patients without possibility of cure within the context of palliative care, and identify what is the attitude of such professionals before the manifestation of this autonomy.

METHODS

The present study is a descriptive exploratory type and the resources of qualitative approach were used. The research was conducted in a public hospital in São Paulo in its palliative care ward, a pioneer in Brazil

After the project approval by the Institution Research Committee of Ethics and Research (Process CEP/IAMSPE n° 0109/06) and signature of the Term of Free and Clear Consent by the individuals of research, data gathering was made through individual semi-structured interviews, previously scheduled, which was recorded and later transcribed.

The approach of the individuals and consequent determination of the sample, was made through a formal invitation by the researcher to all the health team of the palliative care ward. It was excluded from the possibility of joining the group the ones that refused to do so, the staff in absence due to vacation, license, etc. From this pre-selection, the methodology process was key to delineation of the study individuals until the speeches that were obtained through interviews demonstrate their saturation content, i.e., until the information collected showed replicates content.

Data were collected according to the following guiding questions:

What is for you a patient with autonomy?

Do you think possible for a patient without possibility of cure exercises the autonomy? If yes, how? Give one of more examples.

How do you expect health professionals to react before expressions of autonomy of the patient without possibility of

cure?

Data gathered were analysed according to the content analysis methodology, which proposes a set of analysis techniques of verbal communication, applied to speeches, to obtain indicators, qualitative or not, allowing the description of the messages from the respondents. The principle of this methodology is to dismantle the structures and elements of content, analyzed by means of careful study of words and phrases that comprise it, looking for meaning and intentions, recognizing, comparing, evaluating and selecting them to clarify their different characteristics and extract its significance⁽¹³⁾.

RESULTS

The individuals interviewed are part of a health team, who develops a pioneering work in Brazil, and the assistance they provide is characterized by everyday dealing with the process of human dying from the perspective of the paradigm of care, the inherent care philosophy of this ward.

Of the interviewed professionals, three are nurses, 12 nursing assistants, one nursing technician, four physicians, one psychologist, one chaplain, totaling 22 professionals. The age of this population varied from 25 to 56 years, and 37.5 years the age average, while the time on the job varied from 2 to 30 years with an average of 10.1 years of experience.

The health team, object of this study, was not homogeneous in its speech, although being a mature team and developing assistant activities for at least two years. Thus, it was not possible to categorize the data obtained and not consider their particularities. It was necessary to sub-segment the sample population into two groups, Group I [Nurses (NUR), Nursing Technician (NT), Nursing Assistant (NA) and Chaplain (CH)] and Group II [Physicians (Phys) and Psychologists (PSY)].

Data gathered from Groups I and II were categorized and led three distinct categories each one.

Group I

Speeches from Group I could be grouped and allowed the characterization of the autonomy of the patient without possibility of cure, the establishment of criteria for the recognition of the patient as an autonomous being, as well as the perception of the reactions of the health team before the exercise of autonomy of such individual.

Category Ia: Characterizing what is the patient without therapeutic possibility of cure to have autonomy

In this category, the professionals characterized autonomy of the individual outside of therapeutic healing as something that permeates the ability of individual choice about their treatment, whether or not healing.

This ability to choose comes often with aggregated terms like freedom, reason, self-control, which end up representing assumptions of this act or the consequences of it, i.e., "I am free" so, I can choose, or even I am right and that legitimates my ability to choose; the same happens to the term self-sufficiency. This process adds to the term autonomy the assumptions on inflexibility and sovereignty, as such the autonomy exercised or

expressed reveals itself supreme and unquestionable.

NA06 (...) *he is right about everything (...)*

NT01 (...) *he's got autonomy, he has the will to do what he wants at anytime he wants (...)*

NUR03 (...) *having autonomy is to understand patients necessity of know how to control, see their difficulties, talk about them, talk about what is currently happening to them, where is the problem they brought to us and on which we can assist him, know how to report the nursing team, to the medical team (...) an autonomy, be self sufficient.*

Category Ib: Identifying criteria for the terminal patient being recognized as an autonomous being

Speeches reveal the consciousness level of patients and information they have available are key to the exercise of their autonomy. The health team has also noted that recognition of an individual as an autonomous being depends, though, that it expresses the desire and the will to exercise its autonomy, to manage its process of life and death.

NUR01 (...) *once the patient, even outside the possibility of therapeutic cure, is conscious, and including about its problem, got the power to decide about its life, about proposed treatment, what is best or not (...)*

NA12 (...) *from the moment the patient has the desire to have this autonomy (...)*

Category Ic: Recognizing health team reaction before the expression of autonomy of patients in palliative care therapy and other specialties

Reactions before patients' autonomy without possibility of cure are expressed in two formats: the first happens from the counterpoint between the health teams that follow the philosophy of palliative care and those that don't do it. And the second, focused on recognizing the reactions of the health team strictly involved with palliative care.

According to the first part, the philosophy of palliative care functions as a "watershed" in the production of qualified health services, as its bases propose strengthening and rescuing the essence contained in the paradigm of care.

NA01 (...) *in other places it has to be at that precise time and patient has no right to choose; patients loose totally their identity, but not here, patients have the right to choose (...)*

NA06 (...) *since palliative was founded we have that idea in which patients decide(...) outside here I think that nursing has tough some restriction, in this case I think that they do not accept (...) it starts with physicians and goes across the last in line and all there, forcing, tubing even knowing the possibility is remote, as for the nursing team is hard to accept (...)*

NA08 (...) *I think at the beginning it scares a little, mainly physicians that are not used to patients asking for what they want, here in our PC team, doctors are very well prepared, this is their work, then they can respect autonomy and patient's rights (...)*

In the second part, speeches do not differentiate, but recognize the philosophy of palliative care as representing something new

and not fully consolidated, which justifies this moment as a transition of paradigms and assimilation of a new philosophy of care.

NA09 (...) *at first we feel sort of (...) it is a situation kind of complicated at start, but then we learn how to deal with it (...)*

NA12 (...) *sometimes is more convenient for us, from the nursing, not allow patients to have such autonomy, leaving them in bed, give them a bed bath (...) we put an effort because some of them want to take a shower, spray, but they are debilitated, there are colleagues who do not. "Ouch, my spine," and this, that and the other (...)*

NUR01 (...) *medical team has a better interpretation; the nursing team works "more or less dancing" as the music plays (...) not very questioning at least the team of nursing, they do not question much that kind of thing, even because much of this information does not reach them. Sometimes a patient communicates its decision to the medical team, they make the decision and we simply implement it (...)*

Group II

The speeches of Group II could be grouped and showed concepts of autonomy, the possibilities a patient has to express its autonomy and the principles that guide the actions of health teams in palliative care or not before the autonomy of these patients

Category IIa: Conceptualizing the autonomy of the patient outside therapeutic possibilities of cure

This Group conceptualizes autonomy as a basic principle of social structuring and is consequently part of an individual ability to act in society, with what the individual is able to act according to what believes and to what expects from themselves and others. In illness, the autonomy of such individual will meet the choices regarding the decisions and attitudes related to its treatment and to the process of restructuring its *modus vivendi*.

It is evident, in the speeches, the disease triggers a process of losses and limitations that could only be overcome, minimized or reorganized if the exercise of autonomy of this individual is preserved.

PHY02 (...) *It is a basic principle of social structure, that means inclusive, so we can live together, you and I, in society, it is mandatory that I respect your right about your own conduct (...). About me, who else knows? Who knows the most? And who must ultimately make decisions regarding the own self? That means, about me, it has to be me.*

PHY04 (...) *Autonomy is part of an individual's ability to act, live in society, being itself, if you have autonomy, you can, in society act according to what you believe, with what you expect (...) this is autonomy and without it one cannot live.*

PSY01 (...) *Autonomy has much to do with the right and ability to choose (...) the patient has already been ill and that has taken a lot more from it, health, possibilities (...) then patient has to have autonomy to choose what it wants, if willing to invest on the therapy, whether it doesn't want, and willing to stay at home instead, if such patient wants to try a more interventionist medicine (...)*

Category IIb: Recognizing the possibilities for terminal patients to express their autonomy

The recognition of the patient as an autonomous being

implies an assessment of their neurological functions, but not limited to that assessment. It is imperative, according to Group II, the professional involved in this process as someone who can inform the patient of his chances with truth and respect, recognizing that the limitations imposed by the disease give the individual less alternative than to all others involved in this process, family and health team. Speeches also reveal that greater will be the chances of preserving the autonomy of these individuals, when they have access to palliative care services.

PHY01 (...) *patient with no chance of cure, is often a patient who has a perfect performance, he is okay and has the capacity to decide, to reason and should be approached that way, until possible, at least while having this insight. Patient in terminal stage can not always make decisions, for that it is very important that the PC will start as soon as possible, still at a stage that he has the opportunity to decide (...)*

PHY01 (...) *if you intend or if you are keen on preserving a patient's autonomy, you have the obligation to inform him upfront, the most accurate possible what he has, what can be done and the effects of treatment, including the possibility of not undertaking such treatment, one has to be very true(...)*

PSY01 (...) *if patient has the capacity of making contact and has preserved the neurological aspect, it does have the possibility of autonomy, it is the patient there suffering, experiencing losses and living life saying goodbye, so he has to live the final stage in the way he believes, wants (...)*

Category IIc: Identifying the principles that guide the health team reaction before the patient's autonomy while in palliative treatment and other services

It was recognized that health teams, in a way, face difficulty in front of the exercise of patient's autonomy, on the other hand, the palliative care has been able to cope with the autonomy of these individuals naturally, and in line with the proposal of the philosophy of palliative care and the aspirations of a new paradigm in healthcare, the paradigm of care.

The principles highlighted by these professionals are related to the need of discussing dilemmas in palliative care practices, to seek alternative attitudes before the patient without possibility of cure; the perception that the issues related to such patient delegates to each area's technical knowledge, a small portion of the decision making process, once the therapy inherent attitudes in palliative care are transcendental and demand the discussion of a biomedical alternative model of healthcare assistance; the abandon of supremacy of health professionals that establishes an unbalanced relationship with those individuals, i.e., "(...) from someone healthy to someone ill, from someone who knows to someone who doesn't (...)"; and founding the palliative care therapy into a shared communication model and an active listening cell for these patients.

PHY02 (...) *decision making involving such complexity that are object of two questions, are transcendental questions, that means, how much time is left for me, how much longer will I live, those questions, all of them are much greater than only situations involving answers which involves questions of a technical character, and then, there is not a single doubt that that is not a domain that is mine or any other single, isolated professional, but instead, there must be a group, and if possible, with a*

rather diverse professionals looking to the patient and to the surroundings where it leaves, which includes family, friends, which includes a way of living(...) and even if we call all of the professionals involved, it lacks the main actor, this is the person who ultimately has the casting vote, and not the least doubt that it is the first, the opinion, the decision of the patient, and in case the patient is unable to speak for itself, of the family(...)

PHY03 (...) *with a service of PC as well structured as ours, we react very well, actually we suggest to the patient a treatment, but the decision is the patient, we call this shared communication (...)*

PHY04 (...) *the autonomy of the patient is a patient's right and that right must at least be heard. This autonomy, this event needs to be heard and that one, as a professional, has to devote some time listening to this, what we call the PC in active listening. In my perception still, the reaction of the professionals is much more than "How?", "You're questioning my role?", "You're questioning my decision?" "I'm the doctor, I'm the nurse, pharmacist and I am the one telling you what you have to do and you just do it", the professional is not trained to listen to the patient, and when I say, listening is not just the verbal, listening - if that is possible - and I think it's the non-verbal, we can see the non-verbal, can hear the non-verbal, feel the nonverbal and the patient and the patient has all the conditions of expressing in such way, it simply takes to the professional the will to listen to what the patient has to say. (...)*

The established principles serve as a guide for actions that constitute as the *sine qua non* condition for the validation of the patients' exercise of autonomy without the possibility of cure, in the care model proposed by palliative care

DISCUSSION

Perceptions of autonomy of the patient without possibility of cure proved heterogeneous, to this health team, although it is driven towards a common philosophy.

The autonomy characterized by Group I had connotations that establish a link with the political-legal concept of autonomy, which focuses exclusively on the decision-making power of the individual, not being able to consider the interfaces with social relations and elements inherent in the *modus vivendi*⁽¹²⁾. Under this view, individual autonomy does not establish relationship with the health team or with other agents, but is configured as an action, it is originated by the individual and it reflects back onto him, and being so, the health team is positioned outside of therapeutic project the very philosophy of palliative care, whose structure brings implicit the interrelation between health team, patient and family as key to the reorganization of mental, physical and social conditions of the individual without possibility of cure, which includes also the autonomy.

The level of awareness of information about their disease and the manifestation of the desire to exercise autonomy, were considered for validation of the autonomous exercise. These professionals consider autonomy, as defined in political and legal templates, free from external interference, i.e., professionals reaffirm their neutrality against the autonomy of these patients. Given the expressed autonomy, it is evident for these professionals, the philosophy of palliative care is viewed as the tool that will guide their actions, but only if manifested. On the other hand there are professionals who suffer interference from

their internal references and admit that palliative care is a philosophy yet unconsolidated, impeding the uniformity of their actions.

Group II perceives the autonomy of the patient without possibility of healing from the structuring of a concept that considers that autonomy is an element that has its origin in the individual, but is constructed in the interface with social relationships and their *modus vivendi*⁽¹²⁾. The concept of autonomy being developed considered the limitations of the patients without healing possibilities and implications of such limitations in the daily life of that individual. And, through these considerations, this group recognizes that health professionals and family are indispensable elements in the process of organizing an autonomous exercise, and can boost it. In considering this aspect, it can be said that autonomy does not only mean to make use of self-determination of that individual, but to help that person reaching its own limits, helping to discover and choose what is consistent with the meaning of respecting the human dignity⁽¹¹⁾.

While being included in the therapeutic project of the patient without possibility of healing, this group of professionals allows autonomy be structured on a solid trajectory for these individuals, ensuring that physical conditions such as decreased level of consciousness, are not limiting at developing a plan of care sustained by ethics. It is considering the importance of this aspect, that the late access to palliative care service is considered by them as a limiting factor in achieving the fullness of the therapeutic project.

The verbal and nonverbal communication were considered and reported as critical to mediate human relationships (family, individual and health professional) and enable the sustainability and consolidation of autonomy given individual expectations. To permeate human relationships in everyday care, communication is translated as both a diagnostic and therapeutic element, being able to identify care demands and accept them therapeutically, yielding to legitimate rights and grounds of links with patients without possibility of healing.

The element of communication in healthcare settings, particularly in palliative care is viewed as a natural principle, capable of joining one another, and cover all the ways a person can affect another. It refers to the conscious and unconscious perception of the expressed acts of those involved in the communication process. Therefore, one can say that a person can no longer talk to the other, but not to communicate something⁽¹⁴⁻¹⁵⁾. And it is this perspective in which communication transcends the limitations inherent in the everyday care in palliative care.

CONCLUSIONS AND FINAL CONSIDERATIONS

The autonomy of patients without the possibility of healing is an inherent element of the philosophy of palliative care and, through this model of care, can sustain a therapeutic project, ethically and consistently with expectations and with individual rights.

Groups I and II revealed to be at different times of the philosophical and technical understanding of palliative care, and this mismatch can infer the philosophy will be stronger the greater

the integration between health professionals, as well as the technical definition of its functions, in order to enable producing interdisciplinary and uniformity of their actions.

Autonomy in the process of human dying and in light of palliative care particularities that are not addressed in the essence of bioethical theories, therefore, the understanding of autonomy should not be static but to keep the basis in bioethical principles and flexibility in the emergency human needs.

The verbal and nonverbal communication reassert themselves as indispensable elements to the demarcation and recognition of the autonomy of patients without the possibility of healing, and enhance the conduction and adjustment of the therapeutic project according to the individual needs.

The involvement of health professionals in assisting on the exercise of autonomy is symbolic to the individual, while it extends the theoretical framework (internal and external

reference), *locus* from which will emerge the essential autonomy.

The autonomy of terminal patients has sustainable and ethical support routed in the philosophy of palliative care, but in Brazil this practice still faces the immaturity which is reflected in the organizational policies, services and health teams receiving interference, or supporting remnants of the *dressing* model of assistance.

Health education is a coherent alternative to the current moment of palliative care, and assumes a limiting character on its development, since the ignorance, lack of judgment and lack of scientific and technical knowledge about appropriate treatment options for patients with no possibility of cure, and the very essence of palliative care, compromise the autonomy of these individuals and configuration of individualized therapeutic projects, and consequently the dissemination of this philosophy of care.

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