Revista Brasileira de Bioética 2009;5 (1-4):24-33

Social bioethics and transdisciplinary healthcare: an alternative proposal for palliative care

Bioética social e espaço transdisciplinar da saúde: uma proposta alternativa para os cuidados paliativos

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Abstract: This study describes the steps for the construction of a communication environment for a multiprofessional healthcare team acting in a healthcare service for incurable patients. Beginning with discussions on ethical dilemmas concerning the healthcare team's approach to death during home care and based on a human sciences theoretical framework – particularly social anthropology – a professional protocol was drawn up where the major interlocutors are the patient, his family, and care providers. Palliative care was critically discussed from a bioethical standpoint, as a fundamental element for social bioethics.

Key words: Bioethics. Social Bioethics. Transdisciplinarity. Palliative Care.

Resumo: Este estudo descreve etapas da construção de um local de comunicação formado por uma equipe multiprofissional de saúde, atuante em um serviço de assistência a pacientes fora de possibilidade de cura. Partindo de discussões sobre dilemas éticos concernentes às situações de morte defrontadas pela equipe em visitas domiciliares, formulamos um protocolo profissional, tendo por principal objeto os problemas relacionados aos pacientes, seus familiares e cuidadores. Por um olhar crítico aos cuidados paliativos levantamos elementos fundamentais para a Bioética Social.

Palavras-chave: Bioética. Bioética Social. Transdisciplinaridade. Cuidados Paliativos.

The incidence of cancer is increasing throughout the world and in Brazil. It is predicted that 15 million new cancer cases, and according to epidemiological and demographic data, 12 million deaths from cancer by 2020. In the next few years, the elderly population in Brazilian cities, especially Botucatu (with about 120 thousand inhabitants, localized in São Paulo State), will show the highest increases (1). In 2020 the municipal area is predicted to have 15493 elderly people. In this context the aging rhythm of the population is linked with increased life expectancy, but accompanies the incidence of chronic degenerative diseases, especially cardiovascular diseases and the cancer (2). Ours concern extends to the fact that a group of people with incurable diseases receive dignified treatment, one of our commitments to life.

Palliative care is a medical specialty which gives better care to seriously ill patients who have little prospect of improvement or no possibility of therapeutic cure (3). However, we know that the community and city authorities are unprepared to deal with questions related to death. We understand this, too as a historical institutionalized factor in our society. We have the need to add practical biomedical knowledge to the palliative care provided by human sciences (4), which allow us to give value to many different world views, allowing eyes to be opened to the phenomenon of death and end-of-life care.

We are obliged to demonstrate that it is possible to increase this view in a complementary way towards palliative medical care given in professional health environments. In all, we are attempting to distinguish between palliative medicine and the moral, social, and institutional values, found in our activities. According to Hugh Lacey (5) for whom personal, social, and institutional values are entwined in scientific activity. For us, bioethical understanding in medical activity - makes those, carers and family involved in end-of-life care - interested in measures which reflect the different world views in the dying process. How to demarcate transdisciplinary from interdisciplinary and multidisciplinary is obviously a significant analytic issue, we used important references to describe transdisciplinary and bioethics environment (6, 7, 8).

This article describes the construction of a transdisciplinary environment (9) put together by our multiprofessional team within a high complexity hospital in the municipal area of Botucatu. Home care is the focal point of our interdisciplinary activity. It is an important support to patients, families and other carers whose prime objective is giving patients back their dignity.

The pain management and Palliative Care Service (PMPC) of Botucatu Medical School - São Paulo State University (UNESP)

Currently PMPC is a health service within a highly complex hospital structure in a region of the São Paulo State countryside, and part of the Brazilian public health system. Created in 1990, this health service is part of the Department of Anesthesiology. Its goal is to treat patients with chronic and acute pain, the main aim being to alleviate the pain, giving a better quality of life to individuals, independent of the root cause.

The main characteristic in PMPC is the service given to a significant group of tumor patients, many in the advanced stages. The service works in three distinct areas: a) attending inpatients with acute or chronic painful disorders; b) attending outpatients with chronic painful disorders; and c) home care by the multi-disciplinary team. Most hospital outpatient treatment is directed towards curable patients. In 2004, PMPC saw 4500 patients; in 2006 this increased by 50% to 6500. Health treatment for patients across all wards of the University Hospital is considerably concentrated on post-surgical sectors and trauma. For this last group of patients, PMPC provides regular help by two routes: a) 24h telephone cover to provide continuing palliative care support; b) programmed home visits.

In relation to home treatment, the PMPC outpatient service has a home visits team to follow disease evolution. This multiprofessional team is made up of doctors (doctors, resident doctors, and 6th grade medical students), a nurse, social worker, psychologist, nutritionist, and a social scientist philosopher. With the aim of providing complete care, there is a set of procedures for attending to the patient and immediate family. The team contemplate treatment of the different symptoms presented by the patient, prioritize working through anticipatory bereavement by the patient, family and carers, and work closely with the theme of death overcoming taboos through humanized care.

The value of death

Facing death and bereavement is one very difficult part of health care as loss of the patient for the family and team involve human feelings. Also, how do healthcare professionals cope with these values? We know that death is part of human development, and therefore there is a need for us to discuss death. Kovacs (10) proposes that the possibility of opening dialogue on death can be stimulated by asking questions, expressing all types and intensities of feelings, and break down barriers between family, personal friends, and healthcare professionals. Currently death at home is not common practice. We understand that if it is desired, we must make the opportunity viable.

On the other hand, Ariès (11) remembers that the question of death can be seen as taboo. In this situation there is ritual holding back of the fear which can cause more suffering. However, this situation can cause more pain (not necessarily physical), as the subject feels alone away from their family. The manner in which the family confronts death becomes a less painful loss. However, families and those dying develop specific ways of dealing with the losses. They establish their own time and way of dealing with the loss.

Stedeford states that:

> "The professionals who are intimately linked to treating the terminal patient, at least one of those interested in the case – the general physician, nurse, social assistant, or priest – must continue to act as a type of monitor remaining as a support figure at arms length if all goes well, but ready to intervene if the needs of family and friends are not being satisfied" (12).

In this sense, Kübler-Ross (13) highlighted the importance of anticipatory mourning according the five stages of grief. During this process, those involved are permitted more time to work through the losses they suffer which occur before death.

The main question which runs through this work is related to personal, social, and institutional values (moral) about death such as the taboo of death, which is also found among our health professionals. Although home care given to patients and families prioritizes the anticipated bereavement approach and working through losses before death, there are difficulties of linking the concepts of palliative care to this patient reality.

Organization of the pain management and palliative care service (PMPC) and building the transdisciplinary environment at of Botucatu Medical School

The problems which emerge at PMPC are related to health professionals'concepts and the way they react to the death of their patients under local living and health conditions. It is interesting for us to note here some weekly home visits programmed for several patients with different diseases. The palliative care team cares for six seriously ill patients with twice weekly programmed home visits. Supported by transport provided by hospital management, the multiprofessional team goes to patients' homes with a common protocol: on medical diagnosis and guidance, focus on controlling pain in relation to medication use, hygiene, asepsis and dressings, nutrition, psychological treatment and social evaluation. Special attention is given to carers so they will provide stimuli for self-care with the family, taking into account the limitations imposed by the type of disease.

Knowing that the care given by carers and families to oncology patients becomes a crucial point in the successful actions of PMPC service home care we put the following problem. In the practical world of caring, how do we approach the discussion of palliative care from the practice of family care? There seems to be a gap in the debate which supports the link between carers, patients and PMPC healthcare professionals. It has been understood that the team's challenge is to establish these links between carers and the patient at different times in the health-disease process: before and during treatment by PMPC, and that the same links are broken with the advent of patient death.

We justify the relevance of the problem and propose to therefore relate the of value perspectives of patient families and carers with the biomedical knowledge of healthcare professionals. For this we arranged the time and place for discussing cases of home visit patients. Treatment of oncology patients, most of who were beyond cure, generate distancing and decontextualization in the team, even because of work process they are in is distressing. The proposal to create a transdisciplinary environment in the work organization also served the interests of the healthcare professional who struggle with these adverse conditions centered on death (8, 9).

Questions of ethical and emic values in clinical activity: discussion on conduct

In monthly meetings we started to discuss dilemmic situations experienced by health professionals when making family visits. The main theme in these meetings was death, also with theoretical guidance from human sciences, primordially from social anthropology (14). The home visits contextualized the transdisciplinary discussions. Cases are selected in accordance with problems selected from ethical and emic viewpoint. We understand ethical values as the concepts and categories used in describing and analyzing the doctor and healthcare team, and which do not necessarily correspond to those in force in the society or culture of the treated patient. For emic values, we understand the actual internal categories and values of the patients, carers, and families, taken according to the logic and coherence with which they present themselves.

Values bring with them personal convictions, preconceptions, beliefs, but not all these values are shared between the health professionals. Each health professional also has personal values which are in play. In biomedical values, the question of death belongs to the scientific field (ethical dimension) and the moral and social values of patients and carers belong to the cultural field (emic dimension). We agree that the transdisciplinary discussion for each meeting follows the theoretic pretexts of Palliative Medicine and Social Anthropology. We have therefore selected cases which provide discussion on ethical and emic problems faced with a variety of values together with clinical medical activity, always starting from ethical conduct in home visits.

In this context, the parameters which structure interdisciplinary dialogue are given by choosing from two explanatory models of health and disease: 1- the health professionals have chosen theories which arrange explanatory disease and health reasons towards a good death, by reference to the model Natural History of the Disease (15); and 2- the social scientist use parameters taken from anthropology theories (scope of comprehension), which serve as a basis for the discussion of cultural problems in our society (14).

In our transdisciplinary activities and discussions over one year, we were able to establish a methodology from which we created an organized protocol for presenting polemic cases, in the following order:

> 1) To describe the patient's disease from a biomedical view: with reference to the Natural History of the Disease describe the case from the doctor's point of view.
> 2) To describe the socio-psycho-cultural context: with reference to Social Anthropology, describe the case in the following order: a) socio-economic aspects which understand situations of poverty, social exclusion, living conditions, income, family makeup in the home, schooling, religion, and occupation of the patient and family members; b) psychological aspects which understand acceptance or non-acceptance of the disease, including by family members.
> 3) To discuss the personal, social, and institutional values involved in the case: a) medical conduct (knowing the program principles); b) conduct of carers; c) beliefs involved in all stages: death, chronic degenerative disease, health, life after death (religion); d) expectations about the case.
> 4) To discuss the main conflicts of interest on the problems raised: a) the dilemma is hidden; b) it is not only medication which is in play; c) what are the palliative concerns for the professionals.
> 5) To determine possible measures (preserve the most values in the case).
> 6) To choose types of action.
> 7) To defend decision making.

Results

The use of the protocol has helped dialogue between healthcare professionals in ethical discussions about death, including the discussion of their moral values. The patient's medical records include conduct linked to these discussions. We have seen important advances between values and doctor activity, provided by Bioethical guidelines (not to slander, good intentions, autonomy, justice), by Biomedicine (explanatory model of the Natural History of the Disease), and Social Anthropology (cultural values and patient and family histories).

Considering the different points of view equally has provided transdisciplinary understanding, from which we highlight the following:

> a. It is correct in terminal illness to provide the correct medical prescription related to the nature of the disease. But no always do these carry equal meaning according to the patient's social history.
> b. To not have prejudice from medical prescriptions, which can maintain your impartiality faced with a patient's personal and moral values. These social values must be respected and therefore it is necessary to view medical practice as a non-neutral activity.
> c. There is important breaking of preconceptions when we include personal and social values of health professionals in the dialogue with patients' cultural values.

Conclusion

Aiming to guide the team towards ethical/bioethical modus operandi together with healthcare for families and carers of incurable patients, we follow the two levels and points of view with the intention of structuring methodological procedures for home visits. Regular meetings serve as an interdisciplinary space which guarantees that the ethical dimension remains in the multiprofessional team's treatment.

Through the ethical complexity of cases faced with death, we note that the meetings have structured a place for promoting social justice, such changes in values (biomedical knowledge and experiences) make capturing bioethical resources viable, resulting in improvements in professional postures and maturity.

Even with the accelerated rhythm of population aging, we make it clear how important the quality of health services if differentiated when we focus on the relationship between values and medical activity. We can give medical services related to the end of life using directives and concepts from palliative care programs. However it seems there is a need to add aspects of value for each person within the culture and add human science guidance to medical activity, such epistemological tools have been shown adequate and effective in promoting and preserving human dignity.

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Recebido: 18/11/2009 aprovado: 10/12/2009