

# Cultural competence and Cross Cultural Care at the End of Life

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## **MODULE OBJECTIVES:**

1. Identify ways in which an individual's culture, ethnicity, and/or religion may influence his or her experience of terminal illness.
2. Identify beliefs and practices related to dying and death that are held by some individuals within various ethnic, cultural and religious groups.
3. Identify strategies and resources for providing culturally competent care to terminally ill individuals and their families.

## **Suggested Readings**

Cloutier, K., Customs and Traditions-in times of death and bereavement (2<sup>nd</sup> Ed) McInnis and Holloway Funeral Homes.

Chardran, V., A Palliative Program in the East Indian Hindu Community. Palliative care Association of Alberta. Newsletter. Oct/Nov. 1998.

Feser, L., Bon Bernard, C., Enhancing Cultural Competence in Palliative Care - Perspective of a Chinese Community in Calgary. Journal of Palliative Care (2003).

Nueberger, J., Introduction - Cultural issues in Palliative Care. Oxford Textbook of Palliative Medicine. 1998. Oxford University Press, Edited by Derek Doyle, Geoffrey W.C. Hanks and Neil MacDonald. p. 779- 785.

Ying, Wang., Paice, Judith A., People's Republic of China. Textbook of Palliative Nursing. 2001. Oxford University Press, Edited by Ferrell, B and Coyle, N. P. 727-731.

Lapine, A., Wang-Cheng R., Goldstein, M., Nooney, A., Lamb, G., and Derse, A. R., When Cultures Clash: Physician, Patient, and Family Wishes in Truth Disclosure for Dying Patients. Journal of Palliative Medicine. 4 (4) 2001: 475-480.

## **Terminology**

**Culture-** Patterns of learned behaviours and values shared among members of a group that are transmitted over time. Included: ethnicity, language, religious and spiritual beliefs, gender, socio-economic class, age, sexual orientation, geographical origin, group history, education and upbringing and life experiences.

**Diversity-** a broad term reflecting unique characteristics of members of society or race, including colour, ethnicity, ancestry, place of origin age, gender, sexual orientation and physical and mental abilities and qualities. May also include socioeconomic status or class, education, language, marital status and religious beliefs.

**Ethnocultural group-** A group of people who share common distinctive ethnicity, heritage culture, language, social patterns and sense of belonging.<sup>12</sup>

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<sup>1</sup> Bon Bernard, C., Culturally Competent Professional Practice (2001) PLC Multicultural Awareness Program.

<sup>2</sup> Visions: B.C.'s Mental Health Journal, Winter 2000.

## **Introduction**

Within the Canadian healthcare system, ensuring the equitable distribution of limited resources that can be accessed across the life span is increasingly more complex. This fundamental principle of access to services is identified by the Canadian Palliative Care Association (CPCA) as the second of a number of principles of palliative care.<sup>3</sup> The CPCA has indicated that patients and families should have timely access to the information and the services provided by palliative care. Services and information should be provided when patients and families need and are prepared to accept palliative care. In addition, services and information should be provided in a language that the patient and family can understand. The concept of access implies not only linguistic and cultural access but emotional preparedness as well. Beliefs about death, dying and emotional responses to terminal illness are influenced by culture. When, in the course of illness, individuals are prepared to accept palliative services may also be influenced by culture.

As societal mobility and immigration increase so does the potential for increased cultural and linguistic diversity. Palliative care clinicians are increasingly likely to care for patients with language, experiences, beliefs and culture different than their own. While palliative clinicians and providers can not be expected to have extensive knowledge of all immigrant groups and all diverse populations, it is prudent to have some idea of the values and beliefs of the groups that clinicians will come into contact with on a regular basis.

Having sufficient information to be able to identify trends or common beliefs and values within a population is useful. Palliative care providers however, must use cultural information cautiously. To make assumptions about specific individuals based on their religious, ethnic or cultural community alone would be stereotyping and may not accurately reflect the values of an individual or family. A broad range of beliefs might exist within a cultural group. It is important that any cultural knowledge be reviewed and validated with individual and family to determine its relevance for them.

The goal of providing culturally competent care to diverse cultural groups at the end of life is to be aware that a variety of beliefs, values, traditions, and practices exist and to honor these when providing care. Association with a particular cultural, ethnic or religious group may influence:

- **Expression and meaning of pain and suffering**
- **Attitude towards disclosure and awareness (of illness)**
- **Beliefs about the cause and meaning of illness**
- **Choice of healer and treatment regimen**
- **Attitude toward death and dying**
- **Beliefs about the afterlife, the value of human life, and the body**
- **Expressions of loss and grief**
- **Death rituals including preparation for burial, funeral practices or memorial services, customs for disposing of the body and mourning rites.”**

(From the Alberta Palliative Care Resource, 1999)

The aforementioned are discussed within this module in terms of end of life care. In addition, ethical issues faced in cross-cultural care, strategies and resources are so discussed.

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<sup>3</sup> Canadian Palliative Care Association. (1995). Palliative Care: Towards a Consensus in Standardized Principles of Practice. P. 16-17.

## **Cultural competence**

The need for cultural competence is an increasingly integral part of professional practice in health care. The literature on culture increasingly critiques phrases such as “cultural sensitivity” or “multi-culturalism” with recent literature moving to incorporating the notion of cross-cultural competence in health care. Cultural competence includes a set of values, behaviors, attitudes, knowledge and skills enabling providers to offer client care which is respectful and inclusive of diverse cultural backgrounds. Cross-cultural competence starts with an attitude and genuine interest on behalf of the practitioner in experiencing, conversing about and participating in ongoing learning opportunities about diverse cultures.

Cohen and Palos discuss the ‘emic’ and ‘etic’ perspectives of cultural competence. The emic perspective looks for an understanding of how experiences are defined by “natives” or the persons within the culture, having the experience of life within the group. The etic perspective is the “outsiders” or researcher perspective involving observing a culture without learning how those being studied view the experience of the culture or the experience. In the etic perspective, external criteria is used to examine or compare groups or cultures. It is likely that in palliative situations, caregivers bring a combination of these perspectives however, we should always strive to understand from the insider view of the patient and family.

The concept of cultural and linguistic competence extends beyond individuals to organizations and is defined as ‘A set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations.’<sup>4</sup>

Acknowledging the need for support of ethnic and cultural diversity within health organizations led the U.S.A. Dept. of Health and Human Services to set standards for cultural and linguistically appropriate Health Care Services.<sup>5</sup> These include promoting and supporting attitudes, behaviors, knowledge and skills necessary for staff to work in a culturally competent manner as well as ongoing education and training for staff. The standards also include the ability of patients or clients to access qualified interpreters and to ensure the bilingual proficiency of translators. The collection of data for racial and ethnic groups within a service area also a requirement to insure good outcomes by identifying needs within a population, what resources are available and what gaps in service exist.

Discussion of the nuances of some of the complex issues at the end of life depends upon excellent communication between patient, family and caregivers. Linguistic access to palliative services may mean being able to access culturally appropriate pain or symptom assessment tools to communicate about symptoms. It may mean being able to access translated pamphlets about regional palliative services and resources. It may mean being able to access interpretation services which do not breach patient confidentiality, as may be the case if family, friends or hospital staff are asked to act as interpreters.

Studies by McNamara (1997) which assessed the ability of palliative caregivers to deliver competent cross-cultural care found that language barriers, the availability and effective use of written translated materials and the appropriate use of interpreters were significant barriers. Conflicts between patients, families and palliative caregivers existed around beliefs and values about death, dying and bereavement. Conflicts about revealing diagnosis (truth telling) or how and with whom information is shared within families was also found to be significant.

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<sup>4</sup> Cohen, M. Z., Palos, G., Seminars in Oncology Nursing. Vol. 17, No.3,(August) 2001:pp. 156

<sup>5</sup> US Department of Health and Human Services: Assuring Culture Competence in Health Care: Recommendations for National Standards and an Outs-Focused Research Agenda

It is important to be aware of your limits and cultural competencies as a caregiver; to know how your own culture has influenced your beliefs and values prior to assessment of patients. The clinician should also be aware of basic rudiments the patient's culture including awareness of cultural taboos. If the patient's preferred language is not the same as the clinicians, an interpreter should be arranged for, particularly when issues or significant information is being shared. If possible, unless there are extreme circumstances (such as a pain crisis or advanced directives are not known in an imminently life threatening situation) the interpreter should not be a member of the family. A professional and experienced interpreter can act as a resource person about a particular language or community and can educate the health team. They can also assist in identifying the language proficiency and literacy level of the patient and or family (if they are to be included in care and decision-making) and act as an educator to patients and families about assessment tools, palliative resources and other vital information.

To begin identifying potential issues in cross-cultural care at the end of life and to improve communication, an assessment encompassing a holistic overview of the person and family is required. This information may assist the caregiver to understand the person within a familial, cultural and religious context. Questions should be incorporated into discussion as conversation rather than being presented as a list of assessment questions. Open ended questions that give the person permission to talk, environments which are as relaxed and as much physical comfort as is possible are all important to a therapeutic interaction.

The following might be included in an assessment:

- **Tell me about yourself.**
- **Are you married? Do you have any children?**
- **Do you have other family in the city or living with you?**
- **Do you have any brothers or sisters (extended family)? Where are they?**
- **Are there elderly family members still living and how are they doing?**
- **What are the languages spoken at home? Does everyone in the family have the same proficiency in the languages spoken? If not, who acts as interpreter?**
- **How long have you lived in the country? (may determine services that can be accessed)**
- **What circumstances brought you here? (may identify stressful situations or political persecution in refugee families)**
- **Are you a Canadian citizen? ( may identify services that can be accessed)**
- **Where else have you lived? (life experience and world view)**
- **What is the biggest difference you have found coming to Canadian society?**
- **Do you belong to a religious community? If so, what support do you receive from the community?**
- **Are there others whom you turn to for support?**
- **Who in the household is employed and what do they do?**
- **Is there sufficient income/financial support? Are their financial concerns?**

If there are significant pain or physical issues that need to be dealt with, extensive questioning may need to be delayed to another time or collateral information obtained from family members until an interview is possible. Professional interpreters are becoming increasingly available and caregivers should be aware of how to access these services.

Other topics, which may be of significance, follow as well as suggestions for assessments. Questions to be considered in delivering competent cross-cultural palliative care are included in the topic areas.

## Expression and meaning of pain and suffering

**How are we the same culturally when it comes to descriptions of pain? Do we have common points of reference?** McCaffery indicates that three terms—pain, hurt and ache— seem to be used similarly to describe pain intensity. “The term pain is usually used for the most intense pain, followed by hurt, with ache being the least pain”<sup>6</sup> Many palliative practitioners would tend to view these terms as descriptors of pain quality rather than indicators of pain intensity. However, studies (Gaston-Johnsson, Fagen, 1990) of Hispanics, American Indians, blacks and whites as well as Swedes (Gaston-Johnsson, 1984) and Dutch (Francke, Theeuwes, 1994) have found this to be a common set of terms. Thus McCaffery concludes “persons with diverse ethnic-cultural and educational backgrounds use similar words to describe pain intensity.”<sup>7</sup>

Some cultures would seem to differentiate between descriptors. The Chinese have many terms that describe pain and differentiate between the descriptors for pain, discomfort and pressure. For example if a person has what they consider ‘discomfort’ and are asked if they have ‘pain’ they may answer in the negative.<sup>8</sup> Knowing how individuals within a culture perceive pain and suffering can help caregivers understand pain behavior and requests for medication. Some studies have indicated that the more different the cultures of the caregiver and the patient are, the more unlikely it is that accurate pain assessment and subsequently pain management will be achieved.<sup>9</sup> Dalton reviewed factors that influenced a nurses’ perception of pain and found that while the educational level of nurses and the level of experience were not influential; cultural and ethnic background were.<sup>10</sup>

Caregivers who do not share a common language may not be able to assess patients as well as caregivers that share a common mother tongue. How people behave when they are in pain and how others react to them are affected by cultural factors. Therefore, clinicians should be aware of their own cultural backgrounds and the attitudes they bring to the care relationship, as there are implications for practice. Demonstrative behavioral expressions of pain behavior may result in over medication by caregivers that do not share similar norms of pain behavior and mask the need for social attention or acknowledgment of illness.<sup>11</sup> Cleeland found that some aspects of pain are more affected by a person’s ethnicity than others, in particular pain behaviors.<sup>12</sup>

Wright and Leahey indicate that while pain is a universal phenomenon, its expression and interpretation vary dramatically among ethnic groups.<sup>13</sup> Discussing research by Koopmen et al (1984) who “investigated pain in ambulatory patients of Italian and Irish ancestry, they found that Italian Americans reported pain much more frequently than did their Irish-American counterparts. They concluded that the Italian Americans used pain reports to emphasize the immediacy of their somatic problems or to dramatize their attitude toward the sick role. They suggested that the Italian and Irish subgroups both coped with illness by avoidance, the Italians focusing on somatic discomfort to legitimize being cared for and the Irish denying pain.” Within some Asian populations it may be more acceptable to somatize illness than admit to emotional suffering or depression for example.<sup>14</sup> This has

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<sup>6</sup> McCaffery, M., Pasero, C., Pain: Clinical Manual. 2<sup>nd</sup> edition. Mosby Inc., (1999) p. 98.

<sup>7</sup> McCaffery, M., et al. Ibid p.98.

<sup>8</sup> See, I., University of British Columbia Hospital, Palliative care Program. (Personal communication 12/02/2002)

<sup>9</sup> McCaffery et al. Op site. p. 99-100.

<sup>10</sup> Dalton, L.A., Nurses perceptions of their pain assessment skills, pain management practices and attitudes towards pain. Oncology Nursing Forum (1989) 19 (2) 225-231.

<sup>11</sup> Wright, L., Leahey, M., Families & Life Threatening Illness. Springhouse Corp., Springhouse, Pa. (1987) P. 62.

<sup>12</sup> Cleeland, C.S., Nakamura, Y., Mendoza, T.R., Edwards, K.R., Douglas, J., and Serlin, R.C., Dimensions of the impact of cancer pain in a four-country sample: New information from multidimensional scaling. Pain. 76 (1996) p. 267-273.

<sup>13</sup> Wright, L., Leahey, M., Families & Chronic Illness. Springhouse Corporation, Springhouse Pa. (1987) p. 89

<sup>14</sup> Pruegger V., Cross-cultural Communication strategies. Peter Lougheed Centre Multicultural Awareness Program (2000).

the potential to result in over medicating physical symptoms and perhaps result in inadequately addressing social and emotional issues.

Not exhibiting pain behavior may result in undermedicating of pain symptoms.<sup>15</sup> Patients may be reluctant to take medication and analgesics for a number of reasons. Some countries may have histories of opioid abuse and may avoid due to fears of addiction. Others may have religious influences, which may mandate that they meet God in a “pure” state (i.e. free of drugs and with a clear sensorium). Within some religious groups there may be a strong belief in life as sacred and a gift from a Devine creator. Medications and analgesics, which may be necessary to treat symptoms, may be greeted with moral difficulty if it is perceived that they might also shorten life. Indigenous people and those with genetic sensitivities to drug and alcohol usage may also choose to avoid some medications. Palliative caregivers should be aware that some patients might choose to deal stoically with pain. Suffering may be endured particularly if there is cultural support for it. Stoicism may be viewed as strength or endurance. Patients have the right to be as pain free as possible however; some may choose a certain amount of pain.

According to McCaffery<sup>16</sup>, while behavioral expressions of pain may differ considerably amongst cultures, pain ratings and the impact of pain on quality of life appears to be quite similar. In several studies (Cleeland 1984; Cleeland, Gonin, Hatfield; Serlin, Mendoza 1994, Nakamura et. al, 1995), ratings of more than 5 on a 0-10 numerical rating scale of pain intensity have been found to impact quality of life, affect and function, in particular activity, mood and sleep. It would appear that pain intensity rating scales might be an accurate way of assessing pain intensity, with a minimum of ethnic or cultural bias.

Some groups however may have difficulty understanding visual analogue scale (VAS) or numerical rating scales (NRS) to describe pain intensity. In a study of Chinese patients the vertical presentation of VAS was better understood than the horizontal presentation which may be because traditionally, the Chinese read vertically downward and left to right.<sup>17</sup> One might wonder, given this information, if there are implications for those countries and regions such as in the Middle East where often script is read right to left. If the client does not have an understanding of a visual analogue or numerical rating scale, or is not literate in the language being presented it may be appropriate to try other intensity rating scales such as the Wong-Baker FACES scale. Donna Wong, a nurse consultant and Morain Baker, a child life specialist working with pediatric burn patients originated the FACES scale in 1983. Since that time, work has been done with a number of groups including children as young as 3, cognitively impaired and those with limited language skills. Some studies have indicated that amongst the general public, half prefer Wong Baker over NRS or VAS.<sup>18</sup> A recent local survey of an elderly Chinese population found 90% preferred Wong Baker over VAS and NRS intensity rating scales<sup>19</sup>.

It should be remembered that comprehensive pain assessment must include other aspects of pain than just intensity. History, location, duration, quality, intensifiers (what makes that pain worse) and nuetrifiers (what makes the pain better) associated symptoms and a variety of social issues must be addressed. These can be facilitated by translated assessment tools, which may be given directly to patient and family or used as a guideline for interpreters. One cannot assume that a people is literate in their language of origin, therefor if translated assessment tools are not being understood well, an interpreter from the Diversity service or language bank may be an important to facilitate communication.

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<sup>15</sup> Wright, L., and Leahey, M., *Families & Life Threatening Illness*. 1987. P. 61

<sup>16</sup> McCaffery, M., Pasero C., *Pain: Clinical Manual 2ne Ed*. Mosby, Inc. (1999) p. 74.

<sup>17</sup> Aun, C., Lam, Y.M., Collett B: Evaluation of the use of visual analogue scales in Chinese patients, *Pain* 25: 215-221, 1986.

<sup>18</sup> Carey SJ, Turpin, C., Smith, J., et. al : Improving pain management in an acute care setting, *Orthop. Nurse* 16 (4) 29-36, 1997.

<sup>19</sup> Feser, L., Bon Bernard, C., *Enhancing Cultural Competence in Palliative Care: Perspectives of an Elderly Chinese Community in Calgary*. *Journal of Palliative Care*.19: 2 /2003; 133-139.

## **Beliefs about the cause and meaning of illness**

In Ayurvedic medicine, the ancient Indian medical system prevalent in South Asia, illnesses are the result of imbalance in the body humours or fluids, bile wind and phlegm and the purpose of treatment is to re-establish balance. Dietary imbalance, overheating the body or excess in activity or social excesses such as use of alcohol or immoral activity may explain other diseases. Demon possession or the “evil eye” may also be responsible.<sup>20</sup> In the West Indies the belief in spirits to cause harm is widespread and therefore treatment of illness often rests upon religious belief. Obeah is a system of belief and practice involving the manipulation of evil spirits. “When the cause of illness or misfortune is unknown as is mental illness, cancer, or oedema of the legs some people are inclined to think that an evil supernatural power is at work”.<sup>21</sup> Assessments of individuals from other cultures should include assessment of what the belief system around illness is. Arthur Kleinmann, a psychiatrist and medical anthropologist devised 8 questions that may shed light on the belief system of an individual/family.

### **Kleinmann’s Eight Questions:**

- 1. What do you think caused your problem?**
- 2. Why do you think it started when it did?**
- 3. What do you think this illness does to you?**
- 4. How severe is your sickness? Do you think it will last a long time, or will it be better soon, in your opinion?**
- 5. What are the chief problems your illness has caused you?**
- 6. What do you fear most about your sickness?**
- 7. What kind of treatment would you like to have?**
- 8. What are the most important results you would like to get from your treatment?**

Having this information can assist the practitioner in how to approach the subject of illness. In Chinese, for example, there is no word for palliative or hospice care and discussions using the words for death and dying can be taboo. It may be more acceptable to talk about “care focused on comfort as one approaches the end of life” or going to a “place of comfort for care towards the end of life”. In addition, linear models of palliative care may not be understood. Illness may be viewed as imbalance or disharmony. In the Chinese and Vietnamese, the cause of illness may be attributed to imbalance in ‘yin and yang’. Germs, fate and ‘bad luck’ are also believed to cause disease<sup>22</sup>. A cancer diagnosis may be seen as being more than a disease, in fact a “curse” and therefore, disclosure of diagnosis may be associated with shame.

Discussions of palliative care to very traditional Chinese individuals and families may be better accepted if the focus is on interactions which create bridges of understanding between cultures. Discussion may be better understood if the focus is aiming to recreate harmony rather than “cure.” Descriptions of the physical, psychosocial and spiritual realms of palliative care could be couched in terms of imbalance. For example, in the physical imbalance caused by disease, pain or other symptoms can occur. Palliative care’s role is to try to regain balance through comfort. Lack of symptoms can be synonymous in this culture with lack of disease therefore it should be explained that being symptom free does not mean that the person is ‘cured’. Discussions about psychosocial issues might be couched in terms of imbalance leading to anxiety or fear while disharmony in the social realm can lead to isolation or difficulty in relationships ‘at the end of life’. Disharmony in the spiritual realm may lead to questions about meaning and purpose. Palliative care, working together with the patient and family, would aim to address these imbalances to regain harmony in these areas and focus on the quality of life that remains.

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<sup>20</sup> Assanard S., Dias, M., Richardson, E., and Waxler-Morrison N., Cross Cultural Caring: A handbook for Health Professionals. Edited by Waxler-Morrison, N., Anderson, J., Richardson, E., UBC Press 1990, p. 158

<sup>21</sup> Glasgow, J.H., Adaskin E.J., The West Indians (1990) from Cross-Cultural Caring: A handbook for health professionals. Op cit p.232

<sup>22</sup> Lai, M.C., Ka-Ming K., Y., (1990) Cross Cultural Caring: A handbook for health professionals. (Edited by Waxler-Morrison N., Anderson, J., Richardson, E.) UBC Press, University of British Columbia



## **Choice of healer and treatment regimen**

**“How we communicate about health problems, the manner in which we present our symptoms, when and to whom we go for care, are all affected by cultural belief. Illness behavior is a normative experience governed by cultural rules: we learn ‘approved’ ways of being ill... and a doctor’s explanations and activities as those of their patients are culture specific.”<sup>23</sup>**

Palliative practitioners may find that they are working with the patient and family as well as traditional and non-traditional healers either directly or indirectly. In First Nation families it may be common that traditional Western Medicine is used in combination with herbal remedies or sweet grass ceremonies. Passes from hospital or hospice may be requested to see a Medicine Man or Woman for special healing rituals in life threatening illness. The nature of this ritual is sacred and may not be discussed with Western health caregivers. Failure to acknowledge this request or to treat alternative healers respectfully may result in impaired relationships between the palliative caregiver and the person, extended family or tribe. Those from the First Nations place a high value on respectful treatment of elders and non-traditional healers from the health care professionals caring for them.<sup>24</sup>

Traditional Chinese medicine may be the first line of treatment for the Chinese community. Western medicine is sometimes viewed as being “too strong” and therefore investigations and diagnosis may be delayed. Some opt for remedies to address heat and cold imbalances or herbal remedies and only seek Western physicians as a last resort. Pain assessments should include inquiries about the use of Tiger balm, herbal remedies and acupuncture. Assessment should also include herbal remedies taken for other reasons. According to the American cancer society, in the last five years Chinese herbal medicines have become the leading cause of hepatotoxicity. On the other hand, “there is some evidence from randomized clinical trials that some Chinese herbals may contribute to longer survival rates, reduction of side effects, and lower recurrence for some cancers, especially when combined with conventional treatment. Many of these studies, however, are published in Chinese, and some of them do not list the specific herbs that were tested. More controlled research is needed to determine the role of Chinese herbal medicine in cancer treatment and prevention.”<sup>25</sup>

Some ethnic groups will postpone medical help, seeking assistance first from advice from a divine power. The Irish will seek help from the clergy and church before pursuing traditional medical opinion.<sup>26</sup> Eastern European Jews on the other hand may seek help as soon as symptoms appear and may consult as many health professionals as necessary to get ‘satisfactory’ results.<sup>27</sup> To assess what other caregivers are involved in care and what treatment modalities are being used, a normalizing statement followed by these kinds of questions may be useful.

**We understand that many people use both traditional and non-traditional means of treating disease.**

- 1. What treatments are you using for your disease?**
- 2. What effect do these treatment have?**
- 3. What healers are you using?**

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<sup>23</sup> Kleinman A. et al. Culture, Illness and Care: Clinical Lessons from Anthropological and Cross-Cultural Research. Annual so Internal Medicine.88; 252, 1978.

<sup>24</sup> Many Grey Horses, D., First Nations Representative, Peter Lougheed Hospital, Calgary Health Region. . Personal Communication Jan 30, 2001.

<sup>25</sup> Chinese Herbal Medicine. American Cancer Society website. Accessed August 18, 2003. [www.cancer.org/docroot/ETO/content/ETO\\_5\\_3X\\_Chinese\\_Herbal\\_Medicine](http://www.cancer.org/docroot/ETO/content/ETO_5_3X_Chinese_Herbal_Medicine).

<sup>26</sup> McGoldrick, M., “Ethnicity and family Therapy: An overview” In Ethnicity and Family Therapy. Edited by McGoldrick M et al. New York Guilford Press. 1982.

<sup>27</sup> Herz, F., Rosen, E., Family Therapy in Jewish Americans. Ethnicity and Family Therapy. Edited by McGoldrick, M., et al New York: Guilford Press .1982.

## Attitudes toward death and dying

Societies are often classified as being death accepting, death denying or death defying. In some societies death is accepted as being a natural part of the life cycle. Western culture is thought to be death denying, in that we tend as a culture to value youth and wellness. Palliative care within western society is a relatively new development. Other cultures are thought to be death defying in that death is not really acknowledged. The ancient Egyptians for example packed food and goods into the pyramids to be used in the next life.

How one approaches death and dying may depend on many factors some cultural and others perhaps not. From a cultural perspective, a death from natural causes may be treated differently than accidental death or a violent death or a miscarriage. It may be dependent upon whether the person dying is male or female and the age of the person may also influence attitude. For example, in some cultures loss of a very young child might be of lesser significance than the loss of a venerated elder.<sup>28</sup> In other cultures, children may be more valued than the elderly who may be thought to have reached the natural end of life. Males may more valued than females. Some cultures determine the person who has the right or obligation to grieve. The 'principle mourner' may not be the widow or widower and the person grieving the loudest may not even be related to the deceased.

The demonstrative expression of grief, in cultures where it is common for extreme behaviors, may be met with shock or unsettled reactions from caregivers. In the Dominican Republic "it is not unusual for a family member to become 'possessed' or to have an 'attack' (*ataque*) resembling an epileptic seizure while thinking about the deceased person. Garrison (1977) refers to a similar *ataque* as the "Puerto Rican Syndrome" where this behavior is culturally approved and sometimes even prescribed under certain stressful circumstances."<sup>29</sup> In some South Asian communities loud wailing and head banging are expressions of grief. Lamentation and tearing of clothing may be seen in Jewish communities.

## Ethics

### **Are ethics culturally determined?**

Surbone<sup>30</sup> has identified how bioethics originated in countries that reflect Anglo value systems. A move to consumerism in health care and legal reforms in the area of informed consent in the 1970's in the United States lead to valuing the principle of autonomy in Western Bioethics. Prior to this time disclosure of diagnosis and prognosis was less frequent than it now is in Western society. Canada, being highly influenced by the United States and the legal traditions of English Common law and Civil law, has followed suite. Other countries however placed a higher value on the role of community and family in influencing self-determination, which has resulted in disparities in 'truth telling', practices between Western and non-Western countries. This disparity is an ongoing source of debate in bioethics.

### Attitude towards disclosure and awareness

The desire to tell or know the truth about illness or death is clearly a Western cultural value. "Truth telling" about diagnosis and prognosis at the end of life or, perhaps more accurately, how, when and with whom information is shared, can be a sensitive cultural issue in some populations. Families may

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<sup>28</sup> Rosenblatt, P.C., Grief in Small Scale societies in *Death and Bereavement Across Cultures*. Edited by Murray Parkes C., Laungani P., and Young, B., Routledge 1998,p. 37-39.

<sup>29</sup> Paulino A. M., *Death ,Dying and Religion among Dominican Immigrants*

<sup>30</sup> Surbone, A., *The Quandary of Cultural Diversity*. *Journal of Palliative Care* 19:1/203; 7-8.

prefer that health professional do not reveal prognosis to the dying person.<sup>31,32</sup> For example, the topic of death and dying is often avoided in the Chinese culture. Tong<sup>33</sup> found distinctive differences that impacted the care of Chinese palliative patients particularly in the area of disclosure of information was thought to be hurtful or harmful. The Eastern belief of silence surrounding the discussion of dying and impending death is in contrast to the Western orientation advocating openness, full disclosure and informed consent. This Eastern belief would seem to extend to Japanese populations as well. Recent studies by Mizuno et al<sup>34</sup> found that truth telling in Japanese families occurred in only 15.1% of patients diagnosed with lung cancer.

Studies by Fainsinger et al<sup>35</sup> found cultural differences in the perceived value of disclosure between Spanish and Canadian populations. Canadian populations in almost all cases wanted to maintain clear cognition and wanted full disclosure of information. The group in Madrid wanted to maintain clear cognition varied between 47% and 67%. Only 2 of 20 families in the Madrid study wanted full disclosure.

When approaching an individual from another culture it is appropriate to assess the willingness of that individual to hear a diagnosis. Even within the norms of Western ethics individuals have the same right 'not to know' as they have 'to know'. Lapine<sup>36</sup> suggested a number of questions that one might ask to ascertain if the patient has a desire for disclosure of information.

These questions included:

- 1. What do you want to know about your condition?**
- 2. Whom should we talk to about your treatments and potential outcomes?**
- 3. Whom do you want to know about your condition?**
- 4. Whom do you want to make health care decisions for you?**

It is important that these questions be done as part of assessment, in advance of situations that might impair ability to make competent decisions and free from duress. Also it is prudent to revisit these questions periodically, to see if they still reflect the wishes of the patient. Finally, it is important that assessments of palliative practitioners avoid stereotyping. While research and studies may be very helpful in identifying trends within populations and may in fact assist caregivers in assessment, it is important to test these assumptions to see if they hold with a particular individual or family.

#### Palliative sedation

Within palliative care the goal of managing pain and other symptoms is frequently very effective and patients are often able to maintain cognition til the end of life. There may be a few occasions when symptoms may be found to be resistant to medical management that may necessitate palliative sedation for intractable symptoms. Palliative or terminal sedation is approached very cautiously by palliative practitioners and performed only under extreme conditions and only after diligently exploring options. Within some cultures sedation or impaired cognition of any kind is to be avoided, sometimes at the cost of good symptom management.

Muslims may refuse analgesics and other sedatives at the end of life in order to meet Allah in a 'pure' state. As with any religion, there are many sects of Islam and degrees of orthodoxy within the

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<sup>31</sup> Lapine, A., Wang-Cheng, R., Goldstein, M.G., Nooney, N., Lamb, G., and Derse A.R. When Cultures Clash: Physician, Patient and Family Wishes in Truth Disclosure for Dying Patients, *Journal of Palliative Medicine*. 2001; 4 (4): 475-477.

<sup>32</sup> Kerr, D., Lin Z.G.H. Terminal Care in China. *American Journal of Hospice and Palliative care*, 1993; 10(4): 18-27.

<sup>33</sup> Tong, K., Spicer, B.J. The Chinese palliative patient and family in North America: A cultural perspective. *Journal of Palliative Care*. Vol.10 (1), 1994, p. 26-28.

<sup>34</sup> Mizuno, M, Onishi, C., and Oishi, F., Truth disclosures of cancer diagnosis and its influence on bereaved Japanese families. *Cancer Nursing* 2002 Oct; 25 (5): 396 –403.

<sup>35</sup> Fainsinger, R.L., Nunez-Olarte, J.M., Demoissac, D.M., The Cultural Differences in Perceived Value of Disclosure and Cognition: Spain and Canada. *Journal of Palliative Care* 19:1/2003; 43-48.

<sup>36</sup> Lapine *Journal of Palliative Medicine* 2001

religion. However in the more traditional Muslim, “acceptance of terminal illness, and the desire to use it as a time of surrendering it to the will of Allah, means that the Muslim patient will often want less in the way of pain relief and more in the way of opportunity for prayer and contemplation. This is not to suggest that Muslims will reject pain relief-there is a strong anti-pain tradition within the religion-but Muslims will often accept less treatment for pain and its associated discomforts in order to keep awake”<sup>37</sup> and mentally alert.

Other cultures may request palliative sedation when it may seem that be not warranted for symptom management. “The traditional way of dying- the so-called “Spanish death” –continues to be influential, in particular manifesting in requests to sedate patients for existential distress at the end of life. The last 48 hours of life are still he time of the *Agonia*. The *Agonia* has been defined, since the 15th century, as ‘the space of time that takes place between the clouding of the senses and the departure of the soul from the body.’ Therefore a certain ‘clouding’ of cognition has, over the course of several centuries become the expected standard.”<sup>38</sup>

### Resuscitation

Palliative care, as a philosophy of care, opts for quality of life in some instances over prolongation of life, particularly in instances where treatment is thought to be medically futile. Some cultural groups may chose to prolong life despite medical assessment of futility. In addition, some religious and cultural groups may view life as ‘gift from God’ and sacred and will go to great lengths to preserve life even when quality of life is poor and prognosis is dismal.

This could hold true for the very orthodox Jew for example. “Large numbers of Jews everywhere regard themselves as Jewish by peoplehood rather than by religion.... In addition, the life affirming strand in Judaism is very strong, even amongst those who are disaffected from the religion itself, and therefore a fight against death, a desire to survive no matter what and am unwillingness on the part of many Jewish doctors to admit to their patients that they are dying are all common features of coping with terminal illness in the Jewish community.... The strength of feeling for life in Judaism is so great that even to lose a few minutes of it is thought to be a terrible thing: indeed, all laws expect three, the prohibition against murder, idolatry and incest, may be broken to save a human life even for a few minutes (Talmud Yoma 85a).”<sup>39</sup> The implications for advance directives and resuscitation at the end of life are obvious.

### Feeding and hydration

Many cultures have dietary restrictions; Hindus are often vegetarian, Jewish depending on orthodoxy may need to be Kosher, Muslims usually will not eat pork and Hindus will not eat beef. Sikhs have traditions of no pork or no beef. Also fasting is common for many groups such as Muslims during the month of Ramadan and other religious holy days.

Within some groups there is a very strong feeling about the discontinuation of feeding and/or hydration and/or nutrition. Even within palliative care there has been changing attitudes about these topics. Hydration did not receive much attention in palliative literature until the mid 1990’s. Bruera et al (1995) found that hydration in the hyperactive confusional state was reported to relieve delirium in some dying patients. It was suggested that improved renal function and promotion of the excretion of drug metabolites was facilitates through hydration. Authors like Burge began examining the issue from sociocultural and legal perspectives. “Almost all cultures

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<sup>37</sup> Neuberger, J., Cultural issues in palliative care (Introduction) in Oxford Textbook of Palliative Medicine. (2<sup>nd</sup> Ed) edited by Doyle. D., Hanks, G.W., MacDonald, N., Oxford Medical Publications Oxford University Press (1998) p.779.

<sup>38</sup> Fainsinger opsit

<sup>39</sup> Nueberger, J., Op sit p.780

see providing food and drink as the most basic act of caring...If this is not done families often feel as though they have cared about and for their loved one inadequately.”<sup>40</sup> Anecdotal experience from my own clinical work would support that this would hold true in the Italian and Chinese communities for example. In a hydration algorithm that partially influenced the Calgary health region’s version) Burge advocated that sociocultural issues are taken into consideration, issues and goals of care explored and caring redirected.

In the South Asian populations however, periodic fasting is common especially, towards the end of life, particularly in elderly women and widows. The practice of refusing food when the individual is felt to be near death is often independent of medical advice or opinion. The *atman* (soul) no longer requires food or fluid and it is believed that it is not good to desire food or water as death approaches<sup>41</sup>. This practice may influence palliative administration of drugs and fluids as it may lead to dehydration, impaired renal function and accumulation of drug metabolites.

**If ethics are culturally dependent, how do we then approach issues of ethics in situations where the values and ethics we hold may not be similar to the cultures we come into contact with?** Do we simply dismiss the ethical and religious concerns of others; do we hold that our ethics and beliefs are somehow of a higher order? Clearly not, these are complex issues and questions. It is also clear that as health caregivers we cannot abandon the professional ethics and or disregard the laws which governs us.

### **Resources available when conflicts arise in Cross-cultural care**

Open non-judgmental discussion and good communication skills can often go a long way to reaching compromise in situations where there are differing opinions on ethical issues. Respect for the opinions of others and listening to concerns can result in a better understanding, which may lead to solutions. In some instances staff, who are from the same community, may be able to help articulate issues. Professional interpreters can also act as references for staff and facilitate communication. There may be situations however, that we need to consult the expertise of ethics committees, diversity services, professional bodies and perhaps even legal opinions to assist us in bridging communication, reach understanding and provide potential solutions.

### **Diversity Services**

Diversity is a broad term reflecting unique characteristics of members of ethnic or cultural groups as well as place of origin, age, gender, sexual orientation and physical and mental abilities and a variety of other qualities. Within the Calgary Health Region, regional and portfolio specific Diversity committees and staff, as well as First Nation’s representatives, are available to assist staff in providing culturally competent care. Language lines are available, as are professional interpreters to assist with communication and education. Palliative consultation teams and designated palliative areas have translations of a number of pain assessment tools including the Calgary Interagency Pain Assessment tool (CIPAT) and the Edmonton Pain Assessment Tool (ESAS). Each designated palliative team and areas should also have a version of the Regional Palliative and Hospice brochure available in number of languages.

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<sup>40</sup> Burge, F.I., Dehydration and provision of fluids in palliative care: What is the evidence. *Can Fam Physician*. 1996; 42:2383-2388.

<sup>41</sup> Justice, C., The “Natural” death While not eating: A type of palliative care in Banaras, India. *Journal of Palliative Care*. 11 (1) 1995; 38-42.

Ethics committees –are available regionally to assist caregivers in articulating issues and identifying solutions for ethical issues. Provincial ethics networks are also available on the Internet for consultation. The Provincial Health ethics network can be accessed online at [www.phen.ab.ca](http://www.phen.ab.ca) or the Dosseter Centre at [bioethic@gpu.sru.ualberta.ca](mailto:bioethic@gpu.sru.ualberta.ca).

Professional Regulatory bodies-can assist the professional in identifying standards of practice for that discipline and often practice consultants are available for case specific problem solving. The Canadian Nurses Association for example, has nurse lawyers available for consultation.

### **Beliefs about the afterlife and Death rituals**

Please see the Customs and Traditions; in times of Death and Bereavement pamphlet by Kathy Cloutier included in your reading package.

### **Conclusion**

According to Masi, “Canada is and has always been a country of immigration. Since Confederation, at least one out of six Canadians have identified an ethnic origin other than British or French.”<sup>42</sup> That said, it is important to remember that not all migrants are from minority ethnic groups and not all ethnic minorities will be migrants. We are an increasingly mobile society and as caregivers we must be aware that a great deal of diversity exists within our communities and that the composition of the communities we serve will be continually shifting. In addition, we can also expect increasingly diverse families as intermarriage between cultural groups increases and as inter-generational differences within in families emerge with varying levels of acculturation within families.

The tradition of palliative care in Canada has been one in which respect for diversity and respect for two founding cultures is embedded in our beginnings. The term ‘palliative care’ was coined by Dr. Balfour Mount who recognized the cultural difference that existed between French and English historical perspectives of ‘hospice.’ He was able to preserving the best of the English philosophy of modern hospice and yet giving it a name that was palatable to European sensibilities (and the stigma around the concepts of the medieval hospice as a poor house). The term palliative meant ‘to cloak’ and in the medical sense, “to treat symptomatically”.

To be aware of cultural diversity is being aware of how we are different but is also about how we are the same. We share common needs for respect, being valued and finding meaning at the end of our lives. The challenge is to find our common ground, to be aware of our differences, to honor them and to create environments in which diversity is welcomed and valued.

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<sup>42</sup> Masi, R., Best Practices: Practical Issues and Approaches for Cross-cultural Care. Handout Calgary 2001.