

Welcome to Yale Cancer Center Answers with your hosts doctors Anees Chagpar, Susan Higgins and Steven Gore. Dr. Chagpar is Associate Professor of Surgical Oncology and Director of the Breast Center at Smilow Cancer Hospital. Dr. Higgins is Professor of Therapeutic Radiology and of Obstetrics, Gynecology and Reproductive Sciences and Dr. Gore is Director of Hematological Malignancies at Smilow and an expert on Myelodysplastic Syndromes. Yale Cancer Center Answers features weekly conversations about the research diagnosis and treatment of cancer and if you would like to join the conversation, you could submit questions and comments to canceranswers@yale.edu or you can leave a voicemail message at 888-234-4YCC. This week you will hear a conversation about culture and spiritually sensitive palliative care of Muslims. Here is this week's guest host, Mark Lazenby.

Lazenby Dr. Al-Shahri, tell us what palliative care is like at the King Faisal Specialist Hospital in Riyadh, Saudi Arabia?

Al-Shahri We started our palliative program in the early 90s. It was started as a home-based healthcare program delivering palliative care to patients in their homes. That is how it began, and then the service developed into a full service with a tertiary inpatient unit in the hospital with a consultation team providing hospital wide consultations with coverage 24x7 for emergency room and home healthcare patients as well and we have now an 8-bedded single tertiary unit and we have outpatient clinics as well.

Lazenby What are some of the services that you provide as a palliative care service to the patients?

Al-Shahri We care for patients. We recommend referral to the service as early as possible, but we also focus on patients towards their end of life, end of life issues and their special needs during this critical period of their life.

Lazenby Gassan Abudari, you are a clinical nurse coordinator in palliative care at King Faisal in Saudi Arabia, what is the role of a clinical nurse coordinator in palliative care?

Abudari The role of clinical nurse coordinator in Saudi Arabia may be a little bit different than what you have in the United States. We have more advanced practitioner nurses and they have more responsibilities. In Saudi Arabia, my role is as a liaison between physicians and patients, between the medical team and the multidisciplinary team like the social workers and physical therapists. We try to work together to provide the best care for our patients, especially in these critical moments in their lives and we try to relieve suffering and maintain comfort for them, so it is more about a partnership with the multidisciplinary team and giving the best efforts of our team to give the best care for the patients.

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Lazenby Dr. Omar Shamieh, you are Chief of palliative care at the King Hussein Cancer Center in Amman, Jordan. What is palliative care at the King Hussein

Cancer Center like and who is on your team?

Shamieh Thank you Mark for this invitation. As you know, King Hussein Cancer Center is the largest cancer center in the country. It is a tertiary cancer center treating about 50% of cancer patients in the country and we have the largest comprehensive palliative care program. We have four services. We have a stand-alone unit, an 8-bedded unit in the hospital. We have an inpatient consultation team and we have inpatient admission and referral team. We have outpatient clinics and we have a home care program. The home care program, is 2 teams covering the capital city Amman and another team covering outside Amman. We see about 10-12 patients per day in a given day and they also do weekends. We have many services that we provide. The main thing we do is the pain and symptom management and preparing patients throughout the trajectory of the illness. We offer psychosocial support. We offer spiritual support and we do end-of-life care as mentioned by other colleagues in our center. Our team consists of physicians. We have 3.5 full-time employee physicians. We have 3 inpatient nurse coordinators. We have 2 clinical pharmacists, one social worker and one spiritual advisor and we have an on-demand physical therapist and clinical psychologists. We have 4 home care nurses and the hospital is building a new expansion across the street which will have an additional 200 beds in addition to the 177 current beds and we have a stand-alone huge outpatient center that accommodates 4 times the capacity of our current outpatient clinic and of course with the expansion, our palliative care service will probably expand 2-3 times the current capacity.

Lazenby You 3 have been here at Yale over the last few days talking about palliative care and Islam. What are some of the principles of palliative care that fit well with Islamic teaching and belief, Dr. Mohammad Al-Shahri?

Al-Shahri I think it is a complete fit between the two, Islamic faith and principles of palliative care. First is the holistic nature of the two, so Islam is a way of belief and also a way of life and it encompasses all the activities and behaviors of Muslims and we know that palliative care is also a very comprehensive type of healthcare that encompasses all the facets of suffering the patients are going through be it psychologically, socially, spiritually or physical aspects of suffering, so they both fit very well from this point of view. Second, the affirmation of life and this is one of the principles in palliative care. Palliative care affirms life and this is a very important concept in Islam as well. The next point is relief of suffering and relief of suffering is a very righteous thing in Islam and it is of course the theme of palliative care.

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Lazenby Dr. Omar Shamieh, at the King Hussein Cancer Center what are some of the methods you use to relieve physical pain and suffering?

Shamieh Part of suffering of cancer is having severe pain which can happen from the beginning of the diagnosis and throughout the disease journey. Patients can

present with different types. We call it either neuropathic and it can be either through the viscera or limb pain or somatic pain, and we have many effective medications for this, a wide variety of medications, but the main medication to treat cancer pain is opioids and we have different kind of opioids and we use them in the right dosage and in the right patient and they are very effective in relieving most of the pain patients have.

Lazenby What is the view of morphine and other opioid medications in the Middle East particularly, Dr. Omar?

Shamieh Opioids actually pose a challenge in the Middle East and all over the world with the fear of addiction, fear of misuse and unlawful use of the medication; however, with constant education to the providers and with putting strict policies and procedures in order for the medication to be used safely for the right patient at the right time at the right setting, I think that helps and making the medication available for those patients plays a major role in relieving suffering and physical pain and other symptoms.

Lazenby Dr. Mohammad, one of the founders of our field, Dame Cicely Saunders, who founded St. Christopher's Hospice in London, talked about pain as having multi-dimensions, not just physical but also psychological, social and spiritual. How do you treat the spiritual pain that patients may feel or the spiritual distress they may feel with cancer or at the end of life?

Al-Shahri As you rightly mentioned, the suffering of these patients is complex and is multifaceted and being presented that way, the approach to it should be by a team rather than by a person or one discipline, so you need a team approach to such a complex problem that has a lot of factors involved. The physical factor is obvious, cancer is there, and it is causing destruction of the tissues and changes physically, but also the other factors are very important, the spiritual, the psychological and the social factors and it has been observed that these interact with each other in a synergistic way so the whole is more than the sum of these facets of suffering. That leads to what is called total pain, so the approach of these patients should be a total approach of care that involves the spiritual care providers, the physicians, the nurses, other colleagues from physiotherapy, dietitians and so on to tackle the problem from all angles.

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Lazenby Gassan Abudari, you have talked over the last few days about the importance of family and what the role of family is in helping patients through this period of pain and suffering that may come with advanced cancer at the end of life. Could you talk about that aspect?

Abudari Of course, one of the principles of end-of-life care is that patients and their families are a unit of care in palliative care and a terminal illness is a family experience because they suffer psychologically because of the patient's condition and deterioration. The family has influence and sometimes that may be because

of lack of education and this is a global issue, they do not get enough information about opioid management, so they show some reluctance of using these opioids, so I think from our part as healthcare providers, we need to explain to the family the benefit of providing these opioids and not to fear addiction or side effects so we can overcome the global barrier of fear of opioids which is mainly related to lack of education. Spiritually, I think for the pain as mentioned by Dr. Mohammad, it is multifactorial, they need more a multidisciplinary team, a spiritual caregiver, a spiritually trained provider for the family and for the patients to guide them for better care for their patients.

Lazenby So it is a team approach that involves the physician, the nurse, the social worker, what we call in the United States the chaplain or the spiritual care provider and a psychologist to help the patient and the family understand the disease and the prognosis and where they are, etc. We are going to take a short break for a medical minute. Please stay tuned to learn more about culturally and spiritually sensitive palliative care of Muslims with Dr. Omar Shamieh, Dr. Mohammad Al-Shahri and Gassan Abudari.

Medical Minute There are over 13 million cancer survivors in the United States and over 100,000 here in Connecticut. Completing treatment is an exciting milestone but cancer and its treatment can be a life changing experiencing. Following treatment, cancer survivors can face several long-term side effects of cancer including heart problems, osteoporosis, fertility issues and an increased risk of second cancers. Resources for cancer survivors are available at federally designated comprehensive cancer centers to help keep cancer survivors focused on healthy living. The Survivorship Clinic at Yale Cancer Center focuses on providing guidance and direction to empower survivors to maximize their health, quality of life and longevity. This has been a medical minute brought to you as a public service by Yale Cancer Center and Smilow Cancer Hospital at Yale-New Haven. More information is available at yalecancercenter.org. You are listening to WNPR, Connecticut's Public Media Source for news and ideas.

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Lazenby Welcome back to Yale Cancer Center Answers. This is Mark Lazenby and I am speaking with my guests, Dr. Mohammad Al-Shahri of the King Faisal Specialist Hospital in Riyadh, Saudi Arabia, Gassan Abudari, a clinical nurse coordinator at the King Faisal Specialist Hospital in Riyadh, Saudi Arabia and Dr. Omar Shamieh of the King Hussein Cancer Center in Amman, Jordan. So Gassan, we just were talking about the role of family. It seems like communication is very important between the palliative care team and the patient's family. What are some of the basic principles of good communication that patients and families might need to know of? If I were talking about my own loved one, what would you want me to know about how to communicate with my team?

Abudari It is mentioned in all the books about effective communication, you have to prepare yourself. There are special steps to proceed before you communicate

with the family and how to break the bad news, there are special techniques that you have to follow because most of the issues at end of life are really not happy news for the family, so you have to provide it in a context that they will accept and they have to work on it as one of their goals for their family. The physician needs help from the multidisciplinary teams in communicating with the family. It is not only the physician that has to communicate, we as nurses face challenges also because we spend most of the time with the patients, so sometimes we get asked by the patients and their families questions where we may be limited or constrained about the nature of the information or the extent of the information to give them, but I think we need to be on the same page as a medical team like all healthcare providers need to be on the same page and it should be done through an effective interdisciplinary team effort. We should set our goals as a medical team about the nature and the extent of information, so we do not contradict each other, this is one of the general rules. For Muslims, I believe communication may involve religion more and more and an emphasis on the meaning of it related to terminal illness, it should be more focused on death and dying, the principles of death and dying for Muslims, their concept of pain, how they should perceiving pain according to the Islamic religion because we have a specific meaning for pain, for death and dying, the issue of belief in predestination for Muslims, as in it is happening on time, the time of death, it is already determined by God, so these issues should be included in the way we communicate with the family. It is a huge topic, but as I mentioned, we need a multidisciplinary team to be together and to provide the best information for the family and the right communication.

Lazenby Dr. Omar from the King Hussein Cancer Center, there is this notion that Gassan just spoke about that God has predetermined the time of our deaths and God knows it and it is written ahead of time, does that cause Muslim patients to be distressed about knowing when death is going to happen or does it bring comfort? What does that principal do in the course of their care?

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Shamieh In order for me to answer that question, I will just shed light on the importance of palliative care in our cancer population, as Mohammad and Gassan mentioned, it is very important to have the principles of palliative care early on for the patients and the families and the more preparation the team does with the patient and family, the better the outcome. The notion of predestination is a fact for Muslims and non-Muslims, that the predestination and the death phenomenon is known and is going to happen for every person on this universe. Muslims believe that God has this predestination set so nobody can alter or bring forward or backward the time of death. However, at the same time, we have to deal with those patients as human beings and we have to relieve the suffering they have throughout their illness and having said so, there is a very important role for the spiritual advisor in the healthcare team as part of the interdisciplinary team. The role of the spiritual advisor is to strengthen the

belief and faith of those Muslim patients, especially towards end of life because when we strengthen these beliefs and faith, we can bring the Muslim patients to a more peaceful environment. They have this, what we call, inner peace. The more they have belief in God, the more they have belief in forgiveness, the more they have belief in the mercy of God, the more they will not be afraid of death because God created human beings to worship him and they created death and life, they created disease and remedy and God created all kind of remedies along with the disease and the patients, in addition to that, believe they have to have patience and they have to bear the amount of suffering, they are also encouraged to seek treatment, seek symptom management, take opioids for pain management, at the same time we have to avoid doing harmful things or harmful interventions, so we have to have a balance between giving the effective medication and trying to take away the not effective or not beneficial interventions especially at this difficult time of their life.

Lazenby Dr. Mohammad, we know that palliative care does not just stop when a loved one dies, it includes bereavement care after death. What might that look like for a typical Muslim family in Saudi Arabia?

Al-Shahri As you know there is strong family support for the Muslim patient in general and also strong community support and encouragement of the community to participate at this process, the process of caring for the person who died and caring for the family who lost one of their members. The community will be participating in the funeral rites from the beginning and they will attend the washing, the shrouding and funeral prayer that is done by a lot of people from the Muslim community and then they will proceed with taking the dead body to the graveyard to also participate in that activity, so all this participation and the community support to the family is actually healthy and will, most of the time, prevent abnormal grieving, but sometimes of course, some patients or some families are under more risk than

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others and this is the duty of the healthcare providers to try as early as possible to identify who of their family members is at risk of developing abnormal grief and welcome that ahead of time in collaboration with the community members.

Lazenby Thank you. Gassan, what are some of the practical religious rituals that your patients might partake in in their hospital rooms at the end of life care?

Abudari It is a big topic, there are many cultural and spiritual practices but I think at the end of life those needs of religious and spiritual practices become substantial for the Muslim patient. Muslims pray 5 times per day, but you will see there is more prayer and you will see patients turning their TV and trying to listen to Quran channels in Saudi Arabia, but in the United States, it is a different story, maybe they have a tape recorder or play a CD with Quran, so this is something we have to do, listening to Quran, more prayer from the

patients and even the family, they will start reading Quran more and one of the issues is the rituals, Muslims, before any prayer, have to do purification, which is ablution, they have to do a special wash and I have been talking to many Muslim nurses as I mentioned and the study we conduct and patients insist to do this and in their religion there is waiver for a few things as a modification like they can do something called Tayammum which is dry ablution using sand for purification. If the patient loses consciousness or has a terminal illness, Muslims have a direction for prayer, they have to be towards Mecca, so most of the family, they will turn the bed so that the patient can face Mecca for direction of prayer, so it is about the prayer, about reading Quran and about the direction for prayer. Of course, there are many things, but this is the main issue.

Lazenby Dr. Omar, you have seen palliative care provided in the United States and in Jordan, what are some of the similarities that you have seen and what are some of the major differences?

Shamieh In a very short answer, palliative care can be applied in the US in a similar way to the way that we apply palliative care in Jordan or in Saudi Arabia, the principles are the same, Muslim patients can have full palliative care services whether they are in the US or outside the US. Some of the principles, opioids are allowed, Muslims can use opioids for pain and symptoms withholding some of the interventions which are harmful; at end of life, it can be applied in a similar way in the US as in do not resuscitate orders for terminally ill patients, it is allowed in Jordan and Saudi Arabia. In addition, withholding or withdrawing some of the interventions which are not useful, like unnecessary antibiotics or investigations which are not really useful. On the other side, the interdisciplinary team fashion is similar, we have a team in Saudi Arabia and Jordan that can provide excellent interdisciplinary care for our patients. The only thing which is practiced in some parts of the US, is some states allow

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euthanasia which is forbidden for Islamic rule. Euthanasia is forbidden for Muslims whether they are in Saudi Arabia or Jordan or even in the US; otherwise, we are discussing with people here and practicing in both parts of the world and we think that there are many similarities of practice between the US palliative care services and the non-US or outside the US in Arab countries like in Saudi Arabia or Jordan or any other Arab country. Of course, there are many cultural differences present even in the US, which plays an important role in having to ask the patients and families about many preferences regarding the decision making, regarding the food preferences, regarding the place of care, whether it is in the hospital or at home, regarding the whole caregiving experience, the importance of family. They play a major role in supporting the patients and disease trajectory, social support and practical support and caregiving towards end of life and they can be a very strong source of spiritual support for the patient as well.

Thanks for joining us for another edition of Yale Cancer Center Answers. We invite you to share your questions and comments, you can send them to cancer-answers@yale.edu or you can leave a voicemail message at 888-234-4YCC and as an additional resource, archived programs are available in both audio and written form at yalecancercenter.org. I am Bruce Barber hoping you will join us again next Sunday evening at 6:00 for another edition of Yale Cancer Center Answers here on WNPR, Connecticut's Public Media Source for news and ideas.