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Rethinking Care Toward the End of Life

Sunday, December 18, 2016

Share your opinion

It's still not too late if you'd like to contribute an op-ed style article for the session report, or a personal reflection blog post for our website. Email your questions or submission directly to Salzburg Global Editor, Louise Hallman lhallman@salzburgglobal.org.

If you intend to write for your own organization after the session, please make sure to observe the **Chatham House Rule** (information on which is in your Welcome Pack). If you're in any doubt, do not hesitate to contact Louise. And please share anything you publish with the group via the Listserve that Astrid will set up after the session!

We'll continue to update our website with summaries from the panels and interviews with our Fellows, all of which you can find on the session page: www.SalzburgGlobal.org/go/562

We're posting photos both our Facebook page www.facebook.com/SalzburgGlobal and our Flickr stream www.flickr.com/SalzburgGlobal. If you require non-watermarked images for your own website or publications, please let Louise know.

We will also be posting photos to Instagram www.instagram.com/SalzburgGlobal, using the hashtag [#SGSHealth](https://www.instagram.com/explore/tags/SGSHealth/).



Mhoira Leng: "Enjoying the beauty of this place and the richness of the interactions at the Salzburg Global Seminar #SGSHealth #CairdeasIPCT... even singing from the 'sound of music' after breakfast!!!"



Cultural nuances in palliative care

Culture Café facilitators give their thoughts on the nuances involved in administering palliative care in their countries

Chris Hamill-Stewart

Participants of *Rethinking Care Toward the End of Life* agree on several important principles of palliative care. They all want to ease pain and suffering, ensure that care is focused on the needs of the patient, and they all aim to provide a "good death" – whatever that may look like. However, across cultural boundaries, the pursuit of these ideals may look vastly different, or face different challenges.

Over the past four days, participants have emphasized how the needs and desires of the patients, the challenges for doctors and nurses, and the attitudes and approaches of all those involved vary drastically across geographic and cultural boundaries.

As one of the major themes of discussion from the session, Salzburg Global explored this further. We spoke with the facilitators of the Culture Café event, examining the cultural nuances, different methods and approaches to palliative care, and the different attitudes from the citizens themselves towards death.

Nandini Vallath, from India, emphasized how the culture in India

has affected peoples' attitude towards death: "There's a lot of death and dying acceptance in India – religion, history and culture contribute to this. The rituals of life talk about life and death as a cycle. There's no fear of the finality of death – the belief is that death is a transition into another life," she explains. In the case of India, a big issue is the dissonance between doctor and patient. "What is making palliative care more difficult is the doctor community. They talk the language of the modern science – there is a death-denying culture. Society is very accepting, but the professional community is not."

Speaking about the Philippines, Liza Manalo explained how religion is an important factor in peoples' attitude towards death and a "good death," saying, "If you ask the average Filipino what makes for a good death, they'll say faith and family make for a good death." She continues, "We're conscious that part of good palliative care and a good death is psychosocial support and spiritual care. By doing this, we take a holistic and spiritual approach to palliative care, and in this sense, we are very good at it."

Religion as an important factor was



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a sentiment shared by Ivan Odiit Onapito from Uganda. However, he also emphasized the shared cultural history of the people. He told us: “Africa is an oral culture – we use stories to share experiences and to find meaning in things. We use this culture of storytelling, which has been with us for many centuries, as a tool to provide spiritual care.” He emphasizes how useful these stories can be in communicating with patients: “We learn about patients through the medium of stories, and, from this, we look at strengthening their support structures – usually their communities and their families.”

Kathy Kirkland, from the US, and Franziska Kopitzsch, of Germany, both implied that their respective cultures have difficulty outright confronting death. Kirkland explained how the US approach is much less community-based, and also told us: “The conversations that occur around dying are often separate, with health care providers having one conversation with each other, and families and patients having a separate conversation.” American doctors take an impersonal approach towards their patients, which may not always be in their best interests. Kopitzsch spoke about palliative care for those around the patient. She believes “[Germans] don’t know how to grieve.” She explained that there is “no tradition, ritual or celebration when people die.” Here, she touched on the wider issue of palliative care not just for the patient, but their family and loved ones. With less sense of a shared culture or religion, it seems that people find it more difficult to approach the topic of death, and to deal with the death of a loved one.

Yi-Jong Suh explains that in South Korea they are experiencing changes in attitudes towards death and palliative care. “Perhaps as a result of the traditional culture of Confucianism, we never used to talk about parents’ deaths and dying... We were always silent on these matters.” He also tells us how when people discuss their plans for end of life care for a family member, they often don’t include them in the conversation. However “Korean culture is changing, and we’re more willing to confront these issues.” Koreans are opening up to providing palliative care across the board, and people are becoming more “individualized” and

willing to openly discuss these issues.

Ultimately, the facilitators of Culture Café have made it clear that history, religion, and culture all have a profound impact on the application of palliative care. Whether it is incorporating cultural aspects of communication into interactions with patients, avoiding the topic of death entirely, or in its effects on the people surrounding a palliative patient, the cultural differences that practitioners and social workers need to take into account when administering palliative care are an inescapable pool of opportunities and challenges.



ECHOing innovations

To drive improvement in health care we need evidence. “In resource poor settings, it is even more important to generate evidence of effectiveness,” said one panelist in a discussion of “which are the most promising evidence-based and cost-effective innovations in end of life care?”

Health care outcomes should be measured from the point of view of those using it, another participant remarked, and in the case of palliative care, that means not only the patient but also their families and caregivers.

One such measure that has been developed is the African Palliative Care Association (APCA)’s African Palliative care Outcome Scale (POS). The POS addresses “the physical and psychological symptoms, spiritual, practical and emotional concerns, and psychosocial needs of the patient and family.” Using the POS, medical staff are able to help reduce the patient’s pain and anxiety and increase family confidence in the patient’s care over a series of hospice visits.

Pain relief can be the most effective measure of palliative care success, but in many countries, staff are not sufficiently trained or the number of doctors who are trained is few. One solution is to train and empower nurses to prescribe and administer pain relief.

Once evidence has been gathered, sharing this knowledge is important, not only through training and journals, but also by using innovative tools such as “Extension of Community Health Outcomes” – ECHO – which is a “telementoring” (“not telemedicine”) platform, enabling doctors and patients across diverse and remote geographies to connect virtually in large video tele-conferences, sharing their experiences across a wide community of practice.



Learning from our past mistakes

“If we want to learn from failure, we have to *share* our failures,” urged a participant on the third day of the Salzburg Global Seminar session *Rethinking Care Toward the End of Life*.

Recognizing that we learn more from our failures than we do our successes, panelists from four continents shared their countries’ experiences.

One failure that needs to be overcome is the belief that death is always a failure – this is not the case in palliative care, especially when that death is in comfort rather than living in prolonged pain. As one panelist remarked, many life-prolonging treatments are “futile.”

Although the UK is often lauded as one of the best countries in the world for palliative care, as one British participant remarked, if she were to rebuild a system from scratch, she would have one piece of advice: be more strategic. Many of the UK’s hospices, especially for children’s palliative care, have been established in an *ad hoc* fashion over several decades, leading to questions of whether these are being used most efficiently in the places where they are most needed.

Fragmentation of services and health insurance is a problem, even in long-established palliative care systems, with patients falling between the cracks of hospital, hospice and home care.

However, one should not assume “strategic” means that the palliative care system should only be built once all other care systems have been fully established; palliative care systems should be built alongside and integrated into the rest of the health care system, not simply “added on” later. If

palliative care can be integrated, this can strengthen the system at large, remarked on participant, with doctors and nurses carrying over their learning in pain management, communication, etc., into other areas of medicine.

Another example of what not to do came from the US: In order to receive hospice care under Medicare, patients must have been given a prognosis of less than six months to live and agree to stop pursuing all other curative treatments. As few doctors are willing to give such a prognosis, many people are ineligible for hospice care. “We should not have put a prognosis requirement on palliative care,” lamented an American participant. “Palliative care access should be based on symptom severity,” he added. Many palliative care systems have been put in place assuming that palliative care is only for the end of life, when indeed palliative care models can also be applied at other stages of illness, perhaps even aiding a recovery.

Transplanting a palliative care model from one country to another without appreciating the local cultural sensitivities surrounding death and end of life care, is rarely successful. In India, once palliative care is offered, patients prefer to leave the hospital and die at home rather than transfer to a hospice. However, national health insurance does not cover this, forcing institutionalization. Whereas, in Nepal, many choose to die in temples to have a holier experience, leading to the question of how can these informal hospices be brought into the wider palliative care system?

Care at the margins

If palliative care is about making sure that all people have the chance of a “good death,” then how do we ensure this is *all* people – including society’s most marginalized?

Marginalized people struggle to access health care services in general, and palliative care is unfortunately no exception. These patients can be hindered by cost barriers, social stigma, or a lack of health literacy.

In many cases, despite knowing these barriers exist, health care systems are failing to serve such patients. Providing care for free (or included in insurance) rather than means-testing can reduce the cost barrier to at-home palliative care, especially for those without family support. Active outreach to the homeless is also vital. In countries where homosexuality is still illegal, access to palliative care can be especially difficult for the LGBT community; social stigma needs to be tackled. Prison populations are aging rapidly; continued incarceration of the elderly will necessitate significant changes in prison conditions.

For those in conflict zones, palliative care is often not considered a priority. For those fleeing conflict, they may find themselves in a country with profoundly different approaches to end of life care and death. Issues can arise when considering how to be culturally sensitive while still avoiding more harmful traditional practices, such as witchcraft and superstitions, but when and where appropriate and possible, host countries should be cognizant and respectful of the cultural differences of their refugee and migrant populations.

Hot Topic: “What is the biggest mistake people should avoid making when building a palliative care system?”

Yeji Park

“When you decide who needs palliative care, it shouldn’t be based on prognosis. In the United States, it is required that two physicians certify that you are likely to die within six months if you want to receive palliative care. This is not a good policy, as we do not have an accurate way to measure when people will end their life. Patients have to give up all curative treatments in order to obtain palliative care as well, but this also is not a good policy. They should be able to make decisions about treatment independently of whether they receive palliative care.”

Stephen Connor

Executive Director, Worldwide Hospice Palliative Care Alliance, USA

“The mistake we will be committing unless we are aware of it, is to create walls, not bridges. In the Philippines, there is a trend where the specialists want palliative care to be recognized as a separate specialty and do not want to share skills or tasks with others. We need to be willing to share the knowledge and technology with more people, especially from the grassroots. Because, in the end, it’s not about competing against colleagues from other specialties or among ourselves, but all about making sure that everyone has access to good end of life care.”

Liza Manalo

Head, Section of Hospice and Palliative Care at the Medical City Hospital, Philippines

Have an opinion on any of our hot topics this week?

Email Salzburg Global Seminar Editor Louise Hallman (lhallman@salzburgglobal.org) with either a short 50-100 word response or a 500-750 word article and we will consider it for publication in the report to be published in early 2017!



“In Germany, we have a slightly unusual structure where hospice care and palliative care unit are two different structures with different organizations. The palliative care unit is a part of a hospital where they provide more acute care, whereas hospice is a special care home where people can stay longer. These two work and function alongside each other, but they do not always cooperate closely, and sometimes they even work against each other. This is not helpful when you want to move a topic forward politically in the society. There has to be a joint force.”

Claudia Bausewein

Director, Department for Palliative Medicine at Munich University Hospital, Germany

“The biggest mistake that has been made, especially within Africa, is the inadequate funding of the entire health care system. Currently in Africa, 15% of the national budget goes to the health sector. In Uganda, it’s only 7%. This is not enough to cover every aspect of health care, especially the palliative care side. In addition, palliative specialists should be recognized and remunerated by the health service commission as such, so that they can fully concentrate on palliative care.”

Emmanuel Luyirika

Executive Director, African Palliative Care Association, Uganda



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“My realization is that one of the greatest sufferings for the human being is loneliness. The sense of separation from everything. It brings to the question of where we are today in the field of medicine. Medical professionals are so separated from their patients. They are so separated from their own humanity. Because science has actually taught doctors and health care providers to see everything through the lens of science, not through the lens of the heart or our own humanity.

That’s probably why I find palliative care so liberating. Because it gives us back the opportunity to merge science, and all of the wonderful discoveries that human development has brought, with the heart. That’s why I’m a huge activist for palliative care.”

Lynna Chandra

Founder and Trustee, Rachel House, Indonesia/Singapore

Lynna Chandra, the founder of Rachel House, a children’s hospice in Indonesia, explains what draws her to palliative care. Having worked as an investment banker over a decade, Lynna opened the first pediatric palliative care service in Indonesia in 2006 with the vision that “No child should live in pain.”

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