



Ethics of cancer palliative care in Sri Lanka. A cross- cultural perspective.

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Abstract

The diagnosis of cancer is associated with an unexpected breakdown of the physical, psychological and social well being. In addition to cancer related physical outcomes, cross-cultural issues are known to hasten patients' clinical deterioration and can impact upon orientation as a healthy human being in society. As members of a developing nation in the second world, to provide patient oriented quality care while maintaining high standards of ethical practice, health care workers in Sri Lanka have to be culturally competent. In Sri Lanka, the cross-cultural ethical issues related to patients with a diagnosis of cancer include, awareness of one's own cultural identity, gaining knowledge of different cultural issues, verbal and non verbal communication skills, respect for patients' autonomy, involvement of the family and the relatives, addressing moral and spiritual backgrounds, development of effective communication skills and provision of social support. Therefore in the management of cancer patients in Sri Lanka, cultural issues should be given a high priority to maintain ethical standards and quality in palliative care. Culturally competent Health care workers safeguard the rights of patients, as well as providing optimal medical and surgical care.

Key Words

Ethics, Palliative care, Cultural issues, Sri Lanka.

Background

During their careers, nearly all health care providers in Sri Lanka will care for some patients who are diagnosed with cancer. A cancer diagnosis is sometimes associated with breakdown of physical, psychological and social well being of the patient. The degree to which it affects one's life depends on the views of the patient as well as those who are immediately present. These impressions are strongly influenced by cultural issues such as religion, race, traditions, spiritual values, economic and social status and cultural norms. The impact of cultural factors on care implies that health care providers have to become more aware of cultural issues in the clinical setting .This paper contends that cross-cultural issues are especially important to consider within the context of cancer care.

Cultural factors reflect on communication issues such as language difficulties. Cancer patients, who are undergoing emotional distress as a result of their cancer diagnosis, must be able to clearly understand diagnoses and treatment options, and make cooperative decisions about their care. The provider, patient, and patient's family must maintain constant and open communication for the patient to understand these issues and take an active role in treatment. For patients and providers who are from different cultural backgrounds, this kind of communication can be challenging. (1)

Cross-cultural issues also become important in light of the disparities in cancer incidence and mortality among different ethnic groups. Improving the quality of care for disadvantaged ethnic groups may help to alleviate these inequalities. (2) Providers have the potential to drastically improve patient care for ethnic minorities by setting aside commonly held stereotypes, familiarizing themselves with



patients' cultural backgrounds, and becoming sensitive to cultural differences.

Awareness of one's own cultural identity

One of the first steps to improving patient care and attenuating cross-cultural conflict is awareness of one's own cultural identity. Health care providers who are members of the dominant ethnic group often assume that they themselves have no ethnic identity, which can lead them to see their own beliefs as "self-evident and natural."⁽³⁾ It is important to recognize the biases of one's own cultural beliefs and attitudes, and to be aware of the dangers of ethnocentrism. ⁽⁴⁾

Ability to empathize with patients and respect their socio cultural and spiritual background plays a key role in adequate hospital and community-based management of these patients. Developing the techniques and skills to communicate well with patients from different cultures is ultimately rooted in self-awareness. ⁽³⁾

Gaining knowledge on different cultural issues

In the clinical setting, health professionals often see cultural issues as barriers that need to be overcome in order to break bad news, communicate with relatives or to obtain informed consent. Rather than perceiving cultural differences as a kind of intrusion into the clinical setting, culture can be viewed as a context within which people live and make decisions.⁽³⁾

Further, knowledge and familiarity with a particular culture can be effectively utilized to gain understanding about patients' behaviour, minimise misunderstandings, and help the health care worker and patient arrive at meaningful decisions together. ⁽⁵⁾ With some effort on the part of the health worker, patient care can be dramatically improved, and valuable time for subsequent palliative care can be saved⁽⁶⁾, where cure is uncertain.

Respect for different languages, values, and ethos can bring the health care provider a greater understanding of individual patients.⁽⁷⁾ By examining their own cultural biases and learning about the influences of cultural beliefs on patients, health care professionals are more able to facilitate effective communication that is likely to be mutually beneficial.

Speaking the Patient's Language

Patients are burdened with tremendous emotional distress when they are diagnosed with cancer. This burden is increased for the patient who does not have language or culture in common with the majority.

Such patients may be unable to clearly communicate fears, problems, and symptoms to the health care provider, and may not be able to follow instructions and recommendations. In addition, the provider may not be able to make an accurate assessment of an individual's physical and mental state. The literature provides evidence that the experience of diagnosis and subsequent management can be negatively changed by misinterpretation arising from language difficulties. ⁽⁸⁾

Further, professional translators are indispensable in relaying symptoms, providing an accurate patient history, communicating instructions about medications, and discussing diagnoses and treatment options. A professional translator who is considered an active part of the medical team may also be able to translate subtle cultural information as well as words. ⁽³⁾ However, in our context employment of translators is costly. Fluency among health care workers in all state languages may play a key role in facilitating a better health service.

Therefore, the authorities often promote the ability to use all three state languages among health care workers in Sri Lanka.

Non verbal communication

Non verbal communication may be a barrier to communication between patients and health professionals who do not share the same cultural background. ⁽¹⁾ Body language varies widely among different cultures. For instance, a touch on the shoulder can be comforting and welcome to one person, while to another it may seem like an invasive gesture.^(1,3) Lack of eye contact may sometimes be interpreted as a sign of depression, disinterest, or inattention, although it may be intended as a sign of respect.

Perception of comfort with regard to physical distance between persons, arrangement of seating during communication, and the desire to have an accompanying person, present also vary from culture to culture. ⁽⁴⁾



Therefore, health professionals need to respect the differences in patients that arise due to variable social, economical, religious and spiritual backgrounds.

Respect for patients' autonomy

The understanding of the role of autonomy varies between different cultural groups. Some patients may come from a group-oriented culture and view the family as an extremely vital aspect of their cancer care. Others who are in their old age would be perceived that dealing with cancer is something they have to do alone. (6)

Therefore, involvement of the family and others in the management of the patient has to take place within the context of patient wishes. The same applies to disclosing patient's information to relatives.

In many children with cancers, parents strive for maximum medical intervention and sometimes this may be experienced as painful and unwanted by the child. The situation is similar for elderly patients who are in the palliative stage, which sometimes leads to unnecessary suffering.

Involvement of the family and the relatives

Handling management issues with patients and family members is one of the biggest challenges that health workers face across cultures. Communication with patients and relatives can be complex, particularly in cultures where families play an important role in illness management and treatment decision-making. Some illness-related issues may be discussed with the patient, whereas others are left unspoken. Particularly in palliative care, the transition from curative to palliative treatment and discussion of death and dying are often topics which have to address the concerns of family members and the moral rights of the patient. Communication patterns may also be influenced by age, gender, age, and family role. (8)

Involving the family can be a powerful way to alleviate some of the stress and pressure, patient feels when making important cancer treatment decisions (9) to move from curative to conservative care.

Family can be guided to provide emotional support. This can be very effective in traditional, oriental cultures in countries such as Sri Lanka where extended families are more common.

Addressing moral and spiritual background

According to certain cultural beliefs, illness can be attributed to both natural and supernatural causes, and cultures where this is the case tend to emphasize the spiritual aspect of illness. (3) It may be tempting for health professionals to discount the significance of patients' spiritual beliefs. In many cases, however, these beliefs can be a powerful coping strategy used by the patients and their families when faced with cancer diagnosis and potential end-of-life issues. (10)

As mindfulness meditation is culturally inherited in Sri Lanka, it is mooted that utilization of meditation in improving patient outcomes may be useful. It is a form in which distracting thoughts and feelings are not ignored but instead acknowledged and observed non-judgmentally as they arise in order to detach from them and gain insight and awareness. (11)

Systematic review has demonstrated statistically significant improvements in spirituality and positive health measures and decreases in depressive relapse, depressive recurrence and psychological distress when mindfulness meditation is used. (12) Further, it had been effective in decreasing mood disturbance and stress symptoms for up to 6 months in males and females with a wide variety of cancer diagnoses, stages of illness, and educational backgrounds, across disparate ages. (13)

A similar study carried out in Sri Lanka, proves that practising mindful meditation for more than 8 weeks, can significantly ($p < 0.05$) reduce physical stress score (SOSI) and depression (Beck's depression score) among cancer outpatients (14).

Development of effective communication skills

"Development of communication skills should start from personal conviction and effort," Maria Die Trill wrote in her article about cross-cultural differences. "Our patients are our best teachers, and sometimes what we learn from them is more than the help we can give them. It is our responsibility to take advantage of our professional experience to improve the overall medical support they deserve." [6]

Communication problems occur in Sri Lanka for several reasons including: increased numbers of patients attending oncology clinics, lack of time among health care workers, and lack of knowledge among patients regarding their illness. In the context



of cross-cultural effects, health care workers have to address individual patients' physical, psychological and social needs, in the face of caring for increasing patient numbers.

Provision of social support

The majority of patients with a cancer diagnosis need significant social, psychological and financial support as many lack the personal resources to cope with the illness.⁽¹⁵⁾ Patients from poor socio economic backgrounds, in particular, benefit from input from supporting agencies.

Discussion

Cultural competence in cancer palliative care requires the acquisition of specific knowledge, clinical skills, and attitudes that facilitate effective cross-cultural negotiation in the clinical setting, thus, leading to improved management 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. ⁽¹⁶⁾

In Sri Lanka, the cross- cultural ethical issues related to patients with a diagnosis of cancer undergoing palliative care include, awareness of one's own cultural identity, gaining knowledge on different cultural issues, verbal and non-verbal communication skills, respect for patients' autonomy, involvement of the family and the relatives, addressing moral and spiritual background, development of effective communication skills and provision of social support.

Health professionals being aware of their own cultural backgrounds and being receptive to cross-cultural patient factors will enhance the health provider-patient relationship, facilitating the provision of palliative care. Respecting to patients' beliefs and wishes, moral and spiritual values will strengthen patients' coping skills and help adjusting to deteriorating clinical status. Gaining family and social support for patient will help lessening effects of functional impairment due to cancer progression and prevent unbearable changes in social roles.

Therefore, cross -cultural issues should be given priority in the management of cancer patients in Sri Lanka to help maintain high standards of ethics and better quality in palliative care. Culturally competent Health care workers safeguard patient rights whilst also enabling provision of optimal care.

Cultural competence always presupposes oncology care takers' awareness of their own cultural beliefs and values. To be able to communicate with cancer patients in culturally sensitive ways, health care providers require knowledge of the concept of culture in all its complexity. The risks of racism, classism, sexism, ageism, and stereotyping must be minimised in competent clinical practice. ⁽¹⁶⁾

Therefore health providers 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.

As a step to further improvement of ethical standards of cancer palliative care in future in Sri Lanka, we suggest that medical schools and oncology training encompasses communication skills and cultural competence, while fostering in all students and doctors those attitudes of humility, empathy, curiosity, respect, sensitivity, and awareness that are needed to deliver effective and culturally sensitive cancer care.

Further, as the current knowledge and information is limited on cross cultural issues of cancer palliative care in Sri Lanka, the authors would like to highlight the value of ongoing studies for optimising patient management.

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