

Autonomy of elder patients suffering from cancer: the right to know about their diagnoses

Autonomia do paciente idoso com câncer: o direito de saber o diagnóstico

Autonomía del paciente anciano con cáncer: el derecho de conocer su diagnóstico

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ABSTRACT

The growth of the senior population in Brazil and in the world poses new challenges for the health professionals, and among those, the increase of the number of chronic diseases, especially cancer. Within the practice of his/her work, the nurse faces countless situations that generate dilemmas and ethical questions that involve the patient and/or his/her family. We aim at contemplating the senior's right of knowing his/her diagnosis and the respect to his/her autonomy. Such reflection is considered significant because the action of taking care, intrinsic in the nursing actions, should be ruled by ethical attitudes and in respect to the patient's right in knowing his/her diagnosis.

Keywords: Personal autonomy; Aged; Oncologic nursing; Patient rights

RESUMO

O crescimento da população idosa no Brasil e no mundo suscita novos desafios para os profissionais de saúde, dentre eles o aumento do número de doenças crônicas, em especial, o câncer. O enfermeiro depara-se, no cotidiano de sua prática de cuidados, com inúmeras situações que geram dilemas e questões éticas que envolvem o paciente e/ou familiares. Tem-se como objetivo refletir a respeito do direito do idoso de saber o seu diagnóstico e do respeito a sua autonomia. Considera-se significativa esta reflexão, pois o ato de cuidar, intrínseco nas ações de enfermagem, deve ser e estar pautado em atitudes éticas e no respeito ao direito do paciente de conhecer o seu diagnóstico.

Descritores: Autonomia pessoal; Idoso; Enfermagem oncológica; Direitos do paciente

RESUMEN

El crecimiento de la población anciana en el Brasil y el mundo genera nuevos retos para los profesionales de la salud, y entre ellos, el aumento del número de enfermedades crónicas, en especial, el cáncer. El enfermero se depara en el cotidiano de su práctica de cuidados con innumerables situaciones que generan dilemas e interrogantes éticas que involucran al paciente y/o familiares. Se tuvo como objetivo reflexionar respecto al derecho del anciano a saber su diagnóstico y sobre su autonomía. Se considera significativa esta reflexión pues el acto de cuidar, intrínseco en las acciones de enfermería, debe ser y estar pautado en actitudes éticas y en el respeto al derecho del paciente a conocer su diagnóstico.

Descriptores: Autonomía personal; Anciano; Enfermería oncológica; Derechos del paciente

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INTRODUCTION

The demographic and social phenomenon of aging has aroused considerable concern, in the scientific community, to the changes that happened at this stage of human being's life which echoes in the society, especially in Brazil.

The panorama of aging brings along seniority, which "has its own social structure characteristics". This places us as subjects and agents of health, opening spaces and new experiences to be undergone⁽¹⁾. To do so, the multidimensionality of aging has to be taken into account, since it comprehends social, political, cultural, economical and ethical issues in the elderly human being's point of view, under a wide scope.

Aging is "the manifestation of bio-psycho-social events that happen throughout time, not with time. This means that chronological age is not directly related to the bio-psycho-social age"⁽²⁾, therefore contributing to the premise that this process is experienced individually, a reason why each senior is unique and seniority presents its particularities. An increased number of chronic diseases while aging happens due to the association of "increased risks of incidence of countless diseases, whether by the biological process itself or by long periods of exposure to pathogenic agents"⁽³⁾. Thus, the development of chronic diseases and illnesses pertaining to elder groups results in changes to the profile of patients who resort to health services, a reason why situations never experienced before appear, regarding ethical issues.

Within this context, the nursing professionals face problems and significant ethical dilemmas that are experienced in the daily routine of attention and care with the senior patient, especially in oncologic gerontology:

"The health professionals, in professional practice, are confronted to dilemmas and controversial situations involving the confrontation of their values to other people's values: patients, family, staff, among others. In these situations, the professional's values on his/her relationship with the patient, i.e., as a subject (a decision-making professional) and object (a patient, who passively suffers the actions) or as subjects (professional and patient, the latter as a participant of decisions that are relative to his/her treatment and well-being), are determining factors in their actions"⁽⁴⁾.

THE DIAGNOSIS OF CANCER IN THE SENIOR PATIENT: NURSING APPROACH

Oncologic Nursing is a specialty that has been confronting several ethical dilemmas that are dealt with by bioethics and that, nowadays, force the professionals to evaluate their attitudes towards the diagnosis of cancer in the senior patient. The first reaction is the reflection regarding the communication of the diagnosis, which

raises a lot of doubts, such as: Is it expected to be done by another professional? In healthcare orientations, how should the talk be done? Should the family be the first to receive the information? Does the way of revealing the diagnosis consider the principle of respect to the senior's autonomy?

Many times, even due to family pressure, the dilemma of telling or not the truth to the senior patient comes up, aiming at sparing him/her the impact and the anxiety. Actually, the dilemma is not about revealing the truth or not, but about the most appropriate way of telling it, and how to choose a viable way that can cause the least harm possible. There are countless studies and proposals on how to communicate "bad news" to patients and their families, according to the same author. This is another ability that can and should be developed, not denied, by health professionals. Not telling the truth may prevent the patient from making important decisions about his/her treatment and his/her personal life. In the same way, it prevents the patient and family from getting ready to probable events, including death⁽⁵⁾.

When the communication about the diagnosis is not given to the senior patient, the possibility of participating in his/her treatment and to make his/her decisions is confronted with one of the main ethical principles: the principle of autonomy. When approaching this issue, there is "a strong tendency in associating autonomy to the notion of social and physical dependence, by adopting a negative approach to aging"⁽⁶⁾. This view contributes to strengthen attitudes that disregard the senior as a participant of the process of life and sickening, and the right of knowing his/her diagnosis to make decisions based on his/her autonomy.

Concerning the subject approached, regarding the revelation of the diagnosis to the senior patient, some factors should be considered, among them, the way, the moment and the place of choice, which are fundamental to understand the information provided.

However, it must be observed the way in which the news is informed, because, if it is transmitted abruptly and without the presence of a competent professional who is trusted by the senior, there may be serious consequences and it may significantly interfere in the processes of decision-making and understanding the truth. Regarding this process, it is claimed that the way the revelation of the diagnosis is given to the patient may be helpful and, when that does not happen, a cold, straight communication of objective information⁽⁷⁾. Thus, the senior should be attended by the nurse during the process of revelation of the diagnosis, establishing the bond that allows questioning, being heard and assisted in a clear and truthful way, by aiding him/her in this context in which the decisions regarding this new stage of life are made.

It is right of the patient to know his/her diagnosis, prognosis and treatment in a clear and truthful way, so that he/she can make his/her own decisions, thus exerting the principle of autonomy. Many health professionals, when undergoing this experience, still question themselves on which is the best attitude to be taken. Article 26 of the Code of Ethics of the Nursing Professionals mentions the duty of "providing appropriate information to the client and the family regarding the nursing attendance, possible risks and consequences that may occur"⁽⁸⁾.

The posture of the nurses towards this dilemma is certainly even greater when it comes to the diagnosis and prognosis to the senior patient outside therapeutic possibilities. They consider that the moment generates stress and insecurity to both the professionals and patient:

"The fact of telling the truth to the patient means that the recognition of his/her autonomy and freedom prevailed over the fragility that the disease and the proximity of the death may cause. However, that moment may cause stress in the professional, because the idea that correct and complete information relieves the anxiety and distress, besides putting aside the sensations of disregard, negligence and exclusion in a moment of fragility and fear, considering the singularity of the experienced situation, opposes to the possibility that, by knowing the situation, it may lead the individual to an extreme despair, making him/her unable to decide what to do, making such a situation even more difficult and delicate"⁽⁴⁾.

The revelation of the diagnosis may generate uncertainty in the health professionals. According to study accomplished by the authors *op cit*, there are factors that can increase said insecurity, such as: "the disease itself, which interferes in the communication; the low level of understanding; the emotional state and the patient's fear of asking questions". Such criteria are subjective and are not enough to justify that the patient's right should be denied. In the same study, the authors note that, when questioning a group of nurses regarding their willingness to receive the appropriate information if they were the patients, it was revealed that the majority would like to have access to the truth in order to improve their quality of life; however, they are the same ones who somehow want to protect the patient from this information which they consider harmful. In this sense, it is prominent to put oneself in the patient's shoes, since this attitude enables one to "rebuild his/her system of meanings in the experience that he or she is undergoing when there is a deep inter-relational sense, preceded by attention, listening, observation and respect towards the other"⁽⁹⁾.

Revealing the diagnosis or not to the oncologic senior patient is not an easy task; it generates dilemmas and ethical inquiries that demand decision-making from the health professionals. Although it is a common action in the professional-patient relationship, it is still an issue that is

not often approached for discussion, and when there is the need to do so, it only happens based on experiences and personal values. It is said that the professional should be prepared to undergo this situation, because he/she commonly lives with it and he/she consider that the patients frequently expect the professional to be qualified to face them, as well as knowing how to make the correct decision⁽⁷⁾.

The oncologic senior patient cannot be decharacterized by not being informed about his/her diagnosis, treatments proposed and the necessary care in this stage of life. It is understood that by telling the senior patient the truth the link between him/her and the professional may be strengthened, dignifying the human being in recognition of his/her autonomy and being able to make decisions about him/herself.

When the nurses interpret their competences related to the ethical dilemmas superficially, they probably only understand whatever regards to technicism and operational processes of nursing attendance, not taking the senior's multi-dimensionality into account. Therefore, assuming a reflexive posture on the patient's right means to obtain answers that go beyond technical-scientific, measurable and Hippocratic knowledge, because it includes the aesthetic and ethical knowledge. Such knowledge makes it possible to recognize the cancer-struck senior as an autonomous, multi-dimensional, human being, with his/her own specificities and who is undergoing an atypical and fragile moment of his/her life.

It is important to point out and understand in this process of reflection that the issue of the autonomy of the oncologic senior patient is multifaceted and complex, because the processing of falling ill quite often brings limits to his/her life. However, respect for this principle takes into account the way of apprehending the world, making choices based on his/her own values, acting in accordance to his/her principles, faiths and world view, leaving aside the paternalist and Hippocratic posture still deeply-rooted in the thinking and actions of the health professionals. The criterion of "autonomy has been provoking, although in a embryonic way, significant changes in the doctor-patient relationship, which was characterized by being essentially objective, where the patient was the object and the physician was the subject"⁽¹⁾. A relationship is started with criteria of mutual respect, showing an exchange between professional and patient.

When contemplating the conflict between the professionals' paternalistic attitude and the patient's autonomy, several factors can be considered. Among them, the relationship of trust and mutual respect, knowing how to speak and how to listen, and the context in which the conflict happens. The escaping attitude when facing the very important decisions is noticed by the authoritarian posture of the health staff that does not

consider the patient's autonomy in his/her process of treatment, in face of their values and personal desires that are inherent to his/her life and existence.

It is well-known that when it comes to oncologic senior patients, it is pointed out that it is not always possible for the patient to understand what happens throughout the diagnosis, treatment and prognosis. If the autonomy of a patient is seriously jeopardized, the relationships of the health staff tend to happen with the family, but if there is the of a the decision regarding the continuity of a treatment or not, "this should be based on conditional data; in other words, what patient's would decision be if he/she could interact, protecting his/her autonomy"⁽¹⁰⁾

Referring to the theme, whether in the relationship with the patient or with the family, the nurse's role is fundamental and, according to the Code of Ethics of the Nursing Professionals from the Federal Council of Nursing, "Nursing comprehends a proper component of scientific and technical knowledge, built and reproduced by a group of social, ethical and political practices that is processed by teaching, research and healthcare attendance"⁽⁸⁾, showing that the improvement and evolution of nursing as a profession happens in parallel to worldwide changes.

The proximity of the nursing staff with the patient raises the frequent possibility of sharing conflicting situations in which the professional posture, the ethical attitude and the patient's care are inseparable. Care is the essence of nursing, and when the responsibility that taking care implicates is considered, it should be reinforced that, besides the need of understanding ethical attitudes in the daily practice with patients, the analysis of the conflicts and ethical and bioethical dilemmas found therein. Thinking about the health professionals' values, meanings, faiths and conducts, especially nursing towards the conflicts that emerge from practical care is a signal of concern towards the other, maturing and personal and professional growth.

We worry about the changes that happened over the world and, especially, those that echo in the health areas such as the technological progresses that enable the diagnosis and treatment of countless diseases, but, on the other hand, make the line that separates the Hippocratic knowledge of the autonomy principle rather tenuous. These conflicts can happen when an inadequate posture is adopted by separating two poles: on one side, we see the health staff dedicated to the scientific and technological knowledge of the diagnosis and the patient's treatment, seeking the success due to the cure or maintenance of life; on the other side, the patient with his/her values and beliefs belonging to his/her lifetime, which will influence in his/her decision-making process.

The multi-professional staff has a fundamental role in the search for equality of thought and action between

patient and professional when facing dilemmas. The principles of the geriatrics/gerontology confirm the importance of a multi-professional staff to attend to the senior patient; this becomes primordial towards the ethical dilemmas of this age group. Therefore, the creation of a multi-professional staff seems to be a sensible and indispensable thing, with the nurse's presence being prominent. The institutions should form a multi-professional staff that is in charge of revealing the diagnosis, which altogether determines, reveals and discloses the diagnosis to the patient the best way possible. The denomination of this staff has little importance; however it is justifiable by aiming at having the best procedure for the patient, always in search of ethical adequacy.

The nurse's essentiality is justified because this is the professional who is closer to the senior and his/her family, consequently establishing stronger bonds and being the mediator of the multi-professional staff. It is believed that decision-making under the responsibility of a multi-professional staff grants privileges to an individualized and conscious care, based on ethical attitudes towards the presented dilemmas, minimizing the stress undergone by everyone in such situations.

FINAL CONSIDERATIONS

By considering that the focus of the discussion is the elderly person struck by cancer, not only his/her diagnosis, we find this to be the main reason for settling a staff whose members belong to several professional categories. Since the human being is not a simple being, neither is the senior; he/she is a complex subject and, as such, in order to assist him/her, there must be multiple professional views regarding him/her. The questions that involve the ethical knowledge towards senior are considered to be complex, and these consequently involve discussions by a multi-professional staff, as previously mentioned. Such senior is the carrier of a disease like cancer, which brings a stigma represented by important ethical questions; consequently, it is necessary to have an attentive and careful view so that the professional behaviors do not exacerbate this cancer condition of the senior. The appropriate decision-making will certainly take into consideration his/her bio-psycho-social-spiritual condition, and also his/her values and principles, avoiding having the senior disregarded in his/her choices. Decision-making is determined by the senior's autonomy and guided by his/her individuality, considering the aging process and his/her disease.

The nurse's fundamental presence is an attitude of care and devotion, including a directed and attentive look when taking care of the oncologic elderly patient based on ethical attitudes. Knowing how to listen is, nowadays,

more than a quality; it is an ethical necessity and it favors the relationships of trust achieved between the professional and the patients. Besides, it makes the following of their decision-making process possible, and also to listen, clarify, explain and, above all, respect them.

This ethical reflection is very important and suggests new studies that involve the nursing attention to the senior patient with cancer.

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