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Family Carers and the Home Hospice Patient in Israel: A Pilot Study of the Need for a Multi-Cultural Perspective

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Sabar Health Home Hospice, Sabar Health Operates the Leading and Largest Home Hospice Service in Israel, Israel

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Abstract

Objective: This pre-feasibility pilot study was carried out to establish aspects of caregivers' ethnic and cultural diversity in home hospice care in Israel and to enable improved communication tools for hospice teams, thereby improving patient and family outcomes. Israel, as a relatively small but diverse multicultural nation with a national hospice service, provides a unique opportunity to survey the interface between the family dynamic and cultural sensitivity in the care of home hospice patients.

Methods: A pilot study of nurses from the Sabar Health Home Hospice examined the need to study ethnic/cultural diversity in families in order to improve caregiver physical, psychological, emotional, and spiritual outcomes. The study utilized The Geiger Davidhizar's Cultural Assessment Model which considers six components relevant to end-of-life care. The questionnaires were sent to 19 nurses by mail following anexplanatory phone call. Five replies were receivedand analyzed for similar or different unique themes pertaining cultural and ethnic aspects.

Results: Two religious ethnic sub-cultures and one non-religious ethnic subculture were identified through the nurse participant replies.

Conclusions: The study illuminates the potential for an increased focus on culturally sensitive care for patient families, resulting in improved outcomes for both patients and families, and the need for further research.

Keywords: Caregivers; Hospice Care; Cancer; Palliative care

Introduction

The vital role of the family in providing support to cancer patients in their home is well documented [1,2]. Recent studies show that a growing number of family members will become caregivers over time, and that the majority of unpaid caregivers are women, most often a daughter, daughter-in-law or spouse [3]. Reasons for becoming a caregiver may include duty, love and affection, family expectation, piety, or no other choice [4]. In the US, 49% of caregivers surveyed feel they do not have a choice. Caregivers cite needing support in both medical procedures such as the administration of drugs, or assisting with toileting, and with psycho-social issues such as the need for emotional support. Studies show that caregiving can have negative consequences for the health of family caregivers, including fatigue, sleep problems, depression, anxiety, burnout and an increased risk of mortality [5].

Increased family support results in better outcomes for patients. Social work services show a significant increase in patients actualizing their wish to die at home [6]. However, family attitudes and behavior can be a main obstacle to effective patient care. Clearly, supporting the family and communicating effectively with the family is a key factor in effective treatment, but research on caregiving intervention evaluation is methodologically challenging, and the evidence historically weak [7]. Hospice assessment tools typically focus on the needs of patients rather than family caregivers [5]. Additionally, it is not clear whether research of families in Western society are applicable to other ethnic groups. In cancer care, communication involves listening, sharing, soliciting information and conveying empathy [8].

In 2009 Israel's Ministry of Health issued a directive requiring community health providers and hospitals to establish palliative care and hospice services to all dying patients within four years [9]. Large-scale hospice programs in Israel are new, and a review of literature in English does not reveal significant research on family caregivers in Israel. Israel, as a relatively small and diversely multicultural country with a national hospice service, provides a unique opportunity to survey the interface between the family dynamics and cultural sensitivity in the care of cancer patients.

Methodology

Israel can be subdivided multi-culturally based on religion, ethnicity, country of origin and location. We wanted to explore whether a study of ethnic/cultural diversity within families could improve caregiver's physical, psychological emotional and spiritual outcomes. Toward this end, we created a pre-feasibility study using nurses from Sabar Health Care, a national home hospice service covering the entire country. All the nurses are registered and trained in palliative care. Each nurse has a patient load of 17-20 in a home hospitalization setting in a specified geographical area with wide ethnic diversity. Based on research by P.R. Coolen [10], we utilized The Geiger Davidhizar's Cultural Assessment which posits six components relevant to end of life care, namely: communication,

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space, time, environment control, social organization, and biological variation [11]. The tool is used as a guide to discuss individual families and develop a composite structure [12]. The survey was translated into Hebrew and was sent to 19 nurses. The nurses received phone calls to explain the study. Five responses were received from the nurses.

Results and Discussion

The various cultures/ethnic themes that emerged included two religious/ethnic subcultures and one ethnic subculture in Israel's overall population, namely: Ultra-Orthodox Jews, comprising 11%; Muslim Arabs, comprising 16%; and one ethnic subculture --Russian immigrants, comprising 9%.

The five responding nurses were familiar with the various ethnic and cultural aspects of the population, even though they did not receive specific instruction about cultural differences and norms that could impact many facets of their care,such as the aggressiveness of treatment, the use of pain medication to reduce suffering, and family interactions.

The Ultra-Orthodox Jewish Community

Characteristics of the Ultra-Orthodox community as identified by staff responding to the questionnaire: "An elderly gentleman was cared for by his wife, he tended not to listen to her, and she, in turn, would ask his friends from the *yeshiva* (the religious school), or their rabbi, to come and assist as they had more authority in his respect than she. Treating the patient with medication such as morphine or midazolam, including the recommended doses, also required consultations with the rabbi. The wife and the nurse spoke freely about all topics, such as end-of-life choices and preferences, but these conversations were conducted privately, away from the patient: All advanced planning, such as whether to use resuscitation, was decided by the rabbi."In a different case, a nurse reported that "the communication with an elderly female observant patient was open and they discussed all the aspects of treatment, including end- of-life and death. The patient had successfully removed all the barriers of her religious faith when talking about taking one's own life, as compared to continuing life, waiting for an inevitable death." Her husband witnessed these conversations but was not a participant. She had been the decision-maker all her life and she succeeded in sweeping her entire family with her." Their rabbi, however, was consulted on different matters pertaining to the end of life, including the subject of "death on a Saturday", a Jewish holy day.

The Ultra-Orthodox community produces large families that tend to be very involved in the care of a patient, often taking shifts. A nurse who works in the Ultra-Orthodox community in the Greater Jerusalem area identified the following: "It can be difficult to determine the communication point person. It is often an older daughter. The family includes children, in-laws, grandchildren and sometimes great grandchildren."There is a strict cultural distance between the sexes. "There is no physical contact between men and women who are not first degree family members. This results in a strong preference for same-gender nurses." A study of Ultra-Orthodox mental health patients showed that they are not necessarily reluctant to be treated by secular physicians as long as they feel respected and acknowledged in their sociocultural affiliation. The study highlights the need for training teams about the importance of culturally sensitive treatment [13].

The Jerusalem nurse continues: "Cultural issues get in the way of trusting social workers or allowing them in." The community is willing to use social work services for accessing benefits connected to health status, but not for spiritual or emotional support. The families have a strong belief in God as the manager of all things. "Families often with hold a diagnosis from the patient in order to shield him/her."There is also a tendency to ask many questions of the medical personnel. With a wide network of inter- communal structures, there is a strong reliance on the familial-community service system, rather than on professional social-work services [14]. Families also consult with prominent rabbis, often those versed in the Jewish laws of medical ethics, before making medical decisions. There is a strict set of religious laws dealing with end-of-life, and many default standard medical practices contradict these laws. This results in a general distrust of the medical system and a concern that modern medicine will negate Jewish law."

The Arab Muslim Community

The majority of Arab patients living in Israel are Sunni Muslims who live in rural areas of northern Israel (https://en.wikipedia.org/wiki/Demographics_of_Israel). They, too are part of large family systems that tend to be very involved in the care of the patient. Researchers discuss the Arab Muslim patient and his family as one unit. This could be attributed to the distinct nature of the Muslim family with strong ties and interrelations [15]. It also explains why in the Middle East, the collective approach prevails, physicians communicate first with the family members, and then with the patient himself/herself [8].

A nurse in the northern area of Israel where a large proportion of patients are Arab Muslims reports common themes among these patients and families. "The stated primary caregiver and contact person is most often the male head of the family, generally the father or eldest son. While he is the main communication source, the actual care of the patient is usually provided by women family members – wives, sisters, daughters-in-law or aunts."Traditionally the extended families dwell in proximity: daughters who marry move to the proximity or to the same house of the husband's family. Sons who marry will live in the family house or proximity. In the everyday reality, nurses report that the women are the actual caregivers. In order to communicate effectively with the family, the nurses, social workers and doctors may choose to visit patients together at any time point, especially if one team member speaks Arabic. The nurse, being the case manager, will visit the patient within 24 hours of admission and must operate on two levels simultaneously, initially meeting the patriarch out of respect and offering information, and then, communicating treatment, practical information and empathy to the women. Information can be given only with the permission of the patriarch and each member of the team must make sure that respect for the patriarch is shown.

Muslims perceive pain as atonement for one's sins and believe that life is purposeful even when coupled with suffering. They believe that Allah will reward those who show patience, those who prefer not to receive pain management because they believe that if one feels pain and shows patience, he will be rewarded more by Allah and will be more pure [15].

Russian Immigrants

Some 979,000 Russian Jews and their non-Jewish relatives and spouses emigrated to Israel from the former Soviet Union during 1989-2006. Today they represent 9% of Israel's total population and are largely secular in orientation [16]. The children of elderly Russians have largely integrated in Israeli society, while aging parents have held onto their culture, living largely in Russian-speaking communities and connecting with Russian-language information sources.

The adult children of the emigrants are the primary point of contact with the home hospice teams and will often insist on speaking with the doctor only. In the case of an elderly Russian lady, the nurse reported: "The communication was not open, the patient and family tend to keep things to them, although everyone understood the situation. Death is expected and not discussed with the patient. Fate was accepted. The daughter or daughter-in-law was the decision maker and spokes person "Russian families expect a thorough explanation of a patient's condition and prognosis, and extensive guidance regarding end-of-life choices. In general, they do not want to discuss death and dying during the early stages of treatment [17]. The nurse indicated that the families are self-contained and close. Family is of the utmost importance. They did not rely on community support systems or extended family in this situation. "There was no spiritual context for illness and little interest in creating a spiritual context for illness. While there was a belief in a supreme entity, their attitude and daily behavior was not influenced by this belief. Families are very present-oriented, seeking practical solutions for problems as they present themselves."The Russian background and shorter sojourn in Israel shows a significant impact in terms of a tendency to die in a hospital setting rather than at home [6]. "The patients usually report pain only when symptoms become severe."

Conclusion

The context of caregiving in ethnic communities in Israel is a largely unchartered field in which vast differences in cultural communities must be navigated daily by medical professionals dealing with patients at the end of life. The nurse respondents noted the need to tailor their treatment plans based on the cultural ethnicities and religious needs of patient families.

The pilot study indicates that further research is needed to explore methods of reducing the burden on families and facilitating the work of professionals. It highlights the potential for an increased focus on culturally sensitive care for patient families resulting in improved outcomes for patients and families.

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