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# Rethinking Care Toward the End of Life

Thursday, December 15, 2016

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@DrGregorSmith: Privilege to be participant @SalzburgGlobal Rethinking Care towards End of Life. Great conversations already



Al Mulley, Agnes Binagwaho, David Currow and Irene Higginson

## How to enjoy a “healthy death”

Where do we want to see the field of palliative care in ten years? This was the opening question at the Salzburg Global Seminar session *Rethinking Care Toward the End of Life*.

To consider where we want palliative care to be in ten years' time, we need to first consider what the population will be like in ten years' time, suggested one panelist on the opening panel, who together brought expertise from Australia, Rwanda, the UK and the US.

Many countries' populations are aging rapidly. Co-morbidities are also on the rise as people suffer from more than one condition at a time. Both factors will place strain on existing health care systems. As another participant put it: We've become so successful at preventative and curative care, we now need to address palliative care and ensure that, as well as living a healthy life, we can also die a “healthy death.”

How can we have a good life and healthy death instead of a prolonged life and painful death? Society has become so fixated on living as long as possible that they have forgotten that dying is also part of life, remarked another panelist.

The stigma surrounding death needs to be tackled, much like the stigma surrounding HIV/AIDS has been. To do this we need a societal shift in attitudes.

Society has proven it can profoundly change its behaviors in the past; that smoking would be such a societal taboo was unthinkable a generation ago.

How can we accomplish this shift? It will take both a top-down, policy-based approach, as well as bottom-up, grassroots engagement, with both ends demanding change in the current health care system. One must also not forget the health care professionals in between these two approaches. “We need doctors who can talk about death,” said one participant, rather than induce fear. Palliative care is too often an add-on rather than central to a dying patient's care. Engaging palliative care doctors *before* oncologists, for example, may help to treat the *whole* patient.

Central to the debate on palliative care is the patient and their wants and needs. “I do not want others to have what I do not want to have,” said one panelist. In many countries, dying in hospital is a status symbol and proof of the value a family places on their loved one's life. However, many people would prefer to die in comfort at home; families and doctors need to understand and meet the patient's own preferences.

Achieving these societal and professional shifts is no small undertaking. The experts gathered in Salzburg this week have much to consider and debate.



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## Hot Topic: “What do you hope for palliative care in ten years’ time? What do we need to do to get there?”

Chris Hammil-Stewart & Yeji Park

“Incremental change would not be sufficient to reach the kind of state where people can have access to palliative care that supports people to achieve what they want as life reaches its end – this could be called a good death or a healthy death. It would take not even transformation, but a revolution to achieve that within a decade. There are so many potential actors who can begin the initiative. Wherever it starts, it would have to be coordinated and strategic in order to achieve what we need to.”

### **Albert Mulley**

*Managing Director, Global Health Care Delivery Science at the Dartmouth Institute for Health Policy and Clinical Practice, USA*

“In ten years, I want to see death integrated with life, and palliative care not being a side discipline but rather an integration of death as part of normal life... It’s going to take a revolution, but with cultural specificity acknowledging the different cultures. In other words, it’s not going to take the same face in the United States, in Rwanda, in France, in Germany, and so on.”

### **Veronique Roger**

*Medical Director of the Center for the Science of Healthcare Delivery, Mayo Clinic, USA*

“We need to create an enabling environment for healthy death, so that when the time to leave the world comes, we can die in dignity surrounded by what we like, not in the cold, white environment of a hospital. For this to happen, we need a cultural recovery to readmit death with dignity as part of the ordinary life. To reach that, we need to have national debate about it, led by spiritual and community leaders, and we also need to educate all clinicians to respect death and to stop being afraid of it.”

### **Agnes Binagwaho**

*Professor, University of Global Health Equity, Rwanda*

“In an ideal world, palliative care will have changed its role substantially in ten years. The expectation in the community is that if you have a life-threatening illness, you will get good palliative care, from primary and specialist care, and, if your needs are particularly complex, from specialized palliative care service. That’s going to take a grassroots revolution to occur, for communities to start asking for good palliative care. It’s going to take an enormous change to achieve that in ten years, though.”

### **David Currow**

*Chief Cancer Officer and Chief Executive Officer at Cancer Institute NSW, Australia*

“I think health care has to change to keep up with aging populations, treatments that keep people alive longer, and it should start looking after people with mixed conditions as the norm, not the exception. Palliative care needs to be adjusted to follow these changes – it should become mainstream, not just an additional luxury. Palliative care should help people live well, by adding life to years, and health to years rather than just prolonging dying. I think to get there we need a complete turnaround in how we think of health care.”

### **Irene Higginson**

*Head of Department, Cicely Saunders Institute, King’s College London, UK*

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

Email Salzburg Global Seminar Editor Louise Hallman ([lhallman@salzburgglobal.org](mailto: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!



## #FacesOfLeadership

“In Rwanda, we were able to establish an equitable health sector by sharing the social capital equally. More than 90% of Rwandans have health insurance, and more than 93% of children are vaccinated against 11 antigens. We have universal access to HIV treatment, and the result of our TB treatment is among the best on earth.

“This was only possible because we have built our health sector where health is not the only silo. We have taken other social determinants into account and built a health sector with the sector in charge of gender, local governance, and education. We have created a system of multi-stakeholders’ intervention in synergy and harmony, inside of a multi-sectoral approach.”

### **Agnes Binagwaho**

*Professor, University of Global Health Equity, Rwanda*

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Agnes Binagwaho explains how, as Minister of Health in Rwanda from 2011 to 2016, she was able to contribute to building an equitable health sector in Rwanda. As a pediatrician and having served in the public health sector in Rwanda for 20 years, Agnes has been awarded many renowned prizes for her contribution to improving the health of children.

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Read more profiles in our series of #FacesOfLeadership online:  
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@DrLuyirika: Working on prioritisation of key issues in #EOL #sgshealth



## Finding the patient's pigeons

**On the second day of *Rethinking Care Toward the End of Life*, panelists from the US, Singapore, Canada, Uganda and the UK considered how do we engage patients and families to ensure that end of life care honors what matters most to them?**

Not all patients want to live at all costs. Many want to enjoy what is left of their lives. "Death is not always a failure" of medical care, remarked one panelist. "We are so afraid of death that we harm people" by keeping them alive.

One panelist shared an anecdote of a prize-winning pigeon fancier in Scotland who was told by his doctors that he would live longer if he gave up his sport and his birds. His daughter, upon showing the visiting doctor her father's collection of pigeon racing awards and prized birds, clearly stated: "My father would rather die than give up his pigeons." When considering a patient's – or rather a *person's* – end of life care, clinicians and families need to consider what actually matters most to the patient, and add life to their days and just days to their life.

Patients and their families need a great amount of help and support toward the end of the patient's life. Too often, palliative care specialists are brought in so late that neither the patient nor their families have a relationship with

these new doctors. Developing a good relationship with patients and families depends on good communication. In countries where multiple languages and dialects are spoken, every opportunity should be made to ensure patients can access information and express their preferences in their mother tongue.

As one panelist identified, there are three opportunities to communicate well with patients and their families. Firstly, before they are even sick. Providing people information about end of life care choices when they are still well could help reduce the anxiety and distress of terminal illness and the taboo and fear surrounding death. "Death is a stage of life," added another participant.

Secondly, during illness; medical options and alternatives to medical interventions need to be clearly communicated so that patients can partake in the "shared decision-making" process about their care.

And finally, after death; sensitive, ongoing communication with bereaved families can help further learning and improve systems for future patients.

Cultural understanding was also highlighted. Different faiths and cultures view death differently, and offering patients and their families spiritual as well as medical and community support can be of great help.



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# Elizabeth Namukwaya – “It would be tragic to have a very good life, but have it end in severe distress”

Palliative care physician and senior lecturer in Department of Medicine at Makerere University on what Uganda is doing right in palliative care – and the challenges it faces

Chris Hamill-Stewart

A central theme at the session *Rethinking Care Toward the End of Life* has been how to provide people with a “good death,” understood by many to be dying in comfort, surrounded by loved ones, in a familiar place.

Elizabeth Namukwaya, palliative care physician and senior lecturer at Makerere University College of Health Sciences, has important insights into what makes Uganda a good example of a community-based approach to providing a “good death,” but also highlights some obstacles to the wider implementation of the approach.

Namukwaya begins by stating just how important palliative care is: “We’re all definitely going to die, and it would be tragic to have a very good life, but have it end in severe distress.” This is what she’s working to prevent, but in Uganda, this comes with challenges.

“We don’t have so many resources, especially in terms of doctors,” says Namukwaya. “Our doctor-to-patient ratios are very bad, and we have very few trained people, such as nurses.” This lack of resources has meant the health care system, and especially the palliative care field, has adapted and developed differently to those in the West, with a greater focus on community-based care.

Many participants and panelists of *Rethinking Care Toward the End of Life* expressed a belief that a stronger focus on community-based care could be beneficial to giving people a “good death,” and Namukwaya attests to this: “The community care that Uganda provides is strong – we have a well-developed sense of community.” The result of this is that “people look after each other, especially for home-based care.” She has seen how “someone in your community is likely to understand your needs better than some stranger,” which means care at the end of life is less likely to cause distress.

“Doctors and nurses don’t spend most of the time with the patient – it’s the community that lives with the patient,”



Namukwaya (center) poses alongside other participants for the traditional group photo

she adds. “Therefore, we should empower the community to provide the care for themselves; decisions should be made at the community level. This is also likely to cut a lot of costs within the health system.”

She believes this is where Western countries, with very advanced but often impersonal health care systems, could learn from Uganda’s approach to palliative care.

The community-based approach in Uganda appears more likely to be able to provide a “good death,” but Namukwaya points out that it doesn’t come without its own set of challenges. Primarily, she believes that the sense of community in Uganda is in decline in many places. “As people get more educated, and women have less children, people move to urban areas and the communities shrink... Eventually you may lose the community, and that’s a big problem.” With communities shrinking, the opportunities for community-based care shrink with them.

Community-based care also has the potential to let people “slip through the cracks.” Namukwaya points out that as people leave for cities, “You may find elderly people alone, with nobody to care for them. That’s an obstacle to home based palliative care.” These people can’t rely solely on community-based care.

If patients and their communities rely entirely on the state, they are

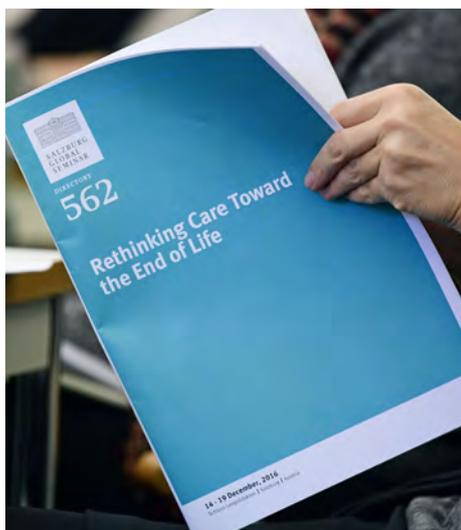
unlikely to receive the care they really want. As Nakamura explains: “Many hospitals in Uganda are very busy. Some people just want to go home, to be with their people.” However, if care relies too much on community, and the state reduces its influence and input into palliative care, there is a chance that isolated individuals will not receive the care they need, especially as these communities shrink.

As well as the West learning from Uganda’s community-based approach, Uganda has taken lessons from the West’s approach to palliative care.

“What has been stressed during this session,” reflects Nakamura, “is that palliative care in developed countries has come as an add-on, something separate, as opposed to being integrated into the systems. That’s one thing that we need to be cautious about in Uganda.”

When it comes to a community-based and state-led approach to palliative care, a balance needs to be struck. The fine line between the two approaches must be based on the needs of the individual societies; there is no sweeping answer to such a nuanced and deeply personal and individualized debate.

“We’re not just treating the disease, we’re treating the person. The person has a family, social, and emotional aspects to consider, and unless you address them... You wouldn’t be truly caring for the person.”



## Meeting the preferences of those who can no longer express them

“Next week will be worst week for palliative care specialists!” exclaimed one panelist in the fifth and final discussion of the second day of *Rethinking Care Toward the End of Life*.

As he went on to explain, the coming week will see many far-flung family members come home for the holidays and visit their loved ones in palliative care units, hospitals and hospices – bringing with them entirely different opinions about the patient’s care.

Patients may have clear ideas of how they wish to spend their final days, however, these wishes may not be shared with their immediate next of kin, direct caregivers or wider families, prompting fierce debate on how best to treat the patient if and when they become incapacitated and unable to express their own preferences.

As one participant pointed out, offspring of incapacitated parents often feel it is their duty to keep their ailing parent alive as long as possible – even if this is of great discomfort to the patient. Keeping their parents in an expensive hospital, rather bringing them home to die in familiar comfort, can also be seen as a sign of respect.

Some countries, such as Singapore, have passed laws that enable people (sick and well) to outline their preferences in “advanced care directives,” detailing whether they wish to be intubated, resuscitated, kept in hospital, brought home, etc. Such “living wills” can help avoid clashes between patients and their families.

Another way to mitigate against

such divergences in preferences would be to have frank, open and honest discussions between family members about what care we want at the end of life – even before we get sick. By discussing these underlying general values during wellness, caregivers and families can be better placed to make more specific decisions during illness – and be reassured that they are carrying out their filial duties.

Children (i.e. minors) who are terminally ill have their end of life care decisions legally entrusted to their parents. Palliative care providers need to be especially sensitive in their communication with young patients and not simply assume that they are too young to understand or be able to express any preference. “We need to upgrade our communications skills as often as we upgrade our clinical skills,” pointed out one participant, a pediatric palliative care specialist.

Much of the discussion surrounding palliative care focuses on cancer patients and their pain management, however there are many more patients who have end of life needs. As our populations age, dementia is increasing, bringing with it complex care needs. Often dementia patients do not wish to disclose their diagnosis to family members, lest they view and treat them differently. Despite their declining health, dementia patients should still be included in decisions about their care, with questions focusing on their emotional, rather than simply medical, needs.

## (Palliative) care in the (online) community

How can we support patients and families within their communities?

If enabling people to stay in their homes and communities is preferable to dying in a hospital, how can this be best supported? While patients may want to die surrounded by their loved ones, not all families are prepared for or able to carry out this care-giving role. Support and care needs to be offered to the *caregivers* as well as the patient to help them fulfill this role. We also need to acknowledge that caregivers might not be the next of kin or even a family member.

One tool that has been developed to help patients and their families is the “Virtual Hospice” in Canada. The first online platform of its kind in world, the website offers practical advice and instructional videos on such things as how to lift patients in and out of bed. These videos reduce strain on local nursing resources, often called out to demonstrate the same skills repeatedly, and offer an immediate source of information to families in need. “People are saying ‘I no longer feel alone’ to a website,” explained one panelist, demonstrating how online communities can be a powerful and supportive resource.

While no participants were advocating for the replacement of in-person care with virtual assistance, online tools can help “plug the gaps” in care provision – especially for rural communities. Developing these tools necessitates active listening to identify where those gaps are.



Cynthia Goh



Anya Humphrey



Amber Barnato

## Hot Topic: “How can we ensure that the preferences and needs of patients and families are met when providing palliative care?”

Yeji Park

“The key to delivering good palliative care is to start the process at the right time. It should not start at the later stage when the end is near. The doctor who initially delivers the treatment needs to convince the patient that there is another team who are going to take care of the patient until the end. Otherwise, the patient will refuse to even take palliative care. After that, palliative care has to be holistic, comprising of medical care, psychosocial support and also, financial and livelihood support when you are dealing with low-income countries with a lot of people living in poverty.”

### **Jagannath Jayanthi**

*Executive Committee Member, Pain Relief and Palliative Care Society, India*

“I think patients and families need to be engaged in three ways, and they are all about conversation. First of all, we need to have more conversation at the beginning between the treatment team, the medical team and the patient and family. After someone has died, we need to have real conversations with the family about how it went. Beyond that, we need to have patients and families who are willing to work on the team together, to design and deliver the system better. In addition, we have to have the fridge magnet – the reliable place to call in an emergency.”

### **Anya Humphrey**

*Patient and Family Advisor, Canadian Fund for Health Care Improvement, Canada*

“I think the most important thing is to listen. To listen carefully to the patient and to the family, and to read in between the lines – not just the words, but the body language and the meaning behind the words. In general, families want the best for the patients, but that is not necessarily true. They may not realize that what they think is the best for the patient may not be the same as what the patient wants. I think we need to distinguish between those things.”

### **Cynthia Goh**

*Senior Consultant, Division of Palliative Medicine at the National Cancer Centre, Singapore*

“When the patient with a terminal case comes to our hospice, we start by assessing the five needs: social, psychological, medical, spiritual, and financial need. With every visit, we reassess the need of the patient so that we can provide the right support at the right time. Through this reassessment, we could meet the expectation of the patients and family members. Sometimes I find family members coming to volunteer for us after the death of the patient, or patients donating their belongings to our organization. I think these indicators prove that our work has met most of their expectations.”

### **Tandiyar Samir**

*General Manager, Josaab Foundation for Social Development, Egypt*

“One of the things I teach first and foremost to medical students is to try to avoid focusing on their own

goals, but to stay present, mindful, and curious so that they can listen to what patients and family members are saying, including their nonverbal communication. In addition, I teach students how to manage their own discomfort when patients go through emotional moments. We usually have a natural compulsion as humans to try to reassure or comfort them. However, I teach students ways to acknowledge the discomfort and sit with it, rather than trying to deflect or distract the situation.”

### **Amber Barnato**

*Tenured Associate Professor of Medicine, Clinical and Translational Science, and Health Policy and Management, University of Pittsburgh, USA*

“Particularly in palliative care, we need to understand the cultural context behind this responsibility. We have seen in today’s discussion that the cultural context, which changes by country, has all to do with the way caregivers, families and patients interact. And in that interaction, it is not only the cultural aspects of the patients and families but also those of the caregivers that need to be acknowledged, in order to enable the three of them to work as a team around the quality of life of the patient.”

### **Juan Pablo Uribe**

*Director General, Fundación Santa Fe de Bogotá, Colombia*

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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](mailto: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*



## #FacesOfLeadership

“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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