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REFLECTIVE ANALYSIS ARTICLE

HUMAN EXISTENCE AND ETHICAL CHALLENGES IN THE CARE TO PATIENTS WAITING FOR LIVER TRANSPLANTATION

EXISTÊNCIA HUMANA E DESAFIOS ÉTICOS NO CUIDADO AO PACIENTE À ESPERA DE TRANSPLANTE HEPÁTICO

LA EXISTENCIA HUMANA Y DESAFÍOS ÉTICOS EN LA ATENCIÓN A LOS ENFERMOS EN ESPERA DE TRASPLANTE DE HÍGADO

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ABSTRACT

Objective: to promote reflections on human existence with a focus on patient care waiting for liver transplant and his ethical-moral challenges. **Method:** theoretical and reflective study based on a review of the literature, from the discipline "philosophy of science", the doctoral course in nursing, of the Federal University of Ceará/UFC, which relates the human existence and the ethical context in the care of the patient who requires liver transplantation. **Results:** the waiting period for liver transplantation is complex process, with physical, mental and emotional repercussions, in which the patient, fragile in its existence, requires special attention. Among the ethical issues, include the rejection familiar to donation, transplant and the heavy use of hard technologies. **Conclusion:** the nurse needs to reflect on the ethical issues that pertain to the care to patients and rethink its practice, seeking to offer humanized assistance and facilitation of health. **Descriptors:** Nursing care; Ethics; Liver Transplant.

RESUMO

Objetivo: promover reflexões sobre a existência humana com foco no cuidado do paciente à espera de transplante de fígado e seus desafios éticos-morais. **Método:** estudo teórico-reflexivo baseado em uma revisão da literatura, oriundo da disciplina "Filosofia da Ciência", do curso de Doutorado em Enfermagem, da Universidade Federal do Ceará/UFC, que relaciona a existência humana e o contexto ético no cuidado do paciente que necessita de transplante hepático. **Resultados:** o período de espera pelo transplante hepático se constitui em processo complexo, com repercussões físicas, psíquicas e emocionais, no qual o paciente, fragilizado em sua existência, requer atenção especial. Dentre as questões éticas, destacam-se a recusa familiar à doação, o transplante intervivos e o uso intenso de tecnologias duras. **Conclusão:** o enfermeiro precisa refletir sobre as questões éticas que perpassam o cuidado aos pacientes e repensar sua prática, buscando oferecer a assistência humanizada e facilitadora da saúde. **Descritores:** Cuidado de Enfermagem; Ética; Transplante de Fígado.

RESUMEN

Objetivo: promover la reflexión sobre la existencia humana, con enfoque en la atención a los pacientes en espera de trasplante hepático y sus desafíos éticos y morales. **Método:** disciplina originaria de la "Filosofía de la Ciencia" teórica y reflexiva basada en una revisión de la literatura, el grado de Doctorado en Enfermería de la Universidad Federal de Ceará / UFC, que se refiere a la existencia humana y el contexto ético en la atención al paciente de la necesidad de un trasplante hepático. **Resultados:** el período de espera para trasplante hepático constituye proceso complejo, que afecta física, mental y emocional, en la que el paciente, debilitado en su existencia, requiere una atención especial. Entre las cuestiones éticas se destacan la negativa familiar a la donación, el trasplante de donante y tecnologías duras. **Conclusión:** la enfermera tiene que reflexionar sobre las cuestiones éticas que subyacen a la atención de los pacientes y repensar su práctica, tratando de proporcionar el humanizado y facilitador de la salud. **Descriptores:** Cuidado de enfermería; Ética; Trasplante de Hígado.

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INTRODUCTION

Care is inherent in the human being, being its primary brand, which permeates through all stages of development. This care permeates several dimensions of life and is present in the attitudes of compassion, zeal, humility, fulfillment of human needs, nursing care, among others.

Reflection on the professional care nurse in the relationship with the patient emerged in the course of reading articles that addressed patient care and ethics involved in this process, during the discipline "philosophy of science", the doctoral course in nursing, of the Federal University of Ceará/UFC.

In front of the situations with which the nurse stumbles over their profession, one realizes the responsibility of taking care of the other, "be request, know how to listen, put yourself in the place of another to understand it in their desires and needs.

In the case of patient waiting for a liver transplant, the care requires attention, as changes occur in your routine, in their behavior, in their feelings, making it fragile in the face of existential situation. In this context, emerging ethical problems in relation to the care of the transplant process, involving the rejection familiar to organ donation, live transplantation and use of technologies in the process.

Given this fact, sought to reflect on human existence with a focus on patient care waiting for liver transplant and his ethical-moral challenges.

♦ Human existence of patient

Before you enter the nursing care in the scenario of the patient waits for a transplant, it is necessary a philosophical reflection on human existence itself, seeking a rapprochement with the sense of caution.

The Heideggerian philosophy brought contributions on the ontological issues related to human, terming *Dasein* as a way of being in the world. According to the author, the pre-tears always understands itself from its existence, a possibility of to be or not to be, bringing a sense of being-in-world, being-with-the-other, be careful, be-to-the-death, within the comprehension of temporality.¹

Authors complement the be-in-world is much more than simply the be-in-world. This is ontic, that is ontological. The ôntico occupies, the ontological cares, cares and is perceived as something intuited, which constitutes, in fact, the benchmark of sense for all human actions: the concern.² in this approach, incorporates the idea of Sartre when States that "existence precedes

essence", from the perspective of existing man in your world within a given political, cultural, economic and scientific, in which man relates to others, to build or destroy, becoming subject to its history.³

The meaning of the word care encompasses several meanings based on the etymological origin of the word. Philosophers point the verb "cogitare", understood as cogitate, think, assume, put attention, show interest, and reveal an attitude of care and concern. There is still your approach with the word of Latin origin "curare", associated with the idea of "treat" "put in care".⁴⁻⁵

(...) the philology of the word ' caution ' indicates that care is more than a singular Act; its way of being, the way the person is structured and takes place in the world with the other ". It is from the way that builds relationships between people and things in the world.^{5:22}

A phenomenological approach to care is a way to exist, which implies permanent behaviors and attitudes of people, doing part of their human essence.³

Taking care of someone expresses a relationship help, which favor the growth of be and gives you greater ability to choose values and ideals based on own experience, extending the self-determination and autonomy over their lifetime.⁵

In the perception of Humanistic Theory:

The existential experience allows human knowledge of being and the quality of being the other. Requires an acknowledgment to every man as singular existence in your situation, fighting and rivaling his companions to survive and come to be, to confirm its existence and understand its meaning.^{6:19}

Under the caring in nursing, the patient considered to be fragile in its existence, therefore, deserve special care. Thus, it is necessary to recognize him as a human being, provided with identity, bio psychosocial values, beliefs and particular needs.

Nursing in their practice based on the inter-human relationship, being in direct contact with the human being, experiencing situations of getting sick and dying, sharing various attitudes and feelings, which require a humanistic attitude with each other, making himself present through competent care, humane and ethical.⁷

With regard to patients waiting for a liver transplant, the experience is so peculiar, considering that the procedure used as single treatment for terminal liver disease, providing patients the possibility of reversal of the disease picture and improvement of physical condition.

Patients face many difficulties arising from clinical complications and emotional problems acquired with the suffering in the chronic phase of the disease, interfering with your quality of life.⁸ The opportunity of realization of the transplant raises hopes of improving the quality of life and health and even of lifetime maintenance, since the decisive cause for the procedure is a terminal liver failure.

Faced with the imminent risk of death, patients face the possibility of finitude and face the challenge of overcoming the disease, pain and suffering generated in the waiting period. The experience of finitude becomes "a provocation to the human subject overcome or enlarge their borders", overstepping your bounds.^{9: 130}

Suffering from the condition caused by a morbid condition, by the presence of complications, the restrictions of social life and the need for long-term use of drugs have a profound impact on quality of life of the patient, thereby weakening it in its various existential dimensions.⁷

In a situation of suffering, is not affected only a part of the body, but the guy in the whole of its existence. In this sense, the proposal is "take care of existence-grief, which brings us to a be permanently with ethics, and ethics in the field of health should be the ethics of care for life".^{10: 98}

The changes in quality and lifestyle caused by chronic liver disease require a reorganization of the personal, family and social dynamics, requiring understanding and support of those who deal directly with the patient, including family, friends and health professionals that attend.

This situation requires the careful approach of multidisciplinary team accompanying the patient, especially of nurses, which is next to the patient in every stage of the transplant process and should be aware of the negative feelings from this stage, helping the patient overcome this moment and valuing its human potential. In this context, the suffering related to the risk of death and the grief of the relatives made us reflect on the importance of a humanized assistance in meeting your needs.

Patients enrolled in the transplant program, who await a liver and fight to safeguard their survival, assistance must guaranteed to make that experience less painful, providing a means for them to express their anxieties, their feelings.

● Ethical patient care context

◆ Ethics in care

The term "ethics" comes from the word "éthos", meaning "character, way of being,"

covers attributes acquired throughout life, comprising habits and actions that guide how to live, make decisions aimed at the well-being of individuals and groups.

The human being is a being ethical. Each man and each woman have a responsibility to yourself. To be responsible is to be able to respond to challenges, the calls, the unforeseen tasks proposed in the way of life of each one.¹¹

Ethics is understood as a branch of philosophy that points reflections on human conduct and its purposes; conflicts between what is justifiable and what is not considered from the moral.¹² Thus, seeks to justify rationally the standards and criteria that guide the people and groups in their actions; proposes the critical review on human behavior, interprets, discusses, discusses and investigates values and principles.¹³

Manifests as a moral requirement from subjectively of the human being, and of its exterior, in which the culture, beliefs and the standards comprise, in addition to the previous form, existing, sourced from organization alive and human genetics.^{14: 150}

From the perspective of the philosopher Kierkegaard, the ethical way to exist represented by the individual who prioritizes the fair, the right, and the good; recognizes the consequences for his actions and assumes responsibility for this leads an existence worried.¹⁵

In this sense, ethics in the context of philosophy seeks to clarify the essence of moral life and their fundamental relationships involved, with the purpose to formulate standards of judgment, which may constitute a valid guideline for the responsible exercise of personal freedom.¹⁶

To that end, the ethics mobilizes the reflection on the conduct of professionals in their daily practice, compared to technologies to ensure humanized care.¹³

Take care of the others, as an ethical dimension is a requirement that needs to be experienced by those who watch and implies "the non-exercise of a knowledge or power over another, they can turn it into an identical order," domesticate it or adapt it, according to the precepts and institutional expectations.^{17: 704}

Understand the reality of the other, leaving their own structural reference is the main aspect of the ethical dimension of care, in which the reality of another us so empathetic, where tolerance becomes critical.¹⁸

Ethics in health leads to reflections on their practices, whereas bioethics seeks to recover the care of themselves and others and requires implementation in the context of the citizenship policies in the areas of knowledge

of human development, formulating since the philosophy of a life that seeks happiness, State of well-being and quality of life in all its aspects and dimensions.¹⁹ bioethics is present in all situations of health and from the moment they take care of each other.

Nursing is a profession that involves great interaction with humans, as in his professional practice remains most time near the patient and frequently stumbles upon multiple ethical dilemmas. However, these cannot paralyse the action of the professionals in the face of complex situations, because, at the time when this occurs, the professional despotencializa, minimizing his ethics capacity and disregarding the caution when another.²

♦ Ethical issues in the care of the transplant process

The health professional, especially the nurse, lives this situation when participates in the process of liver transplant, since contact with the patient on the waiting list until the post-transplant recovery. This care requires an ethical attitude and morale of the professionals involved in the process.

The expectation of a transplant triggers different emotional reactions in patients, as I fear, fear, doubt, worry and anxiety; is associated with pain, change in body image, dependence (immunosuppressant) and even death, due to the great complexity of the surgery. The nurse is responsible for the education of patients and their families about perioperative procedures, as well as long-term measures to promote health by encouraging them to participate in your treatment and health care decisions.⁷

♦ Family refusal to organ donation

The transplant process is complex and involves several ethical dilemmas, starting with the families' decision to donate organs of their deceased ones. Authors point out that the refusal familiar represents an obstacle to the achievement of the transplants, contributing to shortages of organs and tissues and the insufficient number of donors to meet the demands of applicants on waiting lists.²⁰

Among the grounds for refusal to organ donation, are cultural and religious beliefs. The relatives have hopes that a miracle happens and God give the life of your loved one, whereas with the heart beating is still possible the return of vital functions.²⁰

Not understanding the concept of brain death can be a major obstacle to the process of donation, because society still unaware of its parameters, linking the death to cardiac arrest.

The American Academy of Neurology defines brain death as the absence of brain function when the immediate cause known and proven to be irreversible; is confirmed by clinical evaluation by a neurologist and Director of EEG cerebral scintigraphy or, in the case of potential donor.²¹

The transplant team should respect the beliefs and values of the potential donor's family, offering emotional support and necessary information about the entire donation process, in order to help them understand its functioning and demystify inappropriate beliefs of common sense, contrary to donation, how the commercialization of organs and organ removal before the death of the patient.

♦ Live transplant

Transplant mode live also won rebounding about the ethical dilemmas. This technique was employed initially in the Pediatric transplant due to the even greater scarcity of organs, in which the left lobe of the liver from a donor adult is transplanted in the receiver, going on low risk to the donor. However, with technological advancement this technique extended also for adults, with removing the right lobe of the donor, which increases the risk of the procedure, with mortality of up to 2%.²²

The exercise of autonomy of the donor also depends on the decision of the team that the watch, constituting "a trial based on a binomial that includes the donor's will and discernment of the team responsible for transplant". The decision of this type of transplant is of particular importance, since the only situation a major surgery performed in healthy individuals, implicating issues that require ethical reflections.²²

Data from the Brazilian Association of organ transplantation, between 2006 and 2010 were performed live donor transplants 677 in Brazil.²³ accordingly; limit the right to the free will of the donor volunteer would also be denying many receivers the possibility of survival through the transplant.

♦ Technologies and care

The transplant, as a highly complex procedure, involves intense technological tools, requiring professionals to upgrade the knowledge and scientific advances, as well as technical skills in the use of these instruments. On the other hand, such complexity can make people become secondary.

Scientific breakthroughs do not always come accompanied by ethical values, requiring transformation of the biomedical model to a more holistic model. The great

challenge lies in encouraging the use of technologies in assistance, without compromising the quality of human relationships and affectivity in the professional-patient interaction.²⁴

Nursing care are not limited to technical competence, but it must resound the sense of human. Uma ethics based on care and concern for others can be a big contribution to ethics in general health.¹³

In this context, emerges the reflection about the conduct of nurses participating in the transplant process, highlighting the importance of nursing care essence with the focus on the human being, in recognition of the other and the moral commitment, valuing the human being in its entirety.

CONCLUSION

The waiting period for liver transplantation is a complex process for the patient and his family, interfering in the physical, mental and emotional structure of the individual; therefore, needs care of team responsible for his treatment from the moment of the decision of the Director of the transplant to the post-surgical recovery.

This requires ethical and moral care, because the patient, fragile in its existence, needs to recognize in its entirety. In addition, the health professionals, especially nurses, need to reflect on the ethical issues that pertain to the care to patients and rethink its practice, seeking to offer humanized assistance and facilitator of health care.

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