

Culture, Cancer, and the Family

Dr. Gary Mumaugh – Bethel University

Across the world, the experience of cancer is a family affair. The entire family are affected by the cancer diagnosis, as they attempt to deal with the day-to-day stresses of cancer treatment and the potential loss of a family member.



As the world becomes more multicultural, a better understanding about the various cultural variations in families to cancer is needed for anyone who will treat or help these various families and cultures.

Culture and Ethnicity

- Although there is no “gold standard” of the definition of culture, most agree on what makes up “culture”.
 - Culture includes subjective elements
 - Values, attitudes, norms, roles, and beliefs
 - Culture includes objective elements
 - Buildings, roads, infrastructure, etc.
 - These elements are transmitted from generation to generation through language, social institutions, faith centers, and the family.
- Many countries include several subcultures – Examples in the USA
 - Anglo culture primarily from Western European roots
 - African-American
 - Hispanic
 - Asian
 - North vs. South, Rural vs. Metropolitan, East Coast vs. West Coast, etc.
- Most of the research investigating attitudes, behaviors, and health outcomes has relied on ethnicity to define group membership.
- Ethnicity is most frequently defined by blood, i.e., the ethnicity of parents, grandparents and previous generations.
- However, those with a mixed ethnic background, may identify their ancestry to varying degrees.
- “Ethnic Identification” is the racial, ethnic, or cultural label an individual chooses for him/herself. This may be a better indicator of the cultural values and outcomes.
- Even in uniraical regions and countries (e.g. Japan), where virtually all residents report the same ethnic identification, there is still differences in personal preferences and individual family ‘cultures’.



What are culturally linked predictions of a family's experience with cancer?

• International variation in cancer incidence rates

- Although cancer is found in virtually every area of the world, there is a marked geographic difference in incidence rates.
 - Japan reports low rates for most cancers, but they have the highest incidence of stomach cancer in the world.
 - Breast cancer is common in North America and Europe, but rare in Asia.
 - Liver cancer is prevalent in China and Europe, but rare in North America and Northern Europe.
- Cancer incidence rates differences may be explained by a lower life expectancy, meaning that people die before age 65, when the likelihood of a majority of cancers are diagnosed.
- Genetics may also be a factor and behaviors (diet and tobacco) may be an issue.
- Screening recommendations vary greatly from country to country.
 - In many countries, there are few resources devoted to early cancer detection, and as a consequence cancers are diagnosed late.
 - As much as 80-90% of cancer patients in developing countries will continue to be diagnosed with far-advanced incurable cancer, if they are diagnosed at all.
- Cancer tends to be more prevalent in developed “wealthy” countries than developing countries.

• International variations in cancer mortality rates

- Because cancer is more common in developed countries, the mortality rates tend to also be higher.
- However, the 5-year survival rates are much higher in developed countries.
 - 84% of women in USA with breast cancer live more than 5 years after diagnosis, compared to 49% in India.
 - 44% of Australians diagnosed with leukemia live more than 5 years after diagnosis, compared to 10% in China.
- Mortality rates are affected by the stage of diagnosis and the availability of treatment.
- The high end expensive cancer treatments available in developed countries are simply not an option in developing countries.
- In countries where cancer is inevitably linked to pain and death, patient and family anxiety and expectations will suffer accordingly.



- **International variations in family roles in health care**

- The expectations for family participation in cancer care are also culturally conditioned.
- Traditional medicine is often the mainstay of cancer care in western countries.
- Complimentary and alternative use in the USA vary from 7% to 64%, with an average of 30%. These rates are over 50% usage in Europe.
- Many cultures have a strong tradition of indigenous medicine such as herbs, native plants and acupuncture.
- Many cultures have a belief that cancer (an other illness) results from imbalance or disharmony with spiritual harmony and nature.
- Many cultures include interpersonal approaches to restoring spiritual harmony within the family.

- **Migration and acculturation**

- In general, cancer rates of migrants tend to be consistent with the country they came from. But in succeeding generations, the cancer rates tend to take on the rates of the population they migrated to.
- Acculturation explains cancer rates in immigrants and host populations.
 - Acculturation refers to the process of an individual becoming fluent in the beliefs, behaviors and values of the host culture.



- **Historical factors**

- Different cultural groups have distinct histories that must be considered in a patient's reactions to cancer.
 - It is common for cancer patients to identify family members to be involved in treatment discussions. But in patients that have fled oppressive political regimes, identifying a family member led to imprisonment.
 - Holocaust survivors with cancer have higher levels of stress and anxiety. When they see shaved and bald heads in the cancer ward, it can trigger flashbacks to the Holocaust.



What are culturally linked mediators of a family's experience with cancer?

- Attitudes toward autonomy
 - In Anglo cultures, the rights of the patient and emphasis on individual independence are of major importance.
 - In Asian cultures, the emphasis is on interdependence or 'connectedness' are more important.
 - Anglos place more emphasis on individual achievement, and Asians are more likely to value group achievement.
 - Doing things that make you 'stand out' are actively avoided by some cultures.
 - Cancer may have it's greatest impact in Anglo culture
- Desired medical communication
 - Anglo patients and families value and openness and full disclosure of information regarding the diagnosis and treatment options.
 - In many Asian and Hispanic cultures believe in protecting the patient by NOT informing the patient and informing the family.
- Different explanatory models for cancers
 - In Anglo culture, a premium is placed on the scientific explanation of the disease and the latest and best technologies and treatments.
 - Asian cultures place more emphasis on the connection of the body and the mind. Treatment emphasizes restoration of balance of the body and mind.
 - Meditation, herbs, prayer, tai chi, chi gong, yoga, etc.
- Family structure and roles
 - Traditionally, the nuclear family of parents and children has been where most of the family interaction studies have been conducted.
 - The definition of 'family' in American culture has dramatically changed with blended families, single parent families, gay and lesbian couples. Even though the definition of the 'American family' has changed, the two generation model still remains pre-eminent.
 - In other cultures, the definition of family involves multiple generations and extended family.

Implications for research and clinical practice

- Need for additional attention to family issues
 - How do families from different cultures cope with cancer?
 - Clinicians also need to consider carefully the cultural variations in family involvement in cancer care.
- Recognition that cultural considerations are important for all patients and families
 - It is important to recognize that *every* patient and family has a culture, not only individuals who belong to minority groups, people who live in other countries, or those who are immigrants.
 - These cultural factors are key, along with life experiences, socio-economic status, and personality differences that affect the meaning of cancer for individuals and families, as well as they cope with the disease.

Implications for research and clinical practice - continued

- For clinicians, there is a need to ask patients and families questions to provide an understanding of their unique family culture.
 - “Have you tried to understand why you got cancer?”
 - “What ideas do you have about this?”
 - “Are there other family members that should be here to talk about your treatment choices?”
 - “What concerns does your mother (father/spouse/son/daughter/etc.) have about your illness?”
- Personality traits, economic factors, individual and family experiences, past interactions with the health care system, length of current residence (migration), are among the factors that may effect a family’s reaction to cancer.
- Need to develop culturally appropriate support for cancer patients and their families
 - Clinicians need to provide support to patients and families that is comfortable, accepted, and therapeutic to the patient and family.

