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Rethinking Care Toward the End of Life

Friday, December 16, 2016

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If you're interested in writing either an op-ed style article for our website or the session report, or a personal reflection blog post while you're here this week, please let Salzburg Global Editor, Louise Hallman know or email your submission directly to lhallman@salzburgglobal.org.

If you do intend to write for your own organization either while you're here or 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.

We'll be updating 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

You can also join in the conversation on Twitter with the hashtag [#SGSHealth](https://twitter.com/SGSHealth) and see all your fellow Fellows and their organizations on Twitter via the list www.twitter.com/salzburgglobal/lists/SGS-562

We're updating both our Facebook page www.facebook.com/SalzburgGlobal and our Flickr stream www.flickr.com/SalzburgGlobal with photos from the session during this week and also after the session. (If you require non-watermarked images for your own publication, please let Louise know.)

We will also be posting photos to Instagram www.instagram.com/SalzburgGlobal. Use the hashtag [#SGSHealth](https://twitter.com/SGSHealth) and we might feature your photos in the newsletter!



@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

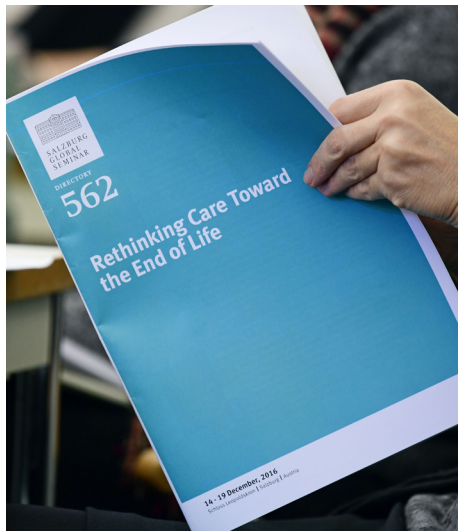
unlikely to receive the care they really want. As Nakamura explains: “Many hospitals in Uganda are very busy. Some people just want to go home, to be with their people.” However, if care relies too much on community, and the state reduces its influence and input into palliative care, there is a chance 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 panelists, 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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