9 Cultural Aspects of Communication in Cancer Care

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Summary

Cancer is increasing in incidence and prevalence worldwide, and the WHO has recently included cancer and its treatments as a health priority in developed and developing countries. The cultural diversity of oncology patients is bound to increase, and cultural sensitivity and competence are now required of all oncology professionals. A culturally competent cancer care leads to improved therapeutic outcome and it may decrease disparities in medical care. Cultural competence in medicine is a complex multilayered accomplishment, requiring knowledge, skills and attitudes whose acquisition is needed for effective cross-cultural negotiation in the clinical setting. Effective cultural competence is based on knowledge of the notion of culture; on awareness of possible biases and prejudices related to stereotyping, racism, classism, sexism; on nurturing appreciation for differences in health care values; and on fostering the attitudes of humility, empathy, curiosity, respect, sensitivity and awareness. Cultural competence in healthcare relates to individual professionals, but also to organizations and systems. A culturally competent healthcare system must consider in their separateness and yet in there reciprocal influences social, racial and cultural factors. By providing a framework of reference to interpret the external world and relate to it, culture affects patients' perceptions of disease, disability and suffering; degrees and expressions of concern about them; their responses to treatments and their relationship to individual physicians and to the healthcare system. Culture also influences the interpretation of ethical norms and principles, and especially of individual autonomy, which can be perceived either as synonymous with freedom or with isolation depending on the cultural context. This, in turn, determines the variability of truth-telling attitudes and practices worldwide as well as the different roles of family in the information and decision-making process of the cancer patient. Finally, culture affects individual views of the patient–doctor relationship in different contexts.

9.1 Introduction

The existence of major healthcare disparities in Western countries due to racial and socioeconomic factors and the presence of major differences in diverse groups with respect to key issues in healthcare have stirred intense debate and action in the medical, sociological and bioethical worlds. As a result, the notions of cultural sensitivity and of cultural competence have developed and have been increasingly applied to clinical medicine (Gostin1995; Kalnins 1997; Zweifler and Gonzalez 1998; Seibert et al. 2002). The acquisition of knowledge and skills in delivering culturally sensitive care became a requirement in medical schools in highly multiethnic societies such as the USA, where demographic projections estimate that minorities will grow from 29% in 2001 to almost 50% in 2050 (Seibert et al. 2002).

Delivering culturally sensitive cancer care is a priority for oncologists who are increasingly facing many ethical dilemmas arising from cross-cultural differences in their daily practices. Ethical issues in oncology are magnified by several factors: the severity of the illness and the negative metaphorical value of a cancer diagnosis; the physical and psychological suffering of the patient, at times extreme at the end of life; the impact of different degrees of social stigmatization and discrimination; the uncertainty related to the cancer prognosis and to the outcome and potential toxicity of experimental treatments; the side effects of many standard cancer therapies; and finally, the difficult balance between patients' desire to be involved in their care and their increased vulnerability due to the complex reality of cancer.

While the need for cultural competence may appear to be less acute in relatively more homogeneous societies and in countries with socialized healthcare systems, culture has profound implications in almost all contemporary societies because multiethnicity is increasingly common and because different cultures always co-exist within main cultures, as exemplified by the differences between North and South in many countries. Moreover, to the extent that both the patient and the physician always engage in an asymmetric yet reciprocal relationship, carrying their own personal and cultural identity, every clinical encounter and every patient–doctor relationship is an exercise in cultural competence (Surbone and Lowenstein 2003; Surbone 2004b).

Cultural differences between patients and healthcare professionals often give rise to some common bedside misunderstandings and conflicts with respect to truth telling, end-of-life choices, prevention and screening, and involvement in clinical trials. An example of the importance of cultural sensitivity in cancer care is the notion of "offering the truth" to cancer patients (Freeman 1993). This notion, based on allowing individual patients to choose their own paths and rhythm, was proposed as an effective means to respecting patients' autonomy to follow their own cultural norms.

In this chapter, I make frequent use of cross-cultural differences in truth telling as an illustration of the role of cultural competence in communication with cancer patients. In any patient–doctor relationship there is an inherent problem of what philosophers call act/object ambiguity, i.e. the fact that the truth of an assertion may refer either to the content or to the assertion of the content. This is especially true when the appropriateness of an assertion needs to be evaluated in the context of particular circumstances, when a person may be right in what she says and may not be right in saying it in a given moment or in a given cultural context (Surbone 2002b). Giving blunt bad news to an uninformed cancer patient whose family has requested the physician not to do so is an example often encountered in multicultural oncology practices.

9.2 Culture and Medicine: Understanding Keywords

9.2.1 Culture

Culture is defined as the sum of the integrated patterns of knowledge, beliefs and behaviours of a given community (Olweny 1994). Cultural groups share thoughts, communication styles, ways of interacting, views of roles and relationships, values, practices, customs (Betancourt 2003). Culture is related to race and to ethnicity, and yet their domains are not superimposable. In essence, culture refers predominantly to the social, while race and ethnicity refer to the sociobiological domains (Betancourt et al. 2003; Kagawa-Singer 2003). We all belong simultaneously to multiple cultures, expressing themselves through specific languages, such as the medical one. Medicine is a culture that involves a specific language and is associated with a specific power position in most societies. As an example, both the patient and the doctor bring their culture(s) and language(s) to every clinical encounter (Surbone 2004b).

Factors such as socioeconomic status, educational level, spoken language, geographic areas, urban versus rural contexts, religion, gender, sexual orientation, occupation and disability define culture as well. All these 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 (Kagawa-Singer 2003).

Culture contributes to our identity by providing a reference framework to interpret the external world and to relate to it, which has been described as a "web of significance" in which our daily lives are embedded (Swendson and Windsor 1996). This "web of significance" affects our perceptions of disease, disability and suffering; our degrees and expressions of concern about them; our responses to treatments; and our relationship to individual physicians and to the healthcare system (Seibert et al. 2002). Culture influences the meaning that each cancer patient gives to the suffering, and the loss of control and the many uncertainties that accompany their illness. The experience of cancer is a trial in the life of oncology patients, who often resort to the grand narratives provided by their own culture in order to interpret the physical and psychological pain of cancer (Nelson 1997). The different values that different persons attribute to suffering—whether of redemption, of punishment or of ill fate—are generally mediated by their culture. The patient and the physician must negotiate between their different views of illness and of health to achieve their common therapeutic goal (Kagawa-Singer and Blackhall 2001; Kagawa-Singer 2003)

The importance of cultural influences on our personal identity, however, should not be conceived in a deterministic way, as this only reinforces prejudicial and stereotyping attitudes that inevitably culminate in more or less overt forms of discrimination. In fact, there is constant redefinition of cultural identity. Cultures are dynamic, interdependent and fluid, and they evolve from within as well as under the reciprocal influence of other cultures. Members of different racial, ethnic and cultural groups undergo assimilation and acculturation. Individual persons or groups do not always conform to their own culture, and cultural identity is only a dimension of one's personal identity. When we make generalizations that are not fully substantiated by evidence, we fail to recognize that cultural identity is not a substitute for personal identity, which is rather primarily grounded in one's own experiences in life as well as in universal human values (Surbone 2004b).

Furthermore, the progressive exposure to global communication and the increasing demographic mobility determine rapid cultural changes in contemporary societies, to the point that cultural identity today goes well beyond geographic and ethnic boundaries. The risk of such globalization is that the Western model, however, would prevail over deeply routed cultural beliefs in a sort of cultural hegemony (Surbone 2003a , 2004b). On the contrary, different cultural identities are a welcome reality of our world, where some cultures continue to privilege individual autonomy, while others are more family- and community-centred. Thus, both cultural differences and cultural similarities need to be acknowledged and respected also in medicine, where personal and cultural sensitivity and competence are equally needed. In oncology practice, as an example, we can now find striking cross-cultural similarities in the approach of cancer patients to the salient moments in the course of their illness, such as when facing end-of-life decisions (Kagawa-Singer and Blackhall 2001).

9.2.2 Cultural Sensitivity

Cultural sensitivity for healthcare workers has been defined as their being "sensitive to the ways in which community members' values and perceptions about healthcare differ from their own" (Zweifler and Gonzalez 1998). Cultural sensitivity is based on the recognition of cultural diversity and on the avoidance of stereotyping, but also common universal similarities beyond cultural differences. It describes attitudes, values, beliefs and personal insight of healthcare professionals, including openness to and curiosity about cultural differences. By contrast, cultural awareness relates to the healthcare professional's knowledge of those areas of cultural expression which mostly affect patients' views on healthcare matters such as language, kinship patterns, religion, and special dietary habits (Doorenbos et al. 2005).

9.2.3 Cultural Competence

Cultural competence in healthcare not only relates to individual professionals but also to organizations and systems.(Kalnins 1997; Betancourt et al. 2003). A culturally competent healthcare system "acknowledges and incorporates—at all levels—the importance of culture, assessment of cross-cultural relations, vigilance toward the dynamics that result form cultural differences, expansion of cultural knowledge, and adaptation of services to meet culturally unique needs" of patients or groups of patients (Betancourt et al. 2003). A culturally competent healthcare system must also consider in their separateness and yet in their reciprocal influences social, racial and cultural factors. In understanding and trying to overcome the causes for major healthcare disparities in many Western countries, it has become evident that cultural variations in patients' health beliefs, values, preferences, and behaviours affect the recognition of symptoms, the threshold for seeking care, and the willingness and ability to communicate and explain symptoms, as well as the understanding of standard information about diagnosis, prognosis and treatment options, the trust in different professionals and the adherence to prescribed treatments (Betancourt 2003). Clearly, these are all essential elements of oncology care—a practice that can no longer exist without cultural competence.

9.3 Teaching Cultural Competence to Clinicians

Cultural competence in medicine is thus a complex multilayered accomplishment. It requires knowledge, skills and attitudes whose acquisition is needed for effective cross-cultural negotiation in the clinical setting. A culturally competent cancer care will lead to improved therapeutic outcome and it may decrease disparities in medical care (Langer 1999; Stewart et al. 1999; Betancourt et al. 2003, Vega 2005). The difficulty of establishing exactly what cultural competence entails for the clinician and the failure of many programmes to really teach about one's culture as well as about other cultures has recently been highlighted. Involving medical students and physician in training in early programmes that will help them understand first their own cultural framework is most important (Fox 2005). This includes understanding the Western culture of medicine and exploring possible biases and prejudices (Newmann 1988).

There are different methods for teaching cultural competence. The "multicultural approach" focuses on providing relevant information about different cultures with respect to different health issues. In oncology, as an example, cultural competence entails a basic knowledge of different cultural practices of truth telling throughout the world, as I illustrate in the next section. Another method, the "cross-culturally based systems approach", focuses on the individual patient as a teacher and on the multiple variables involved in the process of communication. It presupposes the physician's awareness of his/her own cultural beliefs and values, and it aims at the development of attitudes and clinical skills (Betancourt et al. 2003).

Effective cultural competence is based on increasing physicians' knowledge of the concept of culture as well as of the key notions related to culture, such as stereotyping, racism, classism, sexism; on nurturing appreciation for differences in healthcare values; and finally on fostering the attitudes of humility, empathy, curiosity, respect, sensitivity and awareness (Kagawa-Singer 2003). These attitudes, however, are in no way confined to cross-cultural clinical encounters but rather are essential to all physicians and healthcare professionals.

Some unsolved issues related to the teaching and acquisition of cultural competence have recently been analysed in the medical literature. First, most cultural competence programmes are limited to a brief training. Second, comprehensive strategies including individual and also organizational changes require both commitment and resources that are still scarce. Third, there is lack of formal consensus on a clear definition of cultural competence and what the contents of its teaching should be. Finally, research-based empirical evidence on the effectiveness of cultural competence is still missing (Vega 2005).

Despite the difficulties inherent in teaching the complexity of cultural competence, the field has made major progress since it was born approximately 20 years ago. In the USA accreditations bodies such as the Commission on Accreditation of Hospital Organizations require mandatory training in cultural competence for licensure of healthcare professionals (Betancourt 2003; Vega 2005).

9.4 Evolution and Persistence of Cross-cultural Differences in Truth Telling: A Paradigmatic Illustration

Truth telling is central to communication between the patient and the doctor in clinical medicine and especially in oncology. Truth telling is also a core issue in bioethics, as it relates to the doctrines of informed consent and of cultural competence. The debate on truth telling has always been particularly intense in oncology and it has greatly influenced other domains of medicine.

The doctrine of informed consent was born in 1947 as a result of the Nuremberg Trial. One of the first milestone studies of truth telling practices in the USA showed that 10% of surveyed physicians would never reveal a cancer diagnosis (Oken 1961). By contrast, over the following two decades, physicians' truth-telling practices in the USA changed dramatically and in the late 1970s 98% of surveyed US physicians revealed the cancer diagnosis to their patients (Novack 1979). Truth telling and informed consent were a reflection of the growing Anglo-American emphasis on individual autonomy, grounded in a strong tradition of privacy rights and personal liberty (Beauchamp and Childress 1994).

In other cultural contexts and within multiethnic minorities in the USA, truth telling attitudes and practices were rarely discussed until the late 1980s and early 1990s (Holland et al. 1987; Surbone 1992; Mystadikou et al. 1996). The initial debate on truth telling was followed by a wealth of reports from different countries, suggesting major cross-cultural differences in truth telling (Surbone and Zwitter 1997). In countries centred on family and community values, the word "autonomy" was often perceived more as synonymous with "isolation" than with "freedom". Those societies have a more paternalistic vision of the patient–doctor relationship and they attribute a protective role to families and physicians with respect to the ill person (Surbone 1992; Mystadikou et al. 2004). Painful medical truths were often withheld or strongly mitigated to avoid taking away hope from the cancer patient or causing her severe distress. In most cases, physicians only informed the patients' families, while keeping the patient in the dark. Often this resulted in a "conspiracy of silence" where doctors and relatives were often caught in the web of half-truths that in many cases left the patient suffering alone, unable to ask questions and find answers, often even deprived of the chance to put in order their affairs or to say good-bye to their loved ones (Surbone 1992).

A recent worldwide shift in the understanding of the patient–doctor relationship has resulted in a rapid evolution of truth-telling attitudes among patients and physicians. The practice of truth telling to cancer patients is now increasingly common and public polls conducted through the media in different countries show a parallel shift in public opinion in favour of more open disclosure of the truth to cancer patients (Harrison et al. 1997; Seo et al. 2000; Mystadikou et al. 2004; Surbone et al. 2004).

Different medical, legal and societal factors, all intertwined, have contributed to the evolution of truth-telling attitudes and practices in oncology throughout the world. These main factors appear to be very similar to those that influenced the shift from non-disclosure to disclosure in the USA between the 1960s and the 1980s (Novack 1979; Anderlick et al. 2000. Patients of different cultural backgrounds have started demanding respect of their rights, including that of sharing any decision making about their health and illnesses, and physicians have changed their practices of disclosure. As a result of the contributions of physicians, patients, the public and the media, the word "cancer" seems to have lost some of its metaphorical implications related to imminent and inevitable death, and cancer patients suffer less stigmatization and isolation.

Despite the international trend just described, partial disclosure and non-disclosure are still supported and practiced by physicians throughout the world. Studies suggest that even among those physician who assert that patients have a right to be informed, the actual rate of disclosure remains low (Grassi et al. 2000; Tse et al. 2003, Monge and Sotomayor 2004; Surbone et al. 2004; Voogt et al. 2005). Also, surveys of cancer patients reveal a persistent lack of awareness of the severity and curability of their illness

(IGEO 1999). These data may be interpreted as a function of anthropological and sociocultural differences. For example, cultural changes may occur in cohorts related to social and attitudinal changes of different generations (Glenn 1980). Also, partial disclosure may still occur in those cultural contexts where the requirement for a substantive consent allows doctors to separate the medical act from the reasons behind it, or where abiding to traditional family and community values may take priority over following the written law (Surbone et al. 2004). Paternalism may be an expression of traditional hierarchical and authoritarian values that still predominate in specific geographic areas historically less exposed to the Western model.

Variations in patients' and physicians' attitudes and practices, however, may also be related to age, geographic location and the type of treating institution in almost all countries. There are similar observed differences in disclosure and information rates in urban versus rural communities and in northern versus southern areas of different countries. Also, major variations have been reported among patients and physicians in leading teaching institutions and large city hospitals versus private and peripheral practices, regardless of the country (Baile et al. 2002).

According to extensive data from the Anglo-American world, including Australia, Canada, the UK and the USA, most patients expect truthfulness about their illness and wish to participate to the decision-making process involving their treatments (Emanuel et al. 2004) In Western countries, more informed and more involved patients seem to fare better in terms of compliance with difficult therapies, and sharing the decision-making process between the patient and the doctor seems to result in better care and better outcomes (Baile et al. 2002; Fallowfield and Jenkins 2004 ; Katz et al. 2005; Nattinger 2005; Brown et al. 2004).

Recent data collected from the growing number of patients who are now informed of their cancer diagnosis in countries where traditionally the truth was withheld seem to confirm that these patients also do not experience particular distress or discomfort when they are told the truth about their cancer (Elwyn et al. 2002). Furthermore, studies on patient preferences seem to suggest strong similarities with Western types in terms of patients' general needs and preferences for communication (Sekimoto et al. 2004 ; Nayak et al. 2005).

9.5 Culturally Competent Care and Respect for Autonomy

The increased emphasis on personal self-governance in the Anglo-American world is mirrored in the current model of the patient–doctor relationship, which includes doctors' moral obligation to respect and foster their patients' autonomy and to develop equal partnerships with them, first and foremost through the practice of truth telling. The autonomy model is in sharp contradistinction to the paternalistic model of charismatic physicians who, at their discretion, maintain all power, including that of withholding truth (Beauchamp and Childress 1994).

However, the current Western preoccupation with equality and autonomy, uniformity and impartiality, with rules and reciprocity suited for the voluntarily bargaining relations of non-intimate equals often fails to capture the essence of the patient–doctor relationship (Surbone and Lowenstein 2003). This is an asymmetrical relation of help between the patient, who is in a "uniquely dependent state" by virtue of her illness, and the physician who assumes the responsibility to care for the patient (Pellegrino and Thomasma 1988). The patient–doctor relationship thus carries particular ethical implications related to vulnerability, asymmetry, distance and intimacy, which require considerations of care, trust and justice along with respect for relational autonomy (Baier 1994; Sherwin 1998; Anderlick 2000).

The notion of "respect for the patient's relational autonomy" is very helpful in framing the issue of truth telling and in trying to analyse different attitudes and practices. It is also necessary to understand the many unsolved aspects of truth telling that go beyond cultural differences. "Autonomy" is a complex concept, as it refers to the one's capacity to choose, but also to the ability to implement one's choices. Autonomy is a necessary attribute of rational human beings and it is universally valid (Mahowald 2000). However, both internal and external factors and resources contribute to one's autonomy and from the beginning to the end of our lives, we are embedded in a context of social relations, which shape us and sustain us (Sherwin 1998). Regardless of one's cultural identity, autonomy is always relational and situated, rather than simply a matter of individual choice. Imposing the truth onto an unprepared patient whose cultural expectation is to be shielded from painful medical truths is not necessarily an act of respect for autonomy (Pellegrino 1992). Any patient should be free to delegate her autonomy to a certain extent to the physician or the family and the community, when this corresponds to her individual or cultural value system.

Finally, in clinical medicine one cannot ignore the actual sociocultural conditions that make the patient's autonomy possible. As an example, the patient's decision to participate in a clinical trial often does not depend only on the information about the trial, but it is also influenced by socioeconomic barriers to access (Brawley 2003). In the field of genetic screening, the decision to seek genetic information is in large part a function of social perceptions and discriminatory practices, which may greatly limit one's autonomy .

9.6 Common Cross-cultural Issues in Bedside Oncology

9.6.1 Communication About Diagnosis

There is ample evidence that the diagnosis of cancer is now being revealed to most patients in many, if not most, countries. In a survey of 167 oncologists attending the 1999 International Meeting of the American Society of Clinical Oncology, there was no difference between Western and non-Western physicians in disclosure of diagnosis (Baile et al. 2002). By contrast, whether and how to disclose prognosis and to deliver "bad news" is far from being a settled issue even in those countries with a long tradition of truth telling (Butow et al. 1996; Parker et al. 2001; Baile et al. 2002).

The cancer diagnosis, even when complex and difficult, can be established and confirmed with good degrees of certainty that can be conveyed to the patient, though specific modalities of communication may be culturally determined. In many cultures, for instance, doctors often use euphemisms, such as "growth" or "condition" instead of the word "cancer" and patients prefer them, even when they wish to be told the truth (Baile et al. 2002). In some cultures, the utterance of words bearing a negative connotation is believed to affect the reality for worse (Carrese and Rhodes 1995). In other cultures, words such as "cancer" or "depression" do not exist, and people do not share our Western causal explanations. In a poignant essay, Dr. Levy from Zimbabwe reported that her patients perceived cancer as a ghost (Levy 1997). In all cultures, but particularly in those where patients are shielded from open truth telling, non-verbal communication is extremely important (Dunn et al. 1993). As the meaning of non-verbal forms of communication is subject to great cultural variability, oncology professionals practicing in multicultural settings need to have some specific knowledge of cross-cultural differences in non-verbal communication. Pauses and silences always have tremendous effect on our patients, and we know that almost any piece of information can be downplayed or emphasized through body gestures, eye contact and modulation of one's tone of voice. The effect of pauses and gestures, however, is not the same universally. As an example, in most Anglo- and Latin-American cultures, some form of touch from one's physician is generally equated with an expression of empathy. The degree of physical closeness that patients expect and desire, on the contrary, appears to be very different in Asian cultures (Ammann and Baumgarten 2005; Fujimori et al. 2005).

9.6.2 Communication About Prognosis and Risk Assessment

When talking with their patients about prognosis and risk assessment, physicians are acutely confronted with the interplay of certainty and uncertainty at the cognitive level, and of hope and expectations at the psychological and spiritual level (Del Vecchio et al. 1990; Surbone 1997; Clayton et al. 2005 ; Chochinov et al. 2005; Ferrell 2005; Hagerty et al. 2005; Hartmann 2005; Kalemkerian 2005). Many recent studies confirm that the balance between fostering and taking away hope is a very delicate one, and that many physicians may be reluctant to be involved in any discourse on hope. These issues are extensively discussed in other chapters in this book, by Drs. Stiefel and Razavi and by Dr. Lloyd, who addresses specifically communication in palliative care and at the end of life.

Many of the difficulties encountered by patients and physicians alike in discussing prognosis seem to go beyond cultural differences. Even in Anglo-American cultures, the disclosure of prognostic information occurs much less often and it is left to the individual physician, while the disclosure of diagnosis is required by law (Spiro 2005). Often, patients specifically ask not to be kept informed of the details of their diseases, but sometimes it is the physician who does not feel comfortable taking away too much hope from patients.

Prognostication is related to the physician's awareness of the asymmetry and power imbalance inherent in the patient–doctor relationship—something that is universally true, and yet may deserve greater consideration in different cultural contexts. Bye the patient–doctor relationship is an asymmetric relationship, where the vulnerability that the illness creates in the patient meets the expertise of the physician whose help has been requested by the patient. In a relation of help, the power is not equally distributed between the partners, and abuses may occur in different forms. To avoid such more or less subtle abuses of power within the patient–doctor relationship, it is essential for the physician to acknowledge its intrinsic asymmetry as well as the uncertainties of clinical medicine (Surbone and Lowenstein 2003; Howe 2003). As an example, physicians at times may hide behind statistic information to maintain control in the patient–doctor relationship or to mask their own difficulties in accepting their own limitations with respect to the possibility of cure. A profound sense of humility and respect for the patient as "Other", accompanied by individual and cultural sensitivity, may facilitate effective communication about prognosis and about risk assessment (Surbone 2005).

9.6.3 Role of Families

Cancer is an illness that not only affects the sick person, but also their entire family, and the healing and caring process depend also on the interactions of the physician with the family and the community (Baider et al. 2000). The internal dynamics of the family are inevitably altered by the cancer illness and by the caregiving responsibilities that families take upon themselves, especially at the end of life. In almost all cultures, women tend to be the caregivers in the family (Surbone 2003b; Mook et al. 2003; Baider et al. 2000). The relationship with the patient's family is amply discussed by Dr. Firth in this book, and I will thus only briefly treat some cultural aspects.

Families are almost always involved in the course of the evolution of the patient's cancer in every culture, and they are rarely be excluded from participating in the process of information and communication, unless it is the expressed wish of the patient (Farber et al. 1999). The extent and modalities of family involvement are different and in some countries families make decisions in place of uninformed patients. In many countries, especially in Asia, the family is always consulted before revealing a cancer diagnosis to the patient (Seo et al. 2000; Kagawa-Singer and Blackhall 2001). Although most patients in the USA believe that the patient should be the primary decision maker, still major differences were reported in African-Americans and white patients and their families (Phipps et al. 2003).

Often, it is the family that requests the hospital staff not to disclose the truth to the patient, also in countries with strict requirements for informed consent (Kinsella 2001; Anderlick et al. 2000 ; Baile et al. 2002; Elwyn et al. 2002; Phipps et al. 2003). In a recent study of a multicultural patient population attending a large cancer centre, particular emphasis was placed on tailoring the degree of information given to different patients in view of their individual but also family and community values, especially when dealing with specific requests to withhold or to mitigate the truth (Anderlick et al. 2000). In Western countries, it has been reported that the intervention of relatives almost invariably renders much more complicated the discussions between the patient and the physician (Higginson and Costantini 2002).

A 2005 survey of 150 relatives of recently diagnosed cancer patients in Turkey revealed that 66% did not want the diagnosis to be revealed to the patient. Factors that influenced the family request not to tell were male gender of the patient, diagnosis other than breast cancer, stage IV disease, insufficient family knowledge about cancer in general, strong religious beliefs and the absence of the patient's request for disclosure (Ozdogan et al. 2004). Negotiating the concerns of family members while respecting patients' needs in terms of information and shared decision making can be extremely challenging (Benson and Britten 1996).There may in fact be distinct informational needs to be addressed (Clayton et al. 2005). Families may require guidance and support when faced with a tell or not tell situation (Maguire and Faulkner 1988; Maguire et al. 1996). Furthermore, patients, family caregivers and physicians all interact in a connected system and efforts are needed to improve understanding and concordance among them (Farber et al. 2003).

9.6.4 Respecting Cultural Differences in Western Hospital Settings

Respect for cultural differences and for relational autonomy does not have to be blind, nor does it require that physicians subscribe to any form of cultural determinism. Physicians, while being sensitive to and avoiding any form of stereotyping and/or of cultural imperialism, are entitled to advocate for their patients' rights to self-determination. Often, the lack of information conveyed arises from miscommunication or real conflicts between the patient and the family and the physicians' role is to clarify such misunderstanding by being on the patient's side (Clayton et al. 2005). In the clinical setting, physicians foster their patients' autonomy by always putting their patient first and by spending the necessary time to understand what their patients wishes are in truth-telling matters.

Respecting different attitudes toward truth telling of patients treated in a society with a homogenous medico-legal system, in which withholding the truth is considered an infringement on the patient's autonomy, poses major quandaries (Anderlick et al. 2000; Surbone 2003). In the contemporary Western healthcare context, uninformed patients tend be a source of stress for the hospital staff, and lack of information can be an obstacle to good medical care (Fallowfield and Jenkins 1999). It is not advisable to encourage physicians to go against the deontologic and legal requirements of their society. While it may be possible—though no longer recommendable—to withhold some information from cancer patients in countries where this is a commonly accepted practice based on ethically justified norms, it is always a mistake not to be truthful to cancer patients treated in a country where disclosure is the ethical norm and it is legally required. In the course of a chronic illness such as cancer, entailing frequent visits to different specialists and often requiring periods of hospitalization, almost all patients will inevitably be told the truth at some point and consequently lose trust in the treating physicians and team (Fallowfield et al. 2002). Often, in fact, disclosure occurs through staff members, who may not have an established connection with the patients and may be unaware that relevant information had been withheld.

Cross-cultural medical encounters pose many additional difficulties related to language and therefore to the process of translation. Studies in philosophy and anthropology have established that language goes far beyond semantics, and rather it reflects different peoples' ways of life. These, in turn, are based on different meanings and values that are acquired within one's culture. In acquiring language skills, people from early ages learn about the truth-value of different assertions in a specific cultural context (Williams 2002). Translations from a language into another are thus very complex and require particular care when they involve the delivery of medical information and of bad news (Russell Searight and Gafford 2005).

9.6.5 Improving Effective Communication in Cross-cultural Medical Encounters

Establishing rigid guidelines for cross-cultural encounters is a difficult task. Excellent studies have suggested steps that may be followed in cross-cultural patient–doctor encounters (Kagawa-Singer 2003). Following are recommendations based on my own clinical experience and research in cross-cultural encounters with cancer patients (Surbone 2004a). Healthcare professionals should not make assumptions based on race, nationality or language of their patients, and rather they should take the time to ask them to briefly describe their cultural background, including their religious beliefs. Though it may appear superfluous, it is often appropriate for physicians of a different culture to briefly acknowledge their own background.

Physicians should also ask new patients to what type of family they belong—whether extended or nuclear, close or distant—and ask them directly to what extent they wish their family or friends to be involved. In any cross-cultural encounter, the physician should tactfully and yet openly ask patients how informed they wish to be about their illness and to investigate their information preference, while also clarifying that he or she must respect the laws of the country of practice (Butow et al. 1997).

With respect to translation, it often helps to inquire with the patient about the language spoken at home. Professional translation, when available, should always be offered and the translator should be considered and involved also as a “cultural mediator”. When the translation is performed by a relative or a friend, the physician should find a way to double-check at random if the translation is correct or if it leaves out relevant information (Russell Searight and Gafford 2005).

Finally, during the course of a chronic illness that often progresses through many phases, it is essential to verify the patient’s understanding of the illness at different points. This can be done by occasionally pausing to let the patients verbalize their grasp of the situation as well as their concerns and hopes. Listening and observing become equally important in cross-cultural encounters where language barriers are frequent.

9.7 Conclusions

This chapter has treated the most relevant cultural aspects of communication in cancer care. Cultural competence is about the cultural differences and also the cross-cultural similarities that exist within the context of good communication in the clinic. Communication is an art that requires dispositions and virtues, as well as experience and training. Multiple studies have confirmed that communication skills can be taught and learned by physicians at any stage of their career. Being a good and effective communicator helps both physicians and their patients and families. Learning how to break bad news, how to deal with an angry or difficult patient, how to approach end-of-life discussions with cancer patients is essential to oncology professionals, including the most empathic and compassionate ones, who need a solid framework within which to best communicate with their patients as well as to prevent burn-out in their personal lives.

As an experiential skill, communication can and should be taught with different methodologies that have been shown to improve physicians’ communication skills as well as patients’ satisfaction. These subjects are extensively treated by Drs. Fallowfield and Jenkins and by Drs. Favre, Despland and Stiefel in this book. Being a good communicator, however, also involves the moral character of the physician and requires individual and cultural sensitivity, empathy and compassion, respect for the “other” in front of us and genuine interest in what she has to say and in how she feels (Spiro 1993; Butow et al. 1996; Fox 2005; Surbone 2005). A good communicator never betrays the complexity of the patient–doctor relationship and of the cultural differences and similarities that deeply affect any communication process.

In my own experience of over 20 years of practicing medical oncology in different countries and multicultural settings, I have become convinced that rarely are our patients unaware of their own situation, because they are the ones who suffer from the illness and from the cancer treatments with their immediate and long-term sequelae. Communication of the truth is always possible during the course of a long-lasting patient–doctor relationship. Yet, clinical algorithms and guidelines for optimal communication are difficult to establish and they are not necessarily applicable cross-culturally. Furthermore, acquiring and practicing cultural competence can often fail to produce a measurable impact on the delivery of healthcare, especially when it represents the isolated effort of individual healthcare professionals and does not reach and overcome organizational and structural barriers (Betancourt et al. 2003).

Culturally competent cancer care requires knowledge, dedication and time. Oncology professionals are increasingly working under financial and time constraints and often under enormous peer pressure. Yet, delivering culturally competent cancer care has not only become a necessity, but is also an extremely rewarding task. Nurturing the profound sense of privilege, enrichment and fulfilment that derives from meeting uniquely different patients is essential to our ability to care for our patients and also for our inner life as physicians and oncology professionals. Those of us who have been gifted with occasional epiphanies of real communication with our patients know only too well the importance of sharing a unique moment of intimacy or of deep connection with them, even beyond what we consider good standard communication (Matthews et al. 1993; Lowenstein 1997). While these epiphanies may be increasingly rare in today's Western healthcare systems, where patient care is often fragmented and rushed, cultural sensitivity and cultural competency contribute to the ability of oncology professionals to reach deeper levels of communication with their patients and to help them cope effectively with the many challenges of cancer.

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