

## EXPERIENCES IN MIDDLE EASTERN POPULATIONS

### Selected Issues in Palliative Care among East Jerusalem Arab Residents

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#### Abstract

**Understanding of cultural context is important when working with Palestinian patients, particularly in Israeli hospitals. Cultural competence includes individual assessment of communication needs and preferences. "This is God's will and one mustn't protest. A person who believes accepts all that God gives"(patient quote).**

**Keywords:** Cancer patients - cultural competence - Arab culture - cultural stereotyping

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#### Introduction

The Oncology Institute of Shaare Zedek Hospital is located in Jerusalem and treats patients from all sectors of the Israeli society. Twenty four percent of Israel's population is Arab; 82% of which is Muslim. The majority of Arab patients receiving care at Shaare Zedek are East Jerusalem residents. There are 250,000 East Jerusalem Arabs in the city. They are 'permanent residents,' rather than citizens, a status which entitles them to many social rights, such as social security and health care.

Although the general Arab population in Israel is very diverse and is composed of a variety of groups such as Muslims, Christians, Druze, as well as sub-groups belonging to different geographical locations, it does share some common cultural features. Successful treatment of an Arab cancer patient requires a culturally sensitive professional intervention which addresses the significance of his or her cultural identity. In view of this, the Hospital's administration appointed an Arab social worker to assist the treatment of Arab patients in a targeted manner.

The East Jerusalem Arab population is distinguished from other Arabs in Israel in their legal status and insofar as they are less integrated into Israeli society. Their school curriculum is Palestinian or Jordanian rather than Israeli, many cannot speak Hebrew, and they reside in separate Arab neighborhoods. This chapter reflects experience derived from working with this population. By understanding and attending to the culture, beliefs and perceptions of the East Jerusalem Arab community, the social worker can better understand the Arab cancer patient and his family's preferred coping paths. Such insight is the first step toward adequate clinical intervention. Culturally sensitive intervention is the key concept here. A caregiver working with the Arab population needs to possess cultural knowledge, sensitivity and the ability to mediate between the majority culture (which is often Western) and Arab culture. This chapter focuses on the following central topics: the structure of the Arab society,

cultural aspects shaping attitudes toward cancer (shame, secrecy), attitudes toward pain, women's status, dealing with death and preferences at life's end, patterns of caregiving and receiving.

#### The Structure of Arab Culture and Family

Haj-Yahia (1994) sees value-orientation as a structured, general framework which shapes a person's perception of time, nature, his place in nature, his desired and undesired qualities, and his inter-personal interactions. By being attuned to the value-orientation of the East Jerusalem Arab population, the social worker can better understand the coping mechanisms preferred by the Arab patient and his or her family, and can structure intervention accordingly.

Arab society is composed of the following central units; the hamula (a large kin network), the extended family and the nuclear family. The society is stable and strong emotional, social and economic ties exist between its members. Men hold the primary authority within each of these units. The father is the head of the family and has legitimate authority to make decisions regarding all aspects of family members' lives. The father is subordinate to the male head of the extended family, who is in turn subordinate to the head of the hamula. The status of women in the Arab family is usually lower than that of men. "The Arab woman is expected to be dependent on her husband, to submit to his will and needs and to be a source of support for him and for his family" (Haj-Yahia, 1994).

While modern, Western values and behavioral codes are widespread among the Jewish Israeli majority, the Arab Israeli population in general, and East Jerusalem Arabs in particular, still adhere to traditional customs and norms governing family life, gender roles, childrearing, and everyday conduct. The expression of conflict, whether internal or external, and the expression of negative feelings are not well accepted in the Arab culture.

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The anxious self-absorption that often accompanies a depressed mood is viewed negatively as "thinking too much," which is in turn viewed as a narcissistic preoccupation. Physical symptoms, however, are accepted as legitimate and morally acceptable expressions of pain (Al-Krenawi & Graham, 2000).

## Attitudes Toward Cancer and Toward Expressions of Emotional Pain

Among the East Jerusalem Arab population, cancer is accompanied by a sense of shame and fear of genetic transmittance. Secrecy prevails as knowledge of the patient's sickness among the wider society might harm family members' marriage prospects. Keeping the secret is related to society's expectation of the individual to remain calm, suffer quietly, not show signs of weakness and protect the family's interests. Concealment makes it difficult for patients to seek and receive external help, especially through participation in support groups.

Many Muslim families believe that those who suffer more will receive a greater reward in the afterlife. Protesting one's fate is not accepted since fate is considered to be God's will. Patients are expected to accept their disease. Interventions which encourage the expression of emotions or to normalize feelings of anger or protest often elicit reactions such as "This is God's will and one mustn't protest. A person who believes accepts all that God gives." Faisal Azaiza and Miri Cohen in their study of Israeli Arab women's attitudes toward breast and cervical cancer also find that some still perceive cancer "as either a punishment or as a test devised by God." (Azaiza & Cohen, 2008, p.34)

Patients perceive the expression of physical pain as more legitimate in comparison with emotional pain. This is illustrated in the following narrative:

Yusra, a 48 years old female patient with metastatic cancer, suffered from stomach aches every time she dined with her family. This symptom did not appear, however, when she dined with other people. One of the conclusions she reached as a result of counseling was that her expression of emotional pain was not acceptable in her family and that she found it difficult to meet her family's expectations to be strong and to continue functioning as usual within the family. As she developed skill in expressing her emotional distress, the stomach aches disappeared and she no longer needed to find alternative outlets for her emotional pain.

## Coping with Death and End of Life

The main support networks of the Arab family are often informal ones including neighbors, friends and kin. Most Arab families see hospitalization at a hospice in end-of-life situations as disrespectful and believe that the family owes it to the patient to enable him or her to spend their last days at home. Many see the transfer of the patient to a hospice or to any other palliative framework as a failure. In everyday speech they refer to such institutions as "death institutions" and they do not regard them as places which might improve a patient's quality of life.

The following narrative illustrates the impact of these beliefs. In an attempt to admit Ahmad, a 54 years old terminal patient, to a hospice, his extended family became very angry with his wife, claiming that she was shirking her natural role as his caretaker and accusing her of being disrespectful. The wife was hospitalized that same day suffering from a nervous breakdown due to the stress generated by the reaction of the family. The family was not sympathetic to the wife's condition. In response, my professional intervention entailed gathering the family and explaining to them the complexity of the Ahmad's medical situation. I reached out to the head of the family and engaged the physicians on the medical team to add their authority to a discussion about the severity of Ahmad's condition. Following a difficult and painful conversation, he agreed to transfer Ahmad to a hospice in collaboration with Ahmad's wife.

In contrast, the society is more accepting of home care or home hospice, as it combines the tradition of caring for the patient at home and modern medicine. While home care might be the best way to maintain respect for family values and enhance patient care, it is not easily accessible for East Jerusalem Arabs. Today, home care is provided for people residing near the city center while physical and political conditions make East Jerusalem Arab neighborhoods less accessible to such arrangements.

## Seeking Help

Haj Yahia (1994) argues that everyday behavioral orientation among Arabs imposes self-discipline and the notion that a person can attain complete self control, including control of the emotions and meeting one's responsibilities in various areas of life. The Arab individual is expected to be composed, patient, not to protest at times of distress, and to endure painful moments quietly. In many cases, Arab patients find it difficult to share personal problems and feelings with a person who is not a family member or a member of the community. A person who does share such issues with an outsider is perceived as weak and disloyal (Al-Krenawi & Graham, 2000).

Furthermore the special political and legal status of East Jerusalem Arabs makes it even more difficult for them to seek help from Israeli state institutions or their representatives. Meetings of Arab patients, their partners or companions, with the social worker are often very charged and characterized by substantial suspicion. Since many members of the Arab population see social workers as representatives of the establishment, they may not seek assistance. It is critical then, that the social worker explain their role and assert their readiness to work with the family, partner, or children as well as with the patient. Commonly, the social worker's outreach initiatives will be rebuffed until trust is developed, thus underscoring the importance of relationship building and perseverance.

Some patients and family members are apprehensive about the idea of emotional support and about discussing one's feelings, and others are apprehensive about receiving help from a professional external to the family system. The role of the social worker as part of the medical team is not self-evident to many Arab patients. This

understanding starts to develop when the medical team uses the services of the Arabic speaking social worker as an interpreter since most patients do not speak Hebrew and the medical staff often does not speak Arabic. The sensitivity to cultural issues and familiarity of language helps establish trust between patients and the medical team.

Arab men tend to disclose and interact less with the psychosocial staff than do women. They often prefer to suffer quietly and focus on practical assistance. It is unclear if this is affected by the gender of the social worker or mental health clinician or due to the cultural requisite of being reserved. This is a question meriting further inquiry. To address the difficulty that East Jerusalem Arabs have in seeking formal help, we take the following steps:

Σ Raise awareness and educate about the role and work of the social worker

Σ Initiate referral of the patient, as part of the routine work of the medical staff, to the psychosocial staff, since a society which has much respect for authority tends to follow the recommendations of the medical staff

Σ Insist on transmitting information in the patient's native language.

## **Conclusion**

The treatment of cancer patients, along the continuum of illness, requires attention to culture, values and traditions. The East Jerusalem Arab population has a special status and their unique needs must be addressed accordingly. Several issues require deeper attention. It is important to understand that cancer is still accompanied by a sense of social shame among the Arab population and causes some patients and their families to keep it secret, a practice that often leads to feelings of isolation and loneliness. There is still a lack of awareness and information about the disease in the Arab population and efforts must be made to disseminate knowledge about cancer, about treatment options and about attitudes toward those who suffer from cancer. The available support systems must be adjusted to address tradition and culture, especially the cultural inhibition which make it difficult to speak about painful feelings.

It is important to stress that this population suffers from limited access to medical and paramedical care, and that the home care staff that are trained to care for terminal patients cannot access East Jerusalem Arab neighborhoods due to physical and political conditions. This problem becomes even more acute in cases of immobile patients who cannot travel to receive medical care.

The value of accepting one's fate does not contradict the need to provide patients with emotional and medical palliative care. There is an urgent need for a system of home care teams to be established inside East Jerusalem Arab neighborhoods to accommodate the culturally mandated practice of spending one's last days at home. The challenge in treating Arab patients is in creating conditions in which Arab cultural reality and medical services would supplement, rather than contradict, each other. The skills of staff members attending to the Arab population should include, alongside conventional medical

knowledge, awareness of and sensitivity to cultural issues, as well as an ability to mediate between the majority culture, which is often Western, and the minority Arab culture.

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