

Special Edition
**"Palliative Care and Oncology:
 Time for Increased Collaboration
 and Integration"**

Case Study

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Religious Cultural Sensitivity in Israel: A Case Study of an Orthodox Jewish Family

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ABSTRACT

The challenges of hospice care can scarcely be overstated, considering that the complexity of managing the physical, psychosocial and spiritual issues of the patient and of the family may seem daunting. The task becomes even greater when accommodating differences in culture and religious beliefs. This study focuses on a case of bridging cultural gaps by a 26-year-old medical student and his modern Orthodox Jewish family in Israel. The patient was diagnosed with aggressive squamous cell carcinoma of the tongue two months before. The authors joined the family as part of his palliative care team in January and accompanied them for 7 months until his death in July. The case was not only medically and psychosocially complex, but religion was an added factor which needed to be carefully managed. The family identified as religiously observant Jews, while the hospice team, although Jewish and familiar with the traditions, identified themselves as secular. The palliative care team worked with the patient and family to provide a course of treatment that was acceptable for both parties. The team worked to alleviate the patient's suffering and ultimately enabled the patient to have the death of his choice, at home with his family. Identifying as a member of an ethnic group, or as practicing a religion, does not necessarily entail maintaining beliefs that may be associated with ethnicity or religion.¹ As a team, we needed to be sensitive to cultural nuances and family dynamics so that the family felt comfortable to share their struggles of faith with us during their son's/brother's illness.

KEY WORDS: Hospice care; Culture; Israel.

INTRODUCTION

In an early conversation with the patient's mother, she expressed her wonder: "How can God do this to us?" and acted out her fury once the diagnosis was given. How does the care team regard this information? Does one ignore it or acknowledge this crisis of faith openly?

A pilot study by Sabar et al² indicates the potential for a better outcome when an increased focus is aimed at culturally sensitive care for patient's families. As palliative care professionals, we are aware of cultural differences and our need to tend to our patients and their family's needs with consideration for their culture. Koenig & Gates-Williams stated the importance of treating patients as individual unique people in the context of their support systems.^{3,4}

This case study highlights the struggles of a hospice team that delivers services to families throughout Israel – an ethnically and culturally diverse country in the Middle East.

CASE PRESENTATION - MEDICAL ASPECTS

The team consisted of a doctor, a nurse and a social worker, treating the patient and his family initially with palliative care and later with home hospice for 6 months until he passed away in presence of his family members and girlfriend beside his bed at home. He was 26-years-old, the youngest of 4 boys, one of whom was a physician, living at home with his parents, and in a relationship with a nursing student. Two months prior to our first meeting, the patient was di-

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agnosed with aggressive squamous cell carcinoma of the tongue base, metastasis to the brain, lungs and right neck lymph nodes. A transnasal biopsy was performed, resulting in bilateral diplopia due to damage to the 6th cranial nerve. His oncology treatment consisted of Cisplatin and Fluorouracil, Cetuximab, and a series of neck-lymph node radiation. Initially, the patient was functioning at a level of Eastern Cooperative Oncology Group (ECOG) 2. His symptoms included severe headaches, oral mucositis grade 2, and constipation with no bowel movement in the previous week. This caused a decrease in oral intake and appetite. He refused tablets or syrups such as lactulose or oxycodone. Several treatments were suggested for constipation and headaches. The patient chose fentanyl citrate transmucosal Lozenge 600 mcg for headaches and breakthrough/incidental pain, 2 Tabs Bisacodyl 5 mg at bedtime, and Glycerin suppositories. The staff emphasized the importance of fluids and nutrition. A daily menu was introduced. Medical cannabis as cigarettes were used before bedtime. These changes proved effective in improving the symptoms, and the patient remained stable while our weekly visits continued.

Three months into our service, a positron emission tomography-computed tomography (PET-CT) was taken and the patient was found clear of disease. The oncology team decided on completion of chemotherapy, and continued Erbitux fortnightly.

Two weeks later pain arose below the left jaw and gradually worsened, radiating toward the neck, causing swallowing problems and limiting neck and face movement. During the fortnightly treatments, he was examined by an oncologist team, ENT specialist, and maxillofacial specialist, with no results. When hospitalized for Erbitux, acute renal failure and severe hypomagnesemia occurred, which was resolved. He was referred to a physiotherapist, and reported that it alleviated his discomfort. Over the next weeks there was marked weight loss, rising levels of pain and functionality deterioration: ECOG 3.

A biopsy was taken, indicating that the cancer was back. The oncologist recommended that the patient should return to the hospital to be fed with a nasogastric tube. Pembrolizumab was brought up as a treatment option. He refused to be hospitalized and fed artificially, but as his condition deteriorated he agreed to a nasogastric tube feed in the hospital. A few days later he requested to remove the tube and take him home. The team sat with the family, explaining the grave situation and available options. The family had chosen to try to obtain Pembrolizumab and continue treatment. This required transfer to a different hospital.

After 3 days in the new hospital, his condition deteriorated rapidly and he was adamant about going home. His physician brothered and managed to obtain a family consensus to bring the patient home on the condition so that current treatments would continue. The treatment consisted of Ranitidine 100 mgx2/daily, Dexamethasone 20 mg/daily, Metronidazole

500 mgx3/daily for 5 days, Fluconazole 200 mgx1/daily for 2 days, Ceftriaxone 1gx1/daily, PCA - Basal Morphine 5 mg hourly, Bolus dose of Morphine 10 mg every 10 min, and Midazolam 5 mg prn every 10 min for seizure. The palliative team arranged the treatment at home, with clear and concise instructions for treatment. Our goal was to enable the brother to be a family member assisting his brother, rather than a doctor. The patient arrived home late in the afternoon and passed away early in the morning in peace with his family at his bedside.

Psychosocial and Religious Cultural Aspects

It was clear that the patient was aware of his condition and prognosis. His main concern was for his family, aware of the central role he was playing in their lives and voicing these concerns to the palliative care team. "How will they manage the void in my absence"? In contrast, his family members seemed certain that the cancer was curable. The mother repeated that "a miracle from God" would occur. The father kept busy with the needs of the family - work, attending synagogue daily, running errands. While willing to assist in any way he could, he supported his wife as care-coordinator and refrained from joining the palliative team on their visits. The brothers were not involved in the early stages. The extended families met regularly over the weekend for the Jewish Sabbath and on Jewish holidays. The girlfriend was present at times and, while refraining from participating in conversations, was perceived as a family member. Everyday care and decisions were the province of the patient, while his mother executed the recommendations and instructions.

At first, upon receiving the all-clear PET scan results, his mother was certain that her prayers had been answered. The patient; however, was not convinced and when the facial pain began, he knew the cancer had returned. This was never mentioned in front of the family, since he chose to protect them. As the deterioration progressed, in a meeting with the palliative care team, the patient expressed his feelings that his family was complacent, and that none of them was acting as his advocate, not asking the oncologists the right questions. A family member – the physician – had to step in and take over. He saw the deterioration in his brother's condition and realized that he was dying. He had not expressed his opinion to the family. We realized the need to respect their preferences under the brother's guidance.

The palliative care team suggested a plan of action, namely, the patient discussed his feelings with his family. The meeting resulted in a list of questions for the oncologist and an agreement to implement a shared decision process.

We had a frank discussion with the patient about the possibility of a recurring cancer and his preferences in such a case.

A biopsy confirmed that the cancer had returned. Despite ongoing deterioration, the patient initially chose not to be hospitalized, against his oncologist's recommendation. The phy-

sician brother assumed his role as mediator between the patient, the family, the oncologists and our team. A family meeting was held in the hospital. The patient demanded that we should remove the tube and take him home. We sat and talked to the family immediately. This was the first time that the whole family was together for this conversation. It was clear to the palliative team and his physician brother that he was dying. The conversation was managed by the palliative physician. The family was in shock and disbelief.

They then decided that he should come home, on the condition that all the current treatments to be continued.

His mother prepared his room, even though he had been using his mother's bedroom as a sick room previously. Knowing that using his mother's bedroom would be his choice, the team asked if it would be possible to use her bed. His mother expressed concerns about the death occurring in her bed, but agreed. When the ambulance team wheeled him inside, he directed them to continue straight to his parent's room and to his mother's side of the bed. As the end neared, and the patient was unconscious, the team advised the family to move him to his own bedroom, so that he did not die in his mother's bed.

The hospice team and extended family were present at the final hours. Out of respect for the family's religious beliefs, we suggested chanting the important prayers. *Vidui* – the traditional Jewish prayer said before death was recited at this point. We also recommended farewells, and attempted to create a tranquil atmosphere. The palliative team stepped in and supported those who had said their goodbyes and chose not to be at his bedside as he died. He died peacefully at home.

After the death, the patient's body was turned over to the *chevra kadisha* for a ritual purification and he was buried in the local cemetery within 24 hours of his death as it is accepted Orthodox practice. The family then observed the ritual mourning period known as *Shiva* according to the accepted Orthodox practice in accordance with their beliefs. In conversations with the mother in the days following, she commented that she was "still negotiating her problems and issues of belief with God". In a follow-up conversation several months after her son's death, she sounded more at peace with herself.

CULTURAL AND RELIGIOUS REFLECTIONS

Cultural Reflections

This case was particularly complex. Religious practice and faith both played a part in the treatment plan and although they were never explicitly discussed, they were ever-present. One of the benefits for an Orthodox Jewish family of receiving treatment in an Israeli hospital is not having to navigate the challenges of cultural sensitivity on a day-to-day basis. Orthodox patients do not routinely receive general treatments on the Jewish sabbath or festivals and major hospitals throughout the country operate

on special Shabbat mode where non-Jewish doctors and nurses are available to perform tasks – such as writing notes or answering telephones - that are forbidden on the sabbath. They are also well versed in the Jewish value of *pikuach nefesh* – saving a life – which obligates a person to violate the Sabbath under certain situations. All food in major Israeli hospitals is kosher and under Rabbinic supervision. This supervision extends to Passover when the hospitals offer kosher for Passover food. Patients in an Orthodox family will find daily *minyanim* made up of doctors, hospital staff, patients and family members that allow them to participate in the obligatory thrice daily prayer sessions with a quorum of ten men. The sight of a man wrapped in his tefillin – the phylacteries worn during the morning prayer session – and attached to a mobile IV standing next to a janitor on break and a physician in scrubs finishing a shift unit is common in Israeli hospitals.

With this as the background, being the hospice team we do not need to navigate the basic religious needs of a dying Orthodox patient and are free to focus on the medical treatment and larger spiritual issues surrounding death. There is no need for a basic staff training on not making phone calls on the Sabbath or education about a patient's desire to change their medication to refrain from ingesting chametz during Passover. As a Jewish hospice team practicing in a Jewish majority country, there are certain things that patients expect from us that are not explicitly stated but implicitly understood. The mother felt comfortable to speak about her "crack in faith," despite the fact that we were a clearly non-religiously observant team because all of the basic needs of her son's care were taken care of. G-d and our relationship with him or lack thereof is part of the lexicon in Israel. If, despite our religious differences, a patient feels comfortable to have this conversation then we do our job as culturally sensitive practitioners. Health practitioners in Israel must navigate the presence of G-d in the lives of their patients. Had we been busy trying to secure kosher food, both the mother and the hospice team might not have had time or energy for a crisis of faith.

(It should be noted that whereas all of this is true with the modern Orthodox patient, with an Ultra Orthodox or Haredi patient this would not necessarily be true. Ultra Orthodox patients adhere to a stricter interpretation of Jewish law and will not necessarily rely upon the Rabbinic authorities that oversee general hospitals and in some cases request treatment only by religiously observant medical staff.)

The treatments that the family chose were aggressive. While that is partially attributable to the age of the patient, in our experience, Orthodox patients as a rule treat more aggressively. According to virtually all rabbinic authorities who follow *Halakha*, food, water, and oxygen are considered essential components of life that must be offered to the patient.⁵ In contrast with many medical authorities, according to many *halachik* authorities the insertion of a nasogastric feeding tube or a percutaneous endoscopic gastrostomy (PEG) tube is considered indispensable in providing food and water to the dying patient.

Therefore, when the oncologist and the patient's family requested the insertion of a nasogastric feeding tube after his transfer to the second hospital, the hospice team was not surprised and certainly had no objection. Nor did we feel conflicted when he asked for its removal. "If the patient is competent and expresses clear opposition to a feeding tube; however, this choice should be respected." (Ibid)

In this particular case – and in many families from Israel's modern Orthodox community, the family was not directly consulting with a Rabbi for day-to-day questions about what to do. Despite the fact that there were medical professionals in the family and the patient himself was a medical student, they clearly followed the mainstream Orthodox tenet of extending life at all costs. As the patient got sicker and neared death, we viewed our job as simultaneously, facilitating all of the treatments necessary that could allow for a miraculous intervention by G-d and preparing the family for the possibility of death without trampling faith. The mother's faith seemed to delay her understanding of her son's case. Her faith was in a coming miracle, since her religious perspective implied that God would not allow her son to die. We felt that this faith led to denial, which is common in palliative care situations. It is clear that if the patient were not orthodox and this was not the need of the family, we as secular practitioners that place medical standard of care above Jewish law would have acted differently in at least some of these areas.

GENERAL REFLECTIONS

Research shows that there is a growing need to overcome barriers in the delivery of hospice services. These barriers include cultural differences between healthcare providers and patients; cultural differences between patients approaching end-of-life and their family members; under-utilization of culturally-sensitive competencies designed to improve end-of-life care; language barriers; lack of awareness of cultural and religious diversity issues; exclusion of family members in the decision-making process; personal, racial, and religious discrimination; and lack of information to facilitate decision-making.⁶

This case demonstrates the multiple levels at which a hospice team strives to operate every day with every patient and family. The family in this case identified as religiously observant Jews, while the hospice team, although of the Jewish religion and familiar with the traditions, identified as secular. As an interdisciplinary hospice team, our care emerges from the assumption that patients deserve the best care possible. Equity

and equality are the cornerstones of care, and cultural sensitivity is crucial.

It is our responsibility as a hospice team to place the patient and family at the center of care. This patient was very clear in his desire to die at home. His family was clear that they wanted to use every medical intervention possible to prolong his life. In accord with changes and developments, we broadened our scope to include the various parties who needed to be involved, including the brothers, the hospital teams, and finally setting up a "mini hospital" at home, allowing the family to respect the patient's wishes to die at home while respecting the family's wish for the patient to receive medical care up to the very end.

CONFLICTS OF INTEREST

The authors declare that they no conflicts of interest.

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