Autonomy Versus Paternalism in Latin America

January 17, 2012
By Karime K. Machado, MD [1] and Paulo M. Hoff, MD, FACP [2]

In this paper, Dr. Cherny beautifully reviews how to balance the patient's right to be adequately informed about his or her disease with the powerful cultural beliefs held in many parts of the world. This is certainly one of the most difficult tasks in the patient-oncologist relationship. The disclosure of prognostic information to terminally ill patients has emerged within the last 15 years as an important issue, given the greater demands for patient involvement in medical decision making, particularly in the United States.[1] With the evolving emphasis on individual autonomy and freedom, medical paternalism is no longer unquestioningly accepted by society as the principal mode of decision making in health care.[2]

The disclosure of prognosis, even when poor and not completely accurate, is considered ethically justified because it enables patients to exert their autonomy and make treatment decisions that are in alignment with their own goals.[3] Nevertheless, emerging evidence suggests that, too often, realistic conversations about prognosis, the potential benefits and limitations of disease-directed therapy, and the potential role of palliative care occur sporadically and frequently late in the course of the disease.[4-6] While a patient's autonomy is held in high regard in the United States, in many cultures and particularly in Latin America, the number of physicians, and families, who believe in paternalism as a form of beneficence is still significant. With the aim of assuring a patient's welfare, physicians may voluntarily withhold information on diagnosis and prognosis, which may in some way interfere with or overrule the patient's preferences.[7] In this cultural scenario, the illness is commonly considered a shared responsibility of the family. Family members, because of their presumed awareness of the patient's needs, goals, and preferences, play a crucial role in decision making, even when the patient is fully competent, and doctors are often not expected to inform patients that they have a terminal illness.[8-12] In a small Brazilian study, 38 physicians caring for cancer patients in a tertiary hospital responded to a questionnaire addressing the disclosure of diagnosis and prognosis to the patient. Results showed that 97.4% of the physicians informed their patients of the diagnosis in cases of fatal disease. In cases of adverse prognosis, 63.1% preferred to communicate only with family members, while 31.6% preferred to communicate only with the patient.[7] Paternalism seems to emerge as physicians run out of therapeutic resources. At this point, attitudes become conflicting in relation to the principles of beneficence and autonomy.[7] An American study showed that most oncologists report disclosing the aspect of a prognosis that involves a cancer's not being curable; however, they tend to avoid using percentages to convey prognosis.[13] Oncologists generally offer information on prognosis to their patients (1) when the patient asks directly about his/her condition, (2) when the physician perceives that the patient has the emotional resources to receive the information, (3) when treatment is not producing the desired results, and (4) when the patient is symptomatic and/or decisions about the treatment must be made. Nevertheless, oncologists’ reluctance to disclose the prognosis and thus preserve a patient's hope is held in check by the need to assure that patients have realistic expectations for therapy.[13] There are two main situations in which not being informed about the diagnosis or prognosis may be ethically justified: (1) when the patient does not wish to know, and (2) when the information delivered may be iatrogenic.[14] It is worth noting that a patient who desires all the information on his/her diagnosis does not necessarily wish detailed information on his/her prognosis. In fact, most patients feel comfortable with complete information on the diagnosis and partial information on the prognosis.[15] As for the family, we should consider the afflictions precipitated by being responsible for making decisions. Feelings such as regret and guilt during the course of the patient's disease or after his/her death are not uncommon.[7]
Recent studies in the oncology setting have focused on disclosing [8,16-21] or receiving [22] the news that a cancer has reached its terminal stage, and several clinical guidelines and expert recommendations have been published.[4,23,24] We believe that an ethical and effective approach is to enhance a patient's autonomy through a medical beneficence that incorporates the patient's values, beliefs, and perspectives, even when these differ from the physician's own beliefs. This is possible through a model of shared decision making in which the patient makes meaningful decisions and final choices empowered by the physician's beneficence.[2,25] For such a model to function effectively, the restoration of trust in the doctor-patient relationship, respect, and the adoption of patient-centered communication are essential.[2,4]

Financial Disclosure: The authors have no significant financial interest or other relationship with the manufacturers of any products or providers of any service mentioned in this article.

References:

REFERENCES


Source URL:

Links: