

Cultural aspects of communication in cancer care

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Abstract Cultural competence in oncology requires the acquisition of specific knowledge, clinical skills, and attitudes that facilitate effective cross-cultural negotiation in the clinical setting, thus, leading to improved therapeutic outcomes and decreased disparities in cancer care. Cultural competence in oncology entails a basic knowledge of different cultural attitudes and practices of communication of the truth and of decision-making styles throughout the world. Cultural competence always presupposes oncology professionals' awareness of their own cultural beliefs and values. To be able to communicate with cancer patients in culturally sensitive ways, oncologists should have knowledge of the concept of culture in its complexity and of the risks of racism, classism, sexism, ageism, and stereotyping that must be avoided in clinical practice. Oncologists should develop a sense of appreciation for differences in health care values, based on the recognition that no culture can claim hegemony over others and that cultures are evolving under their reciprocal influence on each other. Medical schools and oncology training can teach communication skills and cultural competence, while fostering in all students and young doctors those attitudes of humility, empathy, curiosity, respect, sensitivity, and awareness that are needed to deliver effective and culturally sensitive cancer care.

Keywords Cultural competence · Communication · Cancer care

Introduction

Communication in oncology may be especially difficult due to several factors. Among them are the severity of the illness and the negative metaphorical value that a cancer diagnosis still carries in many contexts, the physical and psychological suffering of many patients (which can become extreme at the end of their lives), the persistence of different degrees of social stigmatization and discrimination for cancer patients and survivors, and the uncertainty related to the cancer prognosis and to the outcome and potential toxicity of standard and experimental treatments [56]. Cultural factors influence the way patients, physicians, and communities deal with communication in the clinical setting, and major cross-cultural differences exist worldwide with respect to information and decision-making in oncology [41]. Cultural factors also play a role in the existing major disparities in access to health care and research for minority and underprivileged cancer patients [4, 34].

The major differences among diverse cultural groups with respect to key issues in health care have recently stirred intense debate and action in the medical, sociological, and bioethical fields. As a result, the notions of cultural sensitivity and of cultural competence have developed and have been increasingly applied to clinical medicine [32, 49, 66]. The acquisition of knowledge and skills in delivering culturally sensitive care became a requirement in medical schools in highly multiethnic societies such as the US, where demographic projections estimate that minorities will grow from 29% of incoming cohorts in 2001 to almost 50% in 2050 [49].

In the patient–doctor relationship, the cognitive and caring dimensions are equally important, and they are both facilitated by effective communication that is based on expertise, empathy, respect, and justice toward each patient.

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Content and supportive aspects of communication influence each other reciprocally and need to be properly balanced, according to the patient's individual and cultural preferences and contexts [14, 55]. Furthermore, the complexity of cancer care potentially enhances some of the tensions inherent in all patient–doctor communication, as cancer patients' desire to be involved in their care is often counterbalanced by their increased vulnerability due to the cancer and by the asymmetry of knowledge and of power between the cancer patient and the oncologist. As a result, the cancer patient's autonomy needs to be understood not only in all its value but also in its potential limitations [56].

It is now accepted that the notion of patient autonomy involves a relational dimension that goes beyond individual rights to self-governance [16, 56, 61]. In western bioethics, we tend to rely on a narrow understanding of individual autonomy that is based on an ideal concept of rational persons who are capable of making the best choices for their own life and health and are free to enact their choices. This view, however, ignores the fact that persons are immersed in a web of relationships and connections with other persons. These connections sustain the individual person and also generate responsibilities toward others, which in turn impose constraints on the abstract notion of self-determination. In oncology, the autonomy of cancer patients is always related to and, at times, limited by their social and cultural contexts, religious beliefs, and personal relationships with friends and families. Awareness of the relational aspects of a patient's autonomy and knowledge of the pre-eminent role of culture in determining how patients, physicians, and communities deal with cancer and with communication in the clinical setting are key to delivering effective and sensitive cancer care during the entire trajectory of each patient's illness and survivorship [59].

Major cross-cultural differences exist worldwide with respect to health matters. These affect the practice of oncology and especially the communication between cancer patients and their physicians and nurses. In most of our societies, where multiethnicity is increasingly common, cultural differences between patients and health care professionals may give rise to bedside misunderstandings and conflicts with respect to truth telling, end of life choices, prevention and screening, and involvement in clinical trials [30, 31]. Delivering culturally sensitive cancer care is now a priority for all oncologists, who should learn how to face in a timely and effective manner those ethical dilemmas that may arise from cross-cultural differences in their daily practices [53]. Furthermore, learning cultural competence will benefit oncologists in all communication processes. Patients and physicians engage in reciprocal, yet asymmetric, relationships, while carrying their own personal and cultural identity; thus, every clinical encounter is an exercise in cultural competence [53].

Culture and cultural competence in oncology

Culture has been defined in the oncology literature as the sum of the integrated patterns of knowledge, beliefs, and behaviors of a given community [43]. Cultural groups share thoughts, communication styles, ways of interacting, views of roles and relationships, and values, practices, and customs [3]. Culture is related to race and to ethnicity, and yet these domains are not superimposable [31]. Factors such as socioeconomic status, educational level, spoken language, geographic area, urban or rural context, religion, gender, sexual orientation, occupation, and disability define culture as well [3, 31, 53]. Moreover, we all belong simultaneously to multiple cultures: medicine, for example, is a culture that involves a specific language and is associated with a specific power position in most societies.

All the nested elements of culture integrate as the woven threads of a tapestry to perform integrative and prescriptive functions whose ultimate goal is to ensure the survival and well being of its individual members [31]. Cultures provide reference frameworks to interpret the external world and to relate to it by providing the “web of significance” in which our daily lives are embedded [60]. Cultural factors affect patients' perceptions of disease, disability, and suffering, their degrees and expressions of concern about them, and their responses to treatments and relationships to individual physicians and to health care systems [49]. The meaning that each cancer patient gives to her suffering—whether of redemption, of punishment, or of ill fate—and the loss of control and the many uncertainties that accompany her illness is always filtered through personal experiences and through the grand narratives provided by different cultures. The patient and the oncologist, therefore, must often negotiate between their different views of illness and of health to achieve their common therapeutic goal [30, 33].

Cultural sensitivity, cultural awareness, and cultural competence are interrelated notions in the clinical context. Oncology professionals should be “sensitive to the ways in which community members' values and perceptions about health care differ from their own” [66] and recognize cultural diversity and avoid stereotyping, while also being sensitive to those similarities that patients worldwide seem to share beyond their cultural differences. Cultural sensitivity is based on attitudes, values, beliefs, and personal insight of each person caring for cancer patients, who should also be interested and curious about cultural differences. Cultural awareness, rather, relates to health care professionals' specific knowledge of those cultural factors that affect patients' views on health care matters such as language, kinship patterns, religion, and special dietary habits [17].

Cultural variations in patient's health beliefs, values, preferences, and behaviors affect the recognition of symp-

toms, the threshold for seeking care, the willingness and ability to communicate and explain symptoms, the understanding of standard information about diagnosis, prognosis and treatment options, the trust in different professionals, and the adherence to prescribed treatments [3, 4, 31]. Cultural competence is, therefore, especially needed in the practice of oncology. The specific knowledge, skills, and attitudes needed for effective cross-cultural negotiation in the clinical setting can be acquired through dedicated teaching and training.

Cultural competence relates not only to individual professionals but also to organizations and systems, which must acknowledge the importance of culture, assess cross-cultural relations, exert vigilance toward the dynamics that result from cultural differences, and adapt services to meet the culturally unique needs of patients or groups of patients [3, 32]. A culturally competent health care system must also consider social, racial, and cultural factors in their separateness and yet in their reciprocal influences. Studies suggest that culturally competent health care leads to improved therapeutic outcome and may decrease disparities in medical care [4, 34, 63]. Teaching cultural competence to western medical student and young oncologists involves the provision of relevant information about different cultures with respect to different health issues, such as different cultural practices of truth telling or different decision-making styles throughout the world [59]. In addition, it involves the provision of a methodology to understand the western culture of medicine and its possible biases and prejudices [23, 42]. Because of the multiple variables involved in the process of communication, the individual patient should be seen as a teacher of his or her own values and preferences, and the physician should be aware of his or her own cultural beliefs and values. Cultural competence training, then, aims at the development of attitudes and clinical skills.

Cultural competence programs have been implemented in many countries over the past 10 years. In the United States, the Commission on Accreditation of Hospital Organizations requires mandatory training in cultural competence for licensure of health care professionals. The effectiveness of cultural competence training programs is now under evaluation, and existing limitations will need to be corrected. Among these are the lack of formal consensus on a clear definition of cultural competence (which inevitably shapes the contents of teaching programs), the fact that most cultural competence programs are limited to a brief training, and the scarcity of commitment and resources to develop comprehensive strategies including individual and also organizational changes. Empirical outcome studies that collect evidence on the effectiveness of cultural competence training programs are needed [63]. In addition, specific research

on cultural competence training in the field of oncology is necessary [10].

Communication of the truth to cancer patients: cross-cultural similarities and differences

An appropriate level of information is necessary to foster patients' understanding of their illness and enhance their cooperation with standard oncologic treatments and experimental therapies, in an effort to provide them with high quality of care and better quality of life. Published data in the international literature suggest that patients' preferences regarding communication of bad news seem to be similar across cultures, especially for those patients treated at major hospitals worldwide [9, 45, 65]. Cancer patients place a high value on their oncologists' expertise and honesty in delivering detailed information and in answering questions about diagnosis, result of tests, treatment options, and prognosis [14, 55]. Also, cultural and individual differences in communication preferences related to gender, age, and education go beyond cross-cultural boundaries [5, 11, 12, 25, 31, 58].

Empirical studies and anecdotal reports showing major cultural differences in attitudes and practices of truth telling to cancer patients worldwide have been published in the international medical and bioethics literature starting in the 1980s. Since the 1990s, there has been a shift in truth telling attitudes and practices toward greater disclosure of diagnosis to cancer patients worldwide [2, 20, 27, 29, 39–41, 50–52, 62]. Despite this trend, however, partial or nondisclosure is still common practice in many cultures that are centered on family and community values [54]. For example, while medical deontology and legislation now require informed consent for all medical acts in most European countries, the general level of patients' awareness of diagnosis and prognosis and their understanding of informed consent procedures is still relatively limited in certain countries [54, 64, 67]. A 2000 survey of Italian physicians revealed a major discrepancy between physician's reported views on truth telling and what they did in practice. One third of surveyed physicians believed that patients never want to know the truth. Forty-five percent indicated that patients should always be informed of a cancer diagnosis, while only 25% said they always disclosed the diagnosis in practice [26]. Older physicians are less inclined to reveal a cancer diagnosis, and disclosure to younger patients is more likely than to older ones.

To understand persisting cross-cultural differences in truth telling to cancer patients, anthropological, historic, social, and philosophical factors must be taken into account [1, 46, 56]. The question of whether or not to disclose information to cancer patients is a complex one, and the subtleties

involved suggest that no claim to a “right way” to approach truth telling can be fully justified in all cultures or for all individuals. Different communication styles exist, along with different views of the roles that family and physicians assume with respect to cancer patients in different cultures. Words do not have the same meaning and resonance in all cultures and, in certain cultures, “cancer” is a “bad word”, the uttering of which is considered to negatively affect patients’ outcomes, or words such as “cancer” or “depression” do not even exist [13, 35]. When addressing patients of different cultures, the right words must, thus, be chosen [1, 18, 19].

Differences in communication preferences are also related to transcultural factors such as gender, age, and education [11, 12]. Specific gender-related differences in patterns and styles of communication have been investigated, and research suggests that women tend not only to appreciate detailed information but also to value the supportive elements of communication, more than men do. In addition, cancer patients treated at large specialized institutions are more likely to request full disclosure of their diagnosis, treatment options, and prognosis from their physicians than patients whose care occurs in nonspecialized or rural centers [55]. Finally, individual preferences for different communication and decision-making styles may also relate to past experience and to the coping mechanisms that each person develops over a lifetime.

Culture and the role of families in communication to cancer patients

Recent advances in the field of psycho-oncology have shown that cancer does not affect the patient alone but also her entire family, whose internal dynamics and relationships to others around them are almost always altered by the cancer event [6]. The healing process, therefore, includes the oncologist’s interactions with the family and the community, as these are the locus of caregiving in most cultures, especially at the end of life [22, 40].

The extent and modalities of family involvement vary in different cultures [40, 57, 62]. In many countries, families make decisions in place of uninformed patients and, in Asian cultures, families are involved in the process of giving information to cancer patients. According to a 2000 Japanese study, 46% of the general population asserted that family should have a protective role in shielding the patient from a painful diagnosis and that most Japanese physicians still consult with the family before disclosing a cancer diagnosis to the patient [50]. A 2005 survey of cancer patients’ relatives in Turkey indicated that 66% did not want the diagnosis to be revealed to the patient, especially when the gender was male, the diagnosis was other than

breast cancer, the stage of disease was advanced, the family lacked sufficient knowledge about cancer in general, or held strong religious beliefs [44].

In countries with strict requirements for informed consent, families at times ask physicians and nurses not to disclose information to cancer patients [1, 7, 30, 59]. Families’ requests to withhold or to mitigate the truth about a cancer diagnosis or prognosis must not be ignored. Rather, they should be taken into consideration in the process of negotiation of cross-cultural issues with patients and their families. In most instances, it is possible to tailor the degree of information given to different patients in view of individual but also family and community values [1, 24].

In many cultures, particularly in Latino American culture, families are involved in the decision-making process throughout all stages of the cancer patient’s trajectory [2]. Even in the US, where most persons strongly believe that the patient should be the primary decision maker, differences have been reported among African–American and White patients and their families [47]. Negotiating the concerns of family members while respecting patients’ needs in terms of information and shared decision-making can be extremely challenging [8].

Consultations involving family members or friends tend to be more lengthy and complex than with individual patients, as the specific informational needs of relatives and caregivers need to be recognized and addressed [15, 28]. Moreover, tensions and disagreements among family members are common and may require guidance and support or specific interventions to improve understanding and concordance among them [22, 36, 37]. In families undergoing acculturation in a foreign country, generational differences may be especially strong [58]. Cultural competence is necessary for effective communication to patients’ families, from the time of diagnosis and treatment decisions, and facilitates the delivery of optimal cancer care to all patients.

Conclusion

Cultural sensitivity and cultural competency contribute to the ability of oncology professionals to communicate more effectively with their patients, by enhancing their active participation in their care, while respecting different cultural and individual preferences and styles. Oncology professionals involved in cross-cultural patient–doctor encounters should not make assumptions based on race, nationality, or language of their patients. Rather, they should take the time to ask them to briefly describe their cultural background, including their religious beliefs. This process may be facilitated by following steps that have been recommended in the literature [31]. Doctors should inquire about the

closeness of their patients to their families and ask them about the extent to which they wish their relatives or friends to be involved in their care. In some cases, physicians may have to briefly describe their own background to their patients. To improve communication in cross-cultural encounters, oncologists should ask their patients how informed they wish to be about their medical condition and treatment options. When patients or families ask for nondisclosure, oncologists should be able to effectively negotiate between the needs and values of their patients and their family members and the need to respect the laws of the country where they practice [59].

In the case of language barriers, professional translation, when available, should be offered, as translation performed by a relative or a friend may leave out relevant information. It is important that the translator be considered as a cultural mediator [59] and that he or she be involved as such in clinical encounters [48]. Regardless of the language spoken, the patient's understanding of the illness should always be checked at different points during the course of treatment and as the cancer progresses through different stages.

Communication is an experiential skill that requires dispositions, virtues and experience and training [5, 7, 21, 59]. Cultural competence consists of both knowledge of cultural differences and cross-cultural similarities in how cancer patients face their illness and of a set of specific clinical skills: both this knowledge and these skills can be taught. The virtues upon which cultural competence is based can also be nurtured. In contemporary societies, oncology professionals work under increasing economical and time constraints and peer pressure and they find it increasingly difficult to share moments of deep connection with their patients [38]. In such a context, oncologists may regard finding the time to achieve cultural competence as an almost impossible task. Delivering culturally competent cancer care, however, is essential to today's practice of oncology not only for patients but also for physicians and nurses who can derive a sense of privilege, enrichment, and fulfillment from meeting and understanding patients from different cultures.

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