Dealing With Ethical Dilemmas in Oncological Communication Involving Issues of Culture and Autonomy

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Beginning with its provocative opening case vignette, Nathan Cherny's article provides an opportunity for us to reflect on and possibly redirect our own attitudes and habits regarding difficult ethical issues in communication with our patients and their families, especially in the setting of cultural and religious diversity.

Communication typically includes the three elements of giving information, receiving information, and the relation between these two activities. But still more is involved: communication can also include the conscious and unconscious use of nonverbal language; the expression and interpretation of life stories, experiences, observations, concerns, and emotions[1,2]; the astonishing experience that somebody may say or express exactly what my inner voice would have said; or the experience of a communication intervention initiating or catalyzing an understanding and maturation process in either an individual or a group.[3] Recent research reveals selected physiologic reactions to compassionate communication, such as the relationship between professionals' heart rate and patients' emotional hints,[4] or insights about the mirror neuron system—namely, how previously experienced movements or physical sensations can, intuitively, be recalled in communication.[5] However, insights such as these may only scratch the surface of human communication. Important social, cultural, existential, and spiritual aspects are involved in the “why” and “how” of our communication.[6] In addition, recent research documents the effectiveness of communication skills training for oncologists,[7] as well as the power of patient and family member education and empowerment.[8]

For an oncologist, communication with patients is the cornerstone of patient care and management; this is acknowledged in the core curriculum of medical oncology. Poor communication can result in less effective anticancer treatment or increased toxicity[9]—and even in shorter survival, something that has been extrapolated from studies of palliative care interventions in which communication plays an important role.[10] Conflicts and dilemmas in oncological communication are bound to occur when strong, culturally diverse backgrounds are involved, and these conflicts may be disconcerting for patients and their families, as well as for the physician and the care team. In this thoughtful article by Nathan Cherny, the controversial issues are illustrated by a case vignette of a young mother with incurable pancreatic cancer. This is followed by a careful discussion of autonomy, patients' cultural backgrounds, and various paternalistic approaches that physicians sometimes choose, either consciously or without proper reflection. The terms “therapeutic privilege” and “hard paternalism” are likely to continue to fuel ethical controversies in oncology.

The case vignette demonstrates that the proximity of death becomes an experienced reality, whether this is verbalized or not. In the context of palliative cancer care, the communication controversies mentioned above, although they can occur in all phases of a patient's disease trajectory, become more apparent and dominant. Indeed, communication interventions are key elements in the five interventions typically used in early palliative care. The latter include promotion of illness understanding, multidimensional symptom management, anticancer treatment decision making, sustaining support networks for patients and families, and coping with life-threatening illness (also described as end-of-life preparation).[11]

Dr. Cherny's discussion of the issues of autonomy, culture, and paternalism in communication may
suggest that isolated, one-time interactions between oncologist and patient occur. In contrast, communication is typically a process that requires the ongoing collection of pieces of information; time and effort to devote to preparing questions; negotiations regarding when, how, and with whom to meet; and finally, the conversation sessions themselves, which rarely consist of a single comprehensive interaction. Single interactions between oncologist and patient can be very intense, productive, and effective—but there must be an awareness that arriving at an understanding of a complex situation, achieving clarity about the patient's own preferences and wishes, and accommodating the (shared) decisional processes of family members with respect to support and care require time and repeated interaction.

Communication typically does not involve just a single oncologist—rather, a team approach is required. Both the different clinicians' perceptions of the patient's situation and a clearly defined lead role are important in difficult situations. Several studies report that oncologists vary substantially in their competence and willingness to address patients' emotions,[9] discuss end-of-life issues,[7] and deal with challenging cultural issues. Oncologist-patient communication is also influenced by time pressure, financial ties,[12] and other factors. Research standardizing information about end-of-life care decisions suggests that patients prefer video-based information, which they believe to be more comprehensive and objective than the narratives that are typically used in clinical care by various members of the care team.[13] Thus, it is important to recognize that the process of forming an understanding and absorbing information is rarely solely in the hands of the oncologist.

The awareness that communication is a process and that it requires a team approach culminates in the fact that there are “right times” when specific information and truths may be timely and appropriate—and other times when they are not. Patients may require different information at different times of their illness and understanding process. The practical, helpful sample questions that Dr. Cherny provides in Table 1 require careful timing, based on the patient's current situation. Can the world really be divided into different, clearly demarcated cultures? Patients coming from so-called other cultures into “our” culture will to some degree be obliged to undergo a process of adaption to the hosting culture. Paternalism can therefore be viewed in two ways: (1) as the oncologist's cultural background dominating that of the patient, but also (2) as aspects of the culture of a patient, especially those that are important to family members, being dominant and viewed as unchangeable. Although we are conscious of the needs of different cultural, religious, and ethnic minorities and willing to adapt to these as much as we can, we must also accept the limits of such an adaptive approach. In some instances, the law will speak clearly and we have to enforce by a process of careful communication the human rights of the individual patient even when family members might wish otherwise.

In clinical practice, ethical dilemmas may arise—situations that are not “solvable” but that need to be dealt with. In Dr. Cherny's case vignette, the female patient is herself incongruent: she says she wants to be told what is going on with her, but at the same time her expressed desire for hope suggests that she does not want to know anything really bad. A decision has to be made: from whom should the discussion of the truth of this patient's situation take its cue? We are therefore challenged to find methods, clinical practice tools, and communication interventions that protect patient rights, and that also acknowledge the cultural integrity of the patient and the family.

Practically, an atmosphere needs to be fostered that facilitates openness to the truth, thereby enabling patients and family members to make appropriate decisions, congruent with both patient rights and their culture. Well prepared and structured family conferences with professional translators and an interdisciplinary team are especially important in situations of discordance.[14] In a timely manner prior to the conference, patients and family members should be asked to formulate questions they want to be answered by the team; assistance with their preparation may be provided by psychologically trained professionals. At the beginning of the family conference, the leader should clearly promise not to reveal any information, unless there is a request. However, the most important part of the intervention is to support the patient in explaining, in the presence of all key family members, his or her understanding of the illness in his/her own words. The patient may be guided to link the current clinical situation and his or her experiences with the status of the illness. It may be necessary to exert a hard paternalism in order to set up and lead such a family conference; however, extensive experience demonstrates clearly that patients and family members are eventually thankful for this.

We therefore believe that in a carefully led communication process, even in a difficult setting, the truth eventually will be accepted by the key family members. This can redirect otherwise wasted compassion and energy into trustworthy and reliable care of the patient by the family.
Case vignettes such as the one presented in Nathan Cherny's paper are possibly the best training tool for helping practicing oncologists improve communication skills as well as develop expertise in dealing with difficult situations and ethical dilemmas. We live in a rapidly changing world, and the migration of people with all kinds of cultural and religious backgrounds is presenting a real challenge to those in our profession. We must rise to that challenge.

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**References:**

**REFERENCES**


