Cultural diversity: family path through terminal illness

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In trying to comprehend a culture and its ways of structuring the world, much can be learned from addressing the manner in which intimate family relationships are ordered and family crises channeled toward care. A family’s experience with illness cannot be considered in isolation from the cultural milieu in which it occurs. Family adaptation to cancer diagnosis is a continuous motion between many critical strata – a fragile oscillation between hope and desperation. Processes for optimal functioning and the well-being of members are seen to vary over time, as challenges unfold and families evolve across the life cycle and illness trajectory. The manner in which the healthcare system and family manage illness and terminal care is a particularly helpful window into the cultural, religious and traditional values of every family in a particular society.

Key words: cultural diversity, cancer, family, terminal illness

culture: entangled perception

What psychological and cultural factors account for disparities in cancer outcomes? This paper explores the differences and similarities of terminal care for patients and considers a number of components that may influence this care based on family culture and systems of belief. There are extensive confounding variables that vary with each family group and trends that may provide healthcare practitioners with a better understanding of quandaries of death and dying in each social group [1].

Each society has its own divergent groups and their particular family culture. This private culture frames attitudes towards family roles, concepts of health and suffering, decisions about life, illness, death, beliefs and critical range of opinions. Systems of belief and cultural values are not static. They form an intrinsic tapestry of responses and implicit questions, suggesting that different types of encounters with the same phenomena under different social and familial conditions could elicit diverse sets of emotional behaviors [2].

It is necessary to understand how the culture of families from dissimilar backgrounds and systems of belief influences the perception of a prognosis and terminal-illness treatment decisions. The combination of traditional beliefs, language barriers and differing health perceptions can lead to a jumbled interpretation of cancer illness and its impact on family health, often resulting in divergent misconceptions.

Although barriers and facilitators to cancer care and treatment are multifactorial and have been studied across many levels of the socio-cultural framework, less studies have examined ways to provide and deliver effective interventions for culturally diverse populations. Sociocultural values are linked to cancer outcomes through beliefs, attitudes and behaviors related to the discourse of a feasible ‘truth’ and adherence to western medical models of autonomy and individual decisions. Deshpande et al. [3], in a critical review of literature, showed that non-consensus exists among studies on what is meant by the various terms employed to define sociocultural constructs of truth within illness and death.

A telephone survey conducted on behalf of the American Cancer Society identified several mistaken beliefs that were widely held, many by minorities. The idea that cancer surgery can spread disease throughout the body was identified as true by 41% of respondents and is most commonly held by African-Americans (odds ratio, 1.41). ‘Pain medications are not effective in reducing the amount of pain people have from cancer’, was noted as ‘true/don’t know’ by 32.2% of respondents and was substantially more common among Hispanic respondents (odds ratio, 163) [4].

family: apprenticeship to illness

Before encountering a major disease, a family may never have had to negotiate a situation that is perceived as threatening not only to the normal life of its members but also to the integrity of the family as a system of growth, development and stability. Above all, the relationship between patient and family culture must be part of any novel equation [5].

The family’s appraisal of the illness becomes an integral part of living and interacting together – of invoking a family legacy of sharing their intra-personal language, learned from one event to the next and from one member to the next. A clear understanding of what to ask and what actions to take, in essence, leads to a greater ability for each one to develop appropriate reactions and comprehensible rules regarding new roles within the family during times of highly stressful events such as cancer and death [6, 7].

Family adaptation to cancer diagnosis is a continuous motion between many critical strata – a fragile oscillation
between hope and desperation. Processes for optimal functioning and the well-being of members are seen to vary over time, as challenges unfold and families evolve across the life cycle and illness trajectory. Consequent stressors caused by the disease are not simply a short-term single event, but rather a complex set of changing conditions with a history of previous family events and an unpredictable future course [8]. The illness process often progresses so rapidly that family members are generally unaware of the intricate impact it has on shaping the psychological and emotional dynamic of this new reality within the family milieu. While no single model of family fits all, a family resilience perspective is grounded in a deep conviction in the potential for family recovery and growth out of adversity [9].

**Awareness of Family Culture**

In trying to comprehend a culture and its ways of structuring the world, much can be learned from addressing the manner in which intimate family relationships are ordered and the manner in which family crises are channeled toward care.

In a world characterized by significant cultural, economic and social complexities, there is a blurred sphere of incongruence and similarities that demarcate Western and Middle Eastern societies [10]. Both domains have different normative meanings and value systems in relation to family health and illness. They differ in their degree of emphasis upon individualist versus collectivist values, their championing of traditional versus ‘modernist’ appraisals of family care, and their degree of tolerance for diversity and pluralism [11].

A family’s experience with illness cannot be considered in isolation from the cultural milieu in which it occurs. Traditional family, community and religious values play a central role in determining people’s attitudes toward life and death. Notably, these values are not held uniformly even within the same country and lead to conflicts in determining appropriate policy and universal practice standards regarding illness and death. Rituals of differing subcultures within society remain a shared basis for channeling the illness and loss experience, and they provide a familiar approach to dealing with illness and death according to the norms of each familial system of traditions [12].

Israel encapsulates the multiplicity of cultural diversity; and as a living laboratory, it encounters illness, family–patient care and death. It has tried to reconcile a degree of autonomy, as characterized by the Western healthcare system, within the framework of a communitarian state – that is, within a society imbued with a high degree of collective consciousness, mutual concern, and family interdependence [13].

The State of Israel has a population of approximately 7,798,600 inhabitants as of September 2011 [14]: 75.3% (5,865,300) of them are Jewish, 20.5% (1,597,300) are Arabs, while the remaining 4.3% (318,200) are defined as ‘others’ (Table 1).

The attitudes of Orthodox Jewish and religious Muslim families towards members affected by cancer are described by the following two vignettes. A glimpse is provided into the cultural variations, religious orientations and differing socio-ethnic backgrounds – as they pertain to behavioral manifestations and narrative meanings – of these families as they experience illness and the trajectory of death.

**Muslim Families**

The Islamic religion is one of the fastest-growing religions worldwide. The total number of Muslims is 1.57 billion, nearly one-fourth of the world’s population (1 in 4 people). Although there is no accurate estimate of the number of Muslims in the United States, statistical reports revealed that there are 6–7 million (about 2% of the entire population) [15].

Islam literally means total submission to the will of Allah (The Almighty God) by conforming inwardly and outwardly to His law. Islam is based on five fundamental pillars, which are adhered to by Muslims who believe in a life after death where retribution will take place and people will be judged to Paradise or Hell based on their deeds. As a fundamental doctrine, people believe in predestination and attribute the occurrence of disease to the will of Allah [16, 17].

Belief in predestination and life after death helps Muslims to cope with the diagnosis of a terminal illness. Nevertheless, breaking bad news can be difficult and considerably impact the family. In the Islamic doctrine, no one but Allah knows the future. The underlying belief is that one should and can take comfort knowing that life and death are in accord with God’s will, that the soul returns to God, and that the community is supportive of the bereaved [18].

When patients are asked if they want to hear the truth when ‘breaking bad news’, most of them say yes – most are seeking reassurance and empathy rather than a detailed medical report [19]. In serious illness, all family members are closely connected, and silent communication is an important feature of family interactions [15]. The family decides whether and how much to tell the patient [20]. When patients are dying, their families might want them to face Mecca; and, therefore, the patient’s bed might need to be moved to achieve the desired position. During this phase, the family usually recites chapters from the Qur’an at the bedside [19].

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**Table 1. Demographics of Israel [14]**

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Distribution of the Jewish population by place of birth:

- 68.8% born in Israel
- 21.6% born in Europe and America
- 9.6% born in Asia and Africa

**Religions**

- Jews: 76%
- Muslim Arabs: 16%
- Others (mostly those not classified as affiliated with religion): 4%
- Syriac Christians: 2%
- Druze: 2%
Muslim culture: Amani’s story

‘Indeed, we belong to Allah and, indeed, to Him we will return.’ [The Qu’ran, 2:150]

Amani is a 24-year-old female, whose family are religious Muslim Arabs. She was diagnosed in 2009 with stage IV metastatic melanoma (lung and liver involvement in lymph nodes), hospitalized in October 2010 and died in December 2010. Amani was never left alone. Her room was filled with the female members of the family and the unspoken expectations of a miracle by God. She never complained and was liked by everyone. They considered her a colleague, an ideal patient. The word ‘cancer’ or ‘melanoma’ was never uttered. Two weeks before Amani’s death, her physical condition deteriorated rapidly with increased pain, but pain cleanses the body and the soul. She never spoke about her illness or her pain. She was silent. Two Muslim nurses, who befriended Amani and her family, encouraged some of the members to allow the medical team to talk to her – to ‘open up her soul’. The family’s refusal was unanimous. The medical team accepted the family’s request that Amani be released under their responsibility. She should be at home, in her own bed facing Mecca and praying, surrounded by all the family who loves her. Her eyes and soul closed little by little.

Silence and unanswered questions prevail.

Jewish families

According to a 2010 Israel Central Bureau of Statistics study [14], 8% of Israeli Jews define themselves as Orthodox; an additional 12% are ‘religious’ (also known as national-religious or religious Zionist); 13% are ‘religious-traditionalists’ (mostly adhering to Jewish law); 25% are ‘non-religious traditionalists’ (only partly respecting Jewish law), and 43% are ‘secular’. Among the seculars, 53% say they believe in God. Due to the higher birthrate of religious and traditionalists over seculars, the share of religious and traditionalists among the overall population is even higher.

the Orthodox family

Orthodox Jews are located at the strict end of the religious spectrum, living in tightly knit and highly integrated communities functioning in self-imposed cultural insularity. They believe that Jewish law is of divine origin and the observance of all biblical and rabbinic laws is obligatory. These laws comprise a sophisticated legal/religious framework guiding every aspect of life.

These families are reluctant to disclose the diagnosis of an end-stage or terminal illness because of the belief that this may lead to emotional trauma for the patient or premature death – or both. In fact, the word ‘cancer’ is often substituted for euphemisms such as ‘the disease’ or the ‘known disease’. The duty and obligation to save and preserve life and non-disclosure or partial disclosure are often linked. Inevitably, this hinders the oncology professional’s ability to communicate directly with the patient about illness matters, and decisions are made only by the family [21]. Judaism dictates that the sanctity of life, which is to be lived as fully as possible and valued above all else, and the imperative to preserve life supersede quality-of-life considerations. Compassion, hope and God are the basic pillars of family care for the dying patient [22].

Jewish culture: Hannah’s story

‘Guard me like the apple of the eye; shelter me in the shadow of Your wings ...’ [Psalms, 17:8]

Hannah, a 47-year-old Ultra-Orthodox Jewish mother of eight sons, was diagnosed with stage IV metastasized breast cancer, and hospitalized due to persistent nausea and neutropenia. She had been diagnosed 5 years prior, had a radical mastectomy and underwent all possible treatments. Although Hannah’s mother and aunt died of breast cancer, Hannah refused any genetic intervention and open dialogue with her family. She felt guilty and ashamed of her illness.

Hannah’s husband and mother-in-law were the only ones who knew about ‘the illness’ and who were allowed to stay with her at the hospital. The illness was explained as ‘women’s problems’. The medical and healthcare team’s efforts to have an open dialogue were rejected, because – in Hannah’s words – ‘you do not understand that God is blessing and testing me; and for more than 5 years, I have blessed His compassion and the strength rooted in my soul. If anyone finds out about my “illness”, my family will be shamed and stigmatized.’ Hannah died peacefully and surrounded by her innermost prayers.

Silence and unanswered questions prevail.

conclusion: path to bounded thoughts

‘There is no sun without shadow, and it is essential to know the night ...’ Thus, convinced of the wholly human origin of all that is human, a blind man eager to see who knows that the night has no end, he is still on the go. The ‘rock’ is still rolling [23, p. 91].

Thinking is learning all over again to see, directing one’s consciousness, making of every image a privileged place. There is no single idea explaining everything, but an infinite number of essences giving a meaning to an infinite number of experiences [23, p. 32–33].

Life means yearning and living with unceasing hope and faith through the questioning between the blurred amorphous night and joyful morning when things get under control again. Thus, life is neither ‘night’ nor ‘morning’ but a dialectic ‘hypothesis’ or ‘question’ between the antithetic ‘night’ and the synthetic ‘morning’.

The manner in which the healthcare system and family manage illness and terminal care is a particularly helpful window into the cultural, religious and traditional values of every family in a particular society. The healthcare system should be able to give adequate information, address concerns and respond to questions based on the family’s particular values and beliefs. In this way, a therapeutic relationship – based on trust and mutual respect – will have developed to facilitate effective communication and allow the family to openly explore treatment alternatives during the terminal phase of the illness [24].
There is a great deal to learn about every family’s culture and shared humanity when focused on losses, illness and death. As the management of grief and care are universal tasks confronting all families, an evidence-based understanding of diverse cultural approaches may provide the ability to stress our similarities without minimizing or overlooking our differences. Ultimately, we have an opportunity to see the nexus of human relationships that comes by learning about a family’s cultural and religious belief system regarding compassion, trust and a bounding respect for open and continual debate [25].

‘Thinking is learning all over again to see,’ argued Camus [23, p. 32]. Our thoughts therefore refer to the ability to see new compositions in old given elements, to envision how the sunny morning emerges from the dark evening without having to eliminate either of them – but simply to integrate both into one …

**Disclosure**

The author declares no conflict of interest.

**References**