

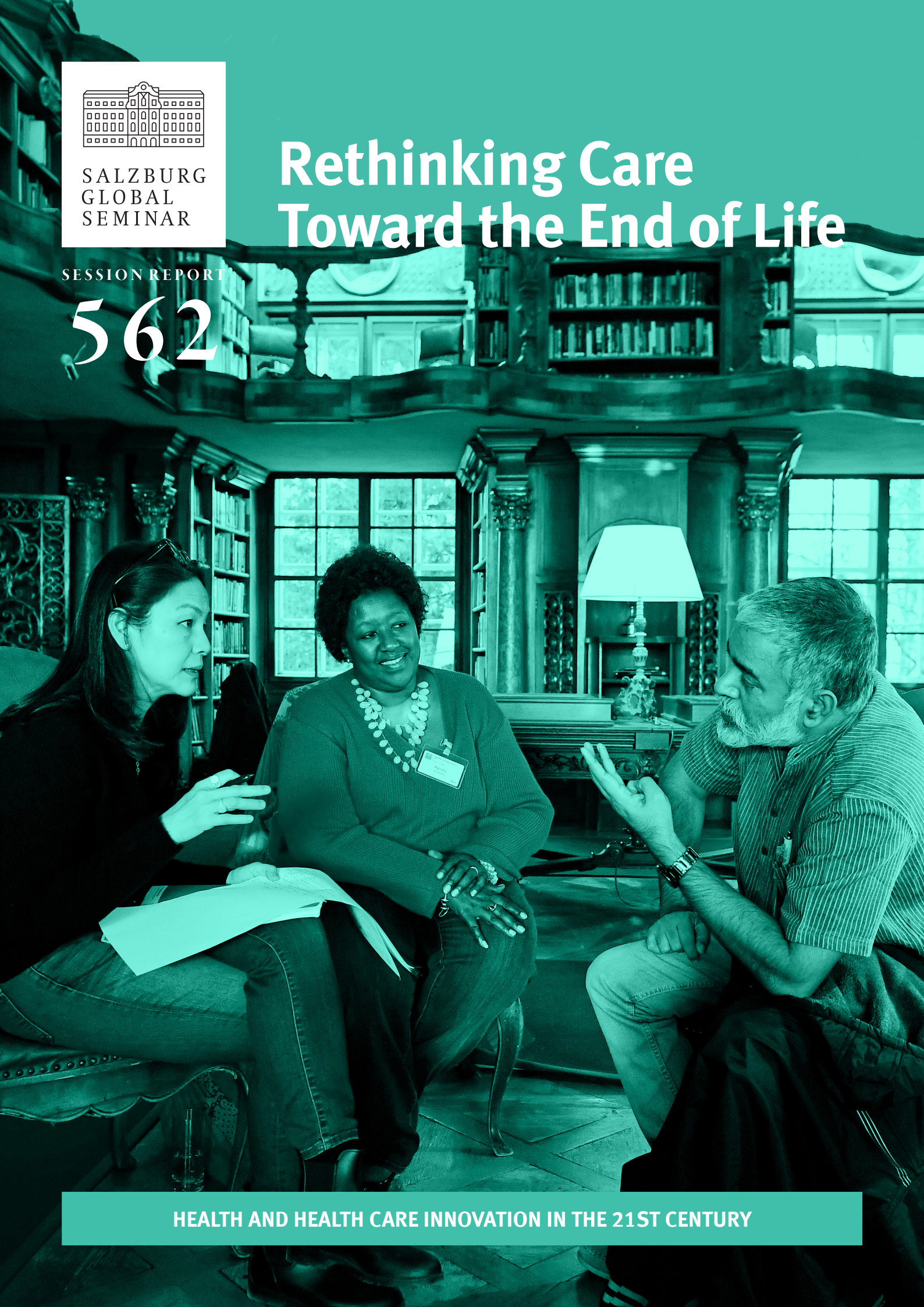


SALZBURG
GLOBAL
SEMINAR

SESSION REPORT

562

Rethinking Care Toward the End of Life



HEALTH AND HEALTH CARE INNOVATION IN THE 21ST CENTURY

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Rethinking Care Toward the End of Life

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Introduction

On December 14, 2016, 60 Salzburg Global Fellows from 13 countries arrived at Schloss Leopoldskron in Salzburg, Austria for a Salzburg Global Seminar session held in partnership with the Dartmouth Institute for Health Policy and Clinical Practice and Mayo Clinic. Drawn from an array of disciplines and sectors, including health and social care leaders and practitioners, innovators, ethicists, policymakers, economists, and representatives of civil society, the media, and other stakeholders, the group was charged with a simple task: to rethink care toward the end of life.

Health care systems everywhere face a multi-faceted crisis, and care toward the end of life is at the sharpest end of that, from care of the increasingly vulnerable through to extensive palliative care. There is a need to re-think such care to make sure it is actually what patients want, what they need to serve their goals at the end of life, and to shape provision through aggregating preferences and through community engagement rather than structuring care as legacy systems dictate. We need to identify best practice, first in ascertaining these preferences and variations among them, and then in acting on them, often when there are growing uncertainties and resources are constrained.

As well as effective shared decision-making necessary to shape treatment in line with patient preferences, the aggregation of data about such choices is required to guide the development of capacity in health systems. And comprehensive end of life care transcends the traditional boundaries of health care systems, of course – ever greater emphasis is being placed on the integration of health care with social care. The way we gather, integrate and deploy data around health and social care toward the end of life is crucial in ensuring that interventions are effectively centered on patients' values, their wants and needs.

Ethically and politically a particularly acute issue is how decisions are taken when a patient can no longer express their own preferences. There are diverse protocols to guide clinicians in these circumstances. But this cannot be resolved technocratically – it requires continuing public engagement and debate.

“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 G. Mulley, Jr., USA



KEY QUESTIONS

1. How do we engage patients and families to ensure that end of life care honors what matters most to them, with respect for culture and for context at the level of the individual and the population?
2. What are the relative contributions of health care and community-based social care in different contexts? How can they best be joined up to maintain function, independence, and agency for people for whom death is near?
3. How can health care systems better support families, caregivers and community members in caring for people of all ages for whom death is near?
4. How are robust processes established and implemented for arriving at decisions when patients can no longer express their own preferences? What role does public engagement and the government have in this?
5. Which are the most promising evidence-based and cost-effective innovations in care toward the end of life? What yields greatest value to patients, especially in low resource settings?
6. What can we learn from the system failures in high-income countries with regard to supporting patients, families, and caregivers with palliative care?
7. How can palliative care best be undertaken in the context of societal deprivation and conflict?

These questions around end of life care are urgent globally, and innovators and pioneering organizations in the US, Europe and low and middle income countries are making breakthroughs. The time is ripe to ensure that these are scaled up and replicated to the benefit of general populations – bearing in mind that the resources necessary for effective care varies greatly across the social spectrum and in low and middle income countries. Less wealthy countries can often teach much across borders as to innovation and the most effective use of resources, to the benefit of other countries, rich and poor. This applies to end of life care for younger populations just as much for elders. But no country, whether the United States or in Europe, is in a position to continue “business as usual” and meet the challenge of aging populations. The Salzburg Global Seminar session sought to foster much cross-border learning, Global South to South as well as South to North and North to South.

In order to *rethink* care toward the end of life, the Salzburg Global Fellows (as participants of Salzburg Global Seminar sessions are called) first had to understand “end of life” in the life cycle context and to explore the current issues people living with terminal illness around the world experience today. Two perspectives – that of integrity and that of despair – illustrate the variation of this experience and the importance of cultural and contextual considerations.

Following this examination, Fellows then offered recommendations for how better to deliver care at the end of life.

“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.”

Veronique Roger, USA

Toward the End of Life

In the Hindu philosophical system, death is a natural process within the cycle of life. “There’s no fear of the finality of death,” Salzburg Global Fellow Nandini Vallath from India said of her home country. “The belief is that death is discarding of the body, while the soul transitions into another life form. Through repeated reincarnations, the soul gets the opportunity to experience and evolve toward perfection; finally merging with the immortal, infinite singular conscious principle.” Through reincarnation, the soul finds a new body in which to rest. Nearing the end of life is thus, from a Hindu viewpoint, a time to reflect on one’s life. If the person has lived a respectable life and performed good deeds, he or she may embrace this transition with a sense of peace and honor.

A Conflict of Integrity and Despair

In Western psychosocial developmental theory, this positive view of aging as a time for reflection is seen again. A person’s nearing to the end of his or her life *can* be a deeply meaningful time for finding a sense of peace and integrity within oneself. During the Salzburg Global session, Amber Barnato from the USA shared psychologist Erik Erikson’s framing of life’s last developmental stage as a conflict between *integrity and despair* with successful resolution in wisdom (see [FIGURE 1](#)). This framing would echo through the Fellows’ discussion over the next days in a search for the answer to a central question: *Where is the wisdom in health care toward the end of life?*



FIGURE 1: ERIKSON'S STAGE THEORY¹

Age	Conflict	Resolution or "Virtue"	Culmination in old age
Infancy (0-1 year)	Basic trust vs. mistrust	Hope	Appreciation of interdependence and relatedness
Early childhood (1-3 years)	Autonomy vs. shame	Will	Acceptance of the cycle of life, from integration to disintegration
Play age (3-6 years)	Initiative vs. guilt	Purpose	Humor; empathy; resilience
School age (6-12 years)	Industry vs. inferiority	Competence	Humility; acceptance of the course of one's life and unfulfilled hopes
Adolescence (12-19 years)	Identity vs. confusion	Fidelity	Sense of complexity of life; merging of sensory, logical and aesthetic perception
Early adulthood (20-25 years)	Intimacy vs. isolation	Love	Sense of complexity of relations; value of tenderness and loving freely
Adulthood (26-64 years)	Generativity vs. stagnation	Care	Caritas, caring for others; and agape, empathy and concern
Old age (65-death)	Integrity vs. despair	Wisdom	Exisistential identity; a sense of integrity strong enough to withstand physical disintegration

¹ Erikson, E.H. (1964). *Insight and Responsibility*. New York: Norton.



Medicine's Evolving Promise of Life

Globally, medical advances and the strengthening of care systems have offered the increasing promise of longer life and slower aging. In developed countries and progressively in developing countries, treatments are increasingly available to prevent, cure, or control infectious illness that once held high mortality rates. Medical progress will discover new cures, and illnesses that were once terminal will continue to shift to new identities as chronic conditions.

Some Western influences are proving to be beneficial in developing nations. Advances in diagnostics and treatment are minimizing the burden of disease and preventive strategies being implemented are reducing the morbidity associated with infectious disease. Health systems overall are growing more complex, with further developments in education and training for health professionals and a broader scope of diagnostic and treatment options available to populations.

Substantial challenges remain across health sectors in developed and developing countries. In developing areas, this includes: lack of specialty care, cost and logistical barriers in access to treatments and medications, and overall health system strengthening needs. Yet through innovation and strategic use of resources and cultural care practices, developing countries are progressing and many can now offer their populations more equitable access to healthcare than ever before.

The Inevitable, Unintentional Side Effect of Advancing Medicine: Diminished Integrity and Increased Despair

A developing medical system has the opportunity to engage people toward the end of life to help define meaning. However, particularly in rapidly advancing medicalized systems, the opportunity to find meaning through individual voice is often missed due to our strongly biological approach to medicine.

The nearing of end of life can, and should, offer a moment to find peace and solace through integrity. Yet aggressive treatments often compromise quality of life and challenge the integrity of death, particularly for those for whom the promise of a cure lies out of reach. As Albert Mulley from the United States said in Salzburg: “We’re not just creating economic harm [by not improving end of life care;] we’re creating isolation and suffering.”

A Story from a Family Caregiver

Anya Humphrey from Canada offered a piece of writing to the Fellows, sharing an incredibly raw and honest depiction of her husband’s death, one that came after moments of comfort and integrity but also of pain. Humphrey expressed a wish to continue to share her story as a means of evidencing the dire need for medicine to refocus on delivering care, comfort, and integrity at end of life:

“Fred began to get confused about things, whether from meds or the death process I didn’t know. But I wanted to help him understand, to explain, to soothe his anxiety, to listen... I felt I was failing him by not somehow helping him to have a clear mind. He was a Tibetan Buddhist. He wanted to go to his death as consciously as possible. He also wanted not to suffer any more pain than necessary. I had no idea how to manage this trade-off... I had promised to do the best I could to make Fred’s death comfortable and painless and conscious. This was not the experience I bargained for.”

Anya Humphrey, Canada

Death as a Failure

In our progress forward to extend life expectancy, there is increasingly no longer any room for death. “No one told me death was an option [in Western medicine,]” one Fellow said. Throughout the week-long session, it became clear that death signifies failure within the medical community, and that clinicians’ training does not often prepare new cohorts of practitioners to discuss death as a potential outcome of medical treatment. It is the clinical trial that did not work;

the science that failed; the provider who not did diagnose soon enough, who did not offer adequate options, who did not escalate care, and who did not try hard enough. And, as some patients feel, death is a sign of giving up and letting go.

In many countries, an expression of preferences that may not align with progressive, curative-focused medicine is colored darkly. Wrapped in care systems designed to cure, patients are too often taught that choosing any alternative to a “fight to the death” is a failure to themselves, their families, and the system.

Globally, a reported 40 million people are in need of end of life care, 78 percent of whom living in low and middle-income countries.² But only an estimated 14 percent of people who need palliative care currently receive it.³



² World Health Organization. (2017). Palliative Care Fact Sheet. Retrieved from: www.who.int/mediacentre/factsheets/fs402/en/

³ ibid

The Medicalized Patient

Specialized medicine is necessary for high quality medicine to be performed; a doctor must be well studied and trained on the minute details of the illness and treatment regime in order to select and perform the best treatment. But with this specialization, a trade-off too often occurs. The person seeking care becomes increasingly medicalized.

This separation is evidenced in the labels we use. The person before us – who has values and preferences and whose choices represent meaning in his or her life – becomes “the patient,” absent of a name and an identity beyond a diagnosis. As diagnostics are further and further complex and increasingly specialized care is delivered, this biological focus even further divides our view of the person: from a person, to a patient, to a “brain tumor patient.”

FIGURE 2: FROM “PERSON” TO “PATIENT”⁴



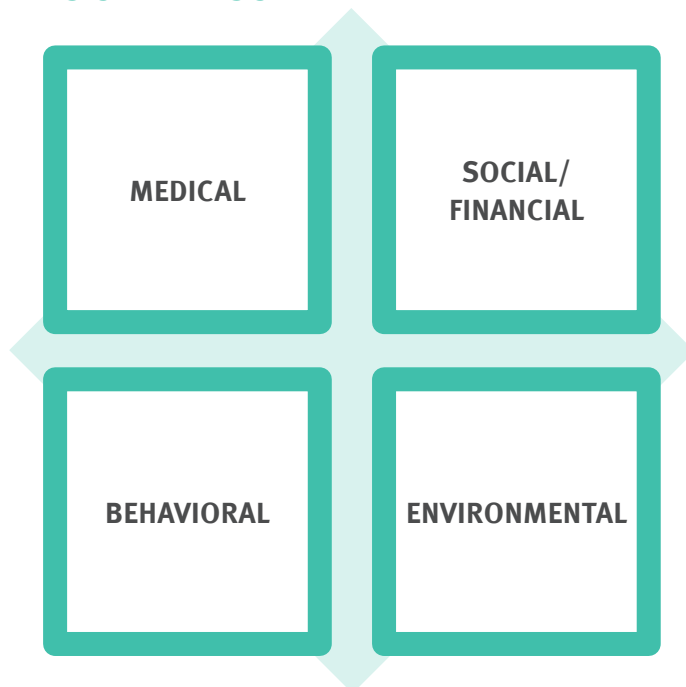
⁴ Eagan, A. (2016). [From “Person” to “Patient”]. Unpublished raw data.





Similarly, we divide a person's biopsychosocial components. "People start out whole; we divide them into parts," Bruce Chernof from the USA said, presenting the following diagram:

FIGURE 3: DIVIDED PARTS OF A PERSON ⁵



⁵ Chernof, B. (2016). [Divided Parts of a Person]. Unpublished raw data.



This division is evident in our language within team structure, through the silo order of patient visits (doctor, social worker, case management, etc.), and in medical charting (i.e. presenting symptoms, past medical history, social history, etc.). “The dichotomy [of health and social “components” of a person] – that is made in the system – is a false dichotomy,” Irene Higginson from the UK said. “A person is not health or social; they are a whole person with many facets that interact.” The Fellows discussed the challenge: as medicine continues to evolve to center on the medical/biological elements of a person, growing increasingly depersonalized and medicalized, we must remain focused on supporting medical advancement while also keeping focus on the whole person behind the segmented pieces of care and his or her values.

The silo approach to medical treatments limits the degree to which physicians can work across disciplines and specialties in order to meet the multifaceted needs of patients toward the end of their lives, many of whom suffer from multiple comorbidities requiring complex care from a range of specialists. The existence of newly embraced language of “interdisciplinary care” and “multi-disciplinary care teams (MDTs)” evidences our global health systems’ grappling with this partialized vs. holistic view.

True “Patient-Centered Care:” “Person-Centered Care”

Fellows discussed how they aim to provide “patient-centered care,” in whatever capacity they can. In developed countries, and increasingly in developing countries as well, hospital websites and pamphlets highlight a dedication to patient-centered care, defined by the US’ National Academy of Medicine (NAM) as care that is “respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.”⁶ Yet even with the best intentions, we often make one central error in our effort to provide patient-centered care: we define the patient and his or preferences ourselves, rather than empowering patients and families to do so.

“Personalized care is more than taking a psychosocial history and putting it in a patient’s medical chart,” one Fellow said. “It’s about asking people, themselves, to define how they value outcomes, risks, decisions, and time trade-offs.” Throughout the session, it became apparent that medical institutions fall short of this gold standard of care; institutional red-tape, time constraints, and inadequate training serve as critical barriers to delivering care that is truly driven by the preferences and needs of the patient, particularly at the end of life.

As developed countries and developing countries continue to advance care and engage in more complex life-extending treatments, it is critical that we navigate and integrate patients’ preferences into care. This is particularly challenging and perhaps most important when the priorities of the patient differ from the priorities instilled in the medical community.

Countless advanced planning tools, trainings, and techniques have been developed to aid medical teams across a variety of settings in engaging patients in complex medical conversations and decisions. Many of these tools have proved effective in specific settings with certain patient populations. In fact, in the United States, some of these advanced planning and care directives hold legal weight, becoming lawful documents that can guide a family and medical team as the patient become less able to speak for themselves. Though such tools hold value for clinical practice, discussion during the session highlighted the limitations of such tools. Patients and their families often do not understand the scope and confines of an advanced directive. Indeed, completing one is not a suitable substitution for having in-depth conversations about end of life preferences and values. It is only through such conversations that one’s wishes toward the end of life can truly be honored. Thus, advanced directives should be viewed as one component, not a replacement, of conversations around end of life care.

“Personalized care is more than taking a psychosocial history and putting it in a patient’s medical chart. It’s about asking people, themselves, to define how they value outcomes, risks, decisions, and time trade-offs.”

⁶ The Six Domains of Health Care Quality. Content last reviewed March 2016. Agency for Healthcare Research and Quality, Rockville, MD. Retrieved from: www.ahrq.gov/professionals/quality-patient-safety/talkingquality/create/sixdomains.html

“Is our personalized approach to care really personalized? Who is deciding? Do we take the peoples’ priorities as seriously as the medications we are using to take care of them? What is it about giving in to the patient who may know better that we are all so afraid of?”

Catherine Calderwood, UK

In developing countries, the foundation of these tools and measurement techniques is not well developed. As care continues to prolong life, advanced treatment options, clinical trials, and mechanical support, conversations must be offered around complex medical decisions, including the continuation or escalation of care, Do-Not-Resuscitate (DNR)/Do-Not-Intubate (DNI) orders, and the use of mechanical medical support. In these areas in particular, the time is ripe to learn from the mistakes of developed countries and mold healthcare systems to be proactively rooted in patient preferences, rather than reactive to them after care patterns have been laid out.

But, as the Fellows discussed, there are two key issues in advanced care planning, particularly when it focuses on select medical choices. The first issue is that, as Eric Finkelstein who works in Singapore shared, “We can’t think about what we want in the future because we underestimate how much we think we can change.” Finkelstein shared examples from a study on patients’ willingness to pay for one additional year of life. “[We found that] most people would pay \$6,000 to extend life by one year,” he said. “But cancer patients would pay \$20,000 to extend life by one year. [This is] because the decision is real to them; they are actually facing [end of life]. Value is influenced by external and internal factors.”

The second issue is health providers often feel the need to always offer an intervention. Rather than filling out Code Status paperwork to determine the patient’s choice for a certain medical intervention that may or may not be applicable as the disease changes, our approach should instead be to “do less and do more” by shifting medicine back into a place of value, relationship, and integrity.

Skilled in relationship building and empathic listening, psychiatry, social work, and spiritual counseling from members of a palliative care inter-professional team can offer a simple but profound way to reorient to a place of knowing the patient – the person – and of striving to have a continued conversation about the person’s values that underpin decisions they may encounter. To have this relationship and conversation means to hold the patient’s values in high regard, no matter their alignment with our own views. “Is our personalized approach to care really personalized? Who is deciding?” Catherine Calderwood of Scotland questioned. “Do we take the peoples’ priorities as seriously as the medications we are using to take care of them? What is it about giving in to the patient who may know better that we are all so afraid of?”

“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

A central theme at the session was how to provide people with a “good death,” understood by many to be dying in comfort, surrounded by loved ones, in a familiar place. But, as David Currow from Australia shared, perhaps our focus as a health system toward the end of life should in fact be with different language and choice; perhaps our goal should be to provide people with a “congruent death” or “authentic death,” meaning a death that is congruent with the life that he or she lived.

Elizabeth Namukwaya from Uganda had important insights into what makes her country a good example of a community-based approach to providing a “good death,” but also highlighted some obstacles to the wider implementation of the approach. “[In Uganda] we don’t have so

many resources, especially in terms of doctors. 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 had to adapt and develop differently than those in the West, with a greater focus on community-based care.”

Many Fellows expressed a belief that a stronger focus on community-based care could be beneficial to giving people a “good death,” and Namukwaya attested to this: “The community care that Uganda provides is strong. We have a well-developed sense of community.” The result 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,” she adds. “Therefore, we should empower the community to provide the care for themselves; decisions should be made at the community level.”

Namukwaya believes that this is where Western countries, with very advanced but often impersonal health care systems, could learn from Uganda’s approach to palliative care. Indeed, participants from Western countries expressed a contrasting approach to end of life care. In the United States, for example, end of life care is not typically a context by which community engagement takes place. Families may choose to keep the death of a loved one private from others, which can lead to further isolation of a patient toward the end of their life. Families often employ formal support (e.g., hospice care) to assist with care toward the end of life as opposed to engaging the community to provide care and support. Thus, in many cases, a patient may be socially isolated and receiving care from strangers toward the end of their life, a stark contrast to the community-based model in Uganda.

The community-based approach in Uganda appears more likely to be able to provide a “good death,” Namukwaya said, though she recognized its own set of challenges. In Uganda, the sense of community is declining 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.” 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 Namukwaya explains: “Many hospitals in Uganda are very busy. Some people just want to go home, to be with their people.” Thus, 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.





Reorienting Toward Integrity: Resolving Conflict through Wisdom

Through a better understanding of patient-centered, preference-based care, Fellows decided that health systems should globally reorient away from the advanced medicine's increasingly depersonalized end of life and move toward a “healthy death,” defined by the patient.

But already well defined in depersonalized, medical terms, care in developed countries will not respond to a slow, timid push to change. And in developing countries, the competition to advance is too strong to be shaken by a slow redirection. Thus, a revolutionary reorientation toward integrity through patient preferences is needed both in developed countries, to reorient medicalized care back to a place of holistic medicine rooted in patient values, and in developing countries, as care is designed and can be oriented in a new biopsychosocial frame. Only through this revolutionary step will we, as clinicians and as society, be able to fiercely protect a person's ability to define and create a “healthy death” that aligns with his or her own values.

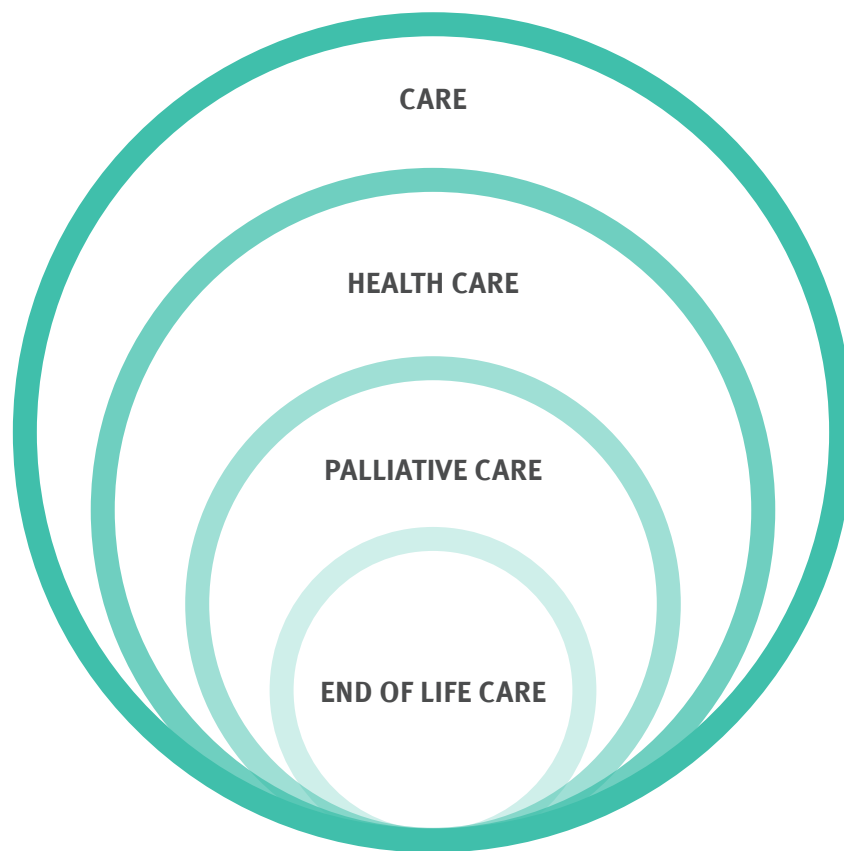
Of importance to note, this “healthy death” is defined by the patient's values and thus may be different from what our parental, provider instinct may envision. A person may choose to receive all available medical interventions up until the last moment of his or her life, driven by a genuine, identity-rooted determination to fight their illness. Another may choose to shift from aggressive, once-curative-focused treatments to more symptom-focused care and return home with their family. This relationship and quality of time with loved ones, rather than quantity, may be what they value most. Constructing the “healthy death” is defined in partnership with clinicians but with ultimate, final direction of what is valued most should come from the patient him or herself.

Widening our Scope: The Context of “End of Life Care”

Armed with a sense of the complexity in challenging the experience of end of life around the world and an agreement that all people deserve the right to a “healthy death,” the Fellows considered the action needed for the task at hand of rethinking care toward the end of life. But in order to do so, our scope had to be widened, so as to understand and frame the environment in which “end of life care” exists. “An integrity-focused revolution it not just needed in end of life care; it is needed across all of health care,” one Fellow advocated.

As **FIGURE 4** depicts, we widened out the scope of care, stretching into several critical levels: recognizing end of life care’s place within the context of palliative care, then health care as a whole, and then of care itself. Integrity in the context of illness has to be infused at all of these levels in order to be effective.

FIGURE 4: END OF LIFE CARE CONTEXT ⁷



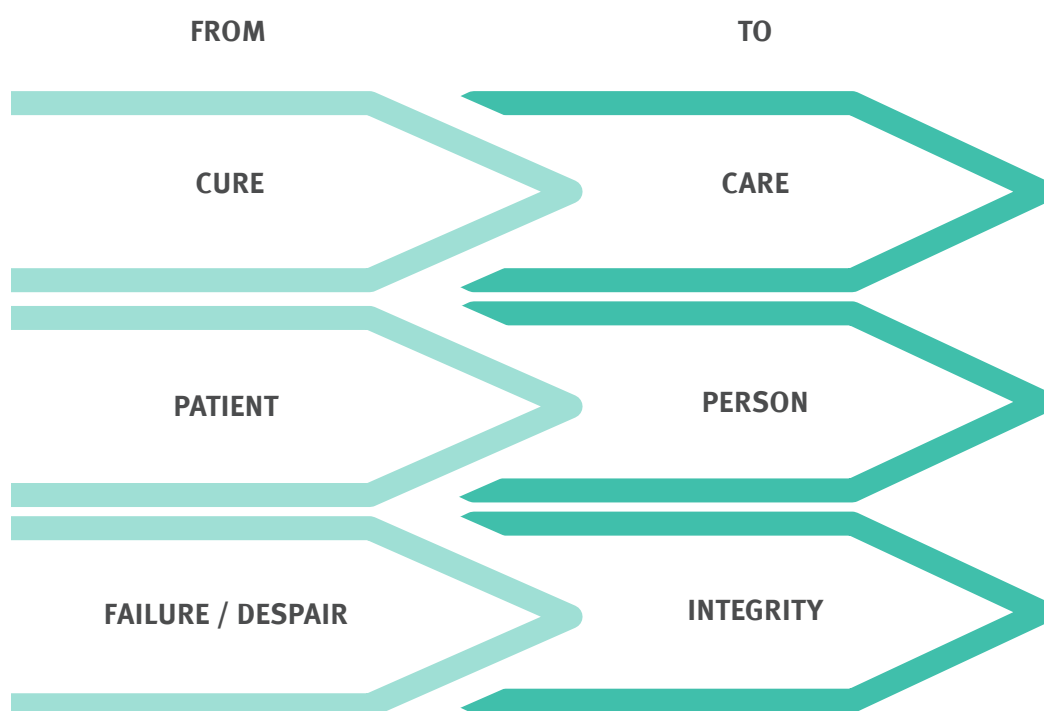
⁷ Eagan, A. (2016). [End of Life Care Context]. Unpublished raw data.

Within this widened scope, new challenges began to emerge, including the need to:

- Envision how the framework of preference-focused care looks and feels;
- Agree upon an approach through which this revolutionary reorientation can be undertaken;
- Define the terms and concepts within end of life care and its surrounding context;
- Analyze the layers of variation that come as end of life takes shape across communities and cultures and to determine the acceptable degree of variation within the framework, approach, and definitions put forth; and
- Continuously question who defines the value attached to this framework, approach, definitions, and acceptable variation.

And with care linked to a larger context, the Fellows' rethinking of care toward the end of life was now driven by an aim to reframe three key areas:

FIGURE 5: KEY REFRAMING AREAS ⁸



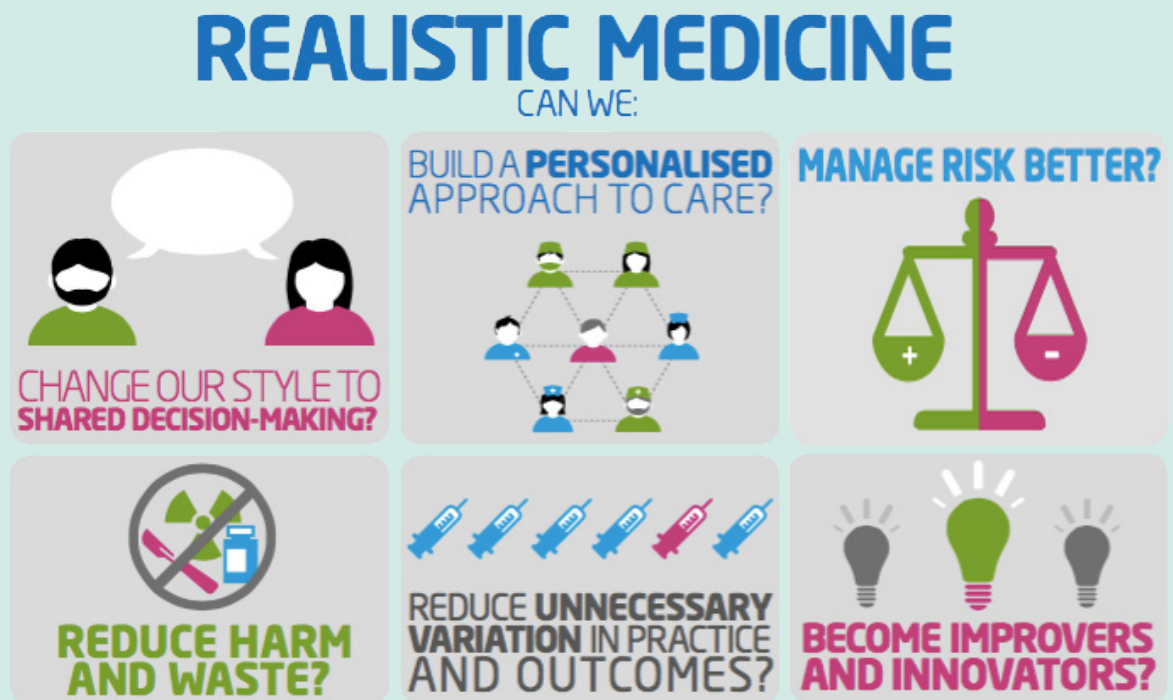
⁸ Eagan, A. (2016). [Key Reframing Areas]. Unpublished raw data.

SPOTLIGHT

Scotland's "Realistic Medicine"

Recognizing that the population of her country "was not comfortable about how medicine [was] being practiced and feel[ing] that it was too much and not necessarily prioritizing what is most important to patients and families," Catherine Calderwood, Salzburg Global Fellow and Chief Medical Officer of Scotland, set out to design a new framework for a different type of medical care. Titled "Realistic Medicine," she designed

a patient-directed, value-based approach that joins medical and social care in an effort to reorient medicine back to the person and his or her values. Targeting key areas that are essential to bring value, efficiency, and efficacy back into medicine, this framework (**FIGURE 6**) challenges the Scottish health system to a degree, asking six key questions of clinicians, health personnel, patients, caregivers, and the population:

FIGURE 6: REALISTIC MEDICINE⁹

⁹ The Scottish Government. (2016). *Chief Medical Officer's Annual Report 2014-15: Realistic Medicine*. Edinburgh, Scotland: APS Group Scotland. Retrieved from www.gov.scot/Resource/0049/00492520.pdf

The Realistic Medicine framework could arguably be further expanded, as its current focus is on medicine instead of care and primarily care physicians rather than all interdisciplinary providers. However, the model has great promise in its innovative framing of value-based care.

Highlighting key action areas in which a shift toward a value-based health care system can occur could offer guidance for other countries worldwide, including both developed (reactively to current care) and developing countries (proactively as care continues to be developed).

The Palliative Care Approach: A Tool to Garner Integrity

Across varying medical systems and cultural contexts throughout the world, how could one frame be applied? The search for wisdom in care toward the end of life should begin with a palliative care approach that is designed to deliver the care that people need and want – no less and no more. Drawing from a vast collection of clinical and cross-sectoral experiences, the Fellows reflected on how the Palliative Care Approach could serve as a global response to develop and sustain integrity-creating, value-based care.

WORLD HEALTH ORGANIZATION'S PALLIATIVE CARE DEFINITION ¹⁰

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering

by means of early identification and impeccable assessment and treatment of pain and other problems: physical, psychosocial and spiritual.

Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

¹⁰ WHO. (2017). WHO Definition of Palliative Care. Retrieved from <http://www.who.int/cancer/palliative/definition/en/>

Striking a Balance: A Need for Cohesion as well as Warranted Variation

Fellows reflected on the ambiguity that is present in palliative care, stressing how clarity and structure must be brought to the field itself before it can be used as a vehicle to develop high-integrity health systems rooted in value delivered at the level of the individual.

“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, USA

Globally, a vast degree of variation exists within palliative care. Many patients, families, clinicians, policymakers, and academics find themselves frustrated as they recognize the difficulty in turning this definition into tangible service structures and implemented care patterns in clinical spaces or policy. This great variation is meant to be protective, with inclusive language allowing palliative care to be shaped to the context. Yet its inclusive linguistics and framework serves as a barrier in and of itself. The field must better clarify its global definition, standards, and structure in order to be effective. This global picture must then, also, be well balanced with the warranted degree of variation as the approach is shaped across specific environments on national and local levels, as well as within specific sub-populations.





Understanding Death Around the World: Cultural and Spiritual Strength

During the session's Culture Café, Fellows shared how their own cultural contexts shape end of life care. Fellows from India, Singapore, Uganda, Germany, the United States, the Philippines, South Korea, and others offered particular considerations about their culture's care toward the end of life, highlighting aspects of holistic care such as communication, spiritual care, and decision-making roles within the hierarchy of the family. Some examples are highlighted here:

India

- Culture has affected peoples' attitudes toward death and dying acceptance
- Religion, history, and culture play a role in this acceptance
- Rituals of life talk about life and death as a cycle
- Less fear of the finality of death
- Dissonance between doctor and patient can exist

“The full spectrum of God-beliefs are prevalent and accepted without any conflict in India – no God, one God and many Gods, Gods from other religious thoughts. The underlying concept is about seeing only God – which makes everything God – stones, trees, people, animals, rivers, mountains, breeze, rain, you name it... all pulsing with divine presence. 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.”

Nandini Vallath, India

Singapore

- Religion is an important factor in peoples' attitudes toward death and a "good death"
 - Personal autonomy may not be the top priority – preserving harmony within the family is most important
 - Rituals around end of life and death may be very important to some people
 - Filial piety, one of the highest virtues, means honoring and respecting your parents' wishes
- Talking about death is not always taboo
- “My grandfather gave my great-grandmother in her old age a birthday gift of a beautiful coffin. Every day, my great-grandmother, who was blind by then, would go and touch the coffin, knowing that her son was filial [showing respect to one's parents, elders, or ancestors] and had made good preparations for her death.”*
- Cynthia Goh, Singapore

Philippines

- Religion is an important factor in peoples' attitudes toward death and a "good death"
 - Good death is made through being at peace with faith and family
 - Holistic and spiritual approach to palliative care
- “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.”*

Liza Manalo, Philippines





Uganda

- Religion is an important factor
- People have a shared cultural history
- Culture of storytelling
- Storytelling used as a tool to provide spiritual care

“Africa is an oral culture – we use stories to share experiences and to find meaning in things. [In health care,] 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.”

Ivan Odiit Onapito, Uganda

Rwanda

- Strong emphasis on community-centered care
- Great importance placed on equity and integration of care
- Spirituality very important
- Strong sense of community

“We have built our health sector where health is not the only silo. We have taken other social determinants into account and we 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, Rwanda

United States

- Difficulty confronting death outright
- Care may be less community- and home-based than in other countries; more hospital/hospice care
- Curative-focused
- Separated goals of care conversations (medical team vs. patient and family)

“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.”

Kathy Kirkland, United States

Germany

- Difficulty confronting death outright
- Much less community-based than other countries; hospital and hospice home-based care
- Curative-focused
- Separated goals of care conversations (medical team vs. patient and family)
- Impersonal approach; less view of patient as person

- Less sense of a shared culture or religion
- Difficult to approach topic of death
- Difficult to deal with the death of a loved one

“[Germans] don’t know how to grieve. There is no tradition, ritual or celebration when people die.”

Fellow from Germany

South Korea

- Do not discuss death
- Spirituality is important
- When family discusses end of life care plans for a family member, the patient is often not included in the conversation
- Experiencing changes in attitudes toward death and palliative care

- People are becoming more “individualized” and willing to openly discuss these issues

“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.”

Fellow from South Korea



What is Palliative Care?

One of palliative care's greatest strengths is its flexibility and holistic design, reaching across biopsychosocial elements in order to support a person facing life-threatening illness. Its definition is intentionally left vague and overarching, allowing its implemented form to be shaped by the environment in which it is delivered.

Unlike hard science, palliative care's borders are less rigidly defined. Using an interdisciplinary approach – at times even a transdisciplinary approach – physicians, nurses, social workers, spiritual care specialists, and other allied health specialists work together to provide an extra layer of support to the primary medical team. While the specialist team may focus on treating the piece of the patient affected by the illness, the palliative care team focuses more holistically on how the person is experiencing their illness, if and how care decisions are aligned with the person's values, and how quality of life can be improved.

“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 lifethreatening illness, you will get good palliative care, from primary and specialist care, and, if your needs are particularly complex, from a 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, Australia

“My realization is that one of the greatest sufferings for human being is loneliness. The sense of separation from everything. It brings us to the question of where we are today in the field of medicine. Many medical professionals today are so separated from their patients and from their own humanity. I believe it is because doctors and health care providers are taught to see everything through the lens of science, not through the lens of their heart or their humanity. This is why I find palliative care so liberating. Because it gives us the opportunity to merge science, and all of the wonderful discoveries that human development has made possible, with the heart. That’s why I’m a huge activist for palliative care.”

Lynna Chandra, Indonesia

In resource-rich, developed settings, an increasingly clear picture of a palliative care team’s structure and services on the inpatient level at tertiary hospitals is beginning to emerge. From honing expert skills to assess and treat physical pain, to communicating with patient and families within complicated interpersonal dynamics and providing counseling to family members as they enter a stage of raw grief and bereavement, specialization of the field is a positive thing; certain skills have to be studied and practiced in order to become effective. Yet with increased specialization, palliative care teams may be enabling or creating partialization of patients, and thus of care.

In country contexts of fewer resources and/or whose health sectors’ development has been stagnated, palliative care currently shows great variation as well. As the Fellows explored, the Western/Northern definition and model of palliative care may not work in a context with fewer resources or a health system that has not been comprehensively strengthened outside of specific disease silos. For example, a Western/Northern palliative care team may include a mental health professional to help the patient reflect on his or her life and find integrity and to identify and attach values to care preferences. In some areas of the world though, severe shortages remain in mental health professionals. In these settings, a palliative care definition strictly defined by the inclusion of a particularly skilled professional would create a significant barrier. Flexibility and innovation is needed.

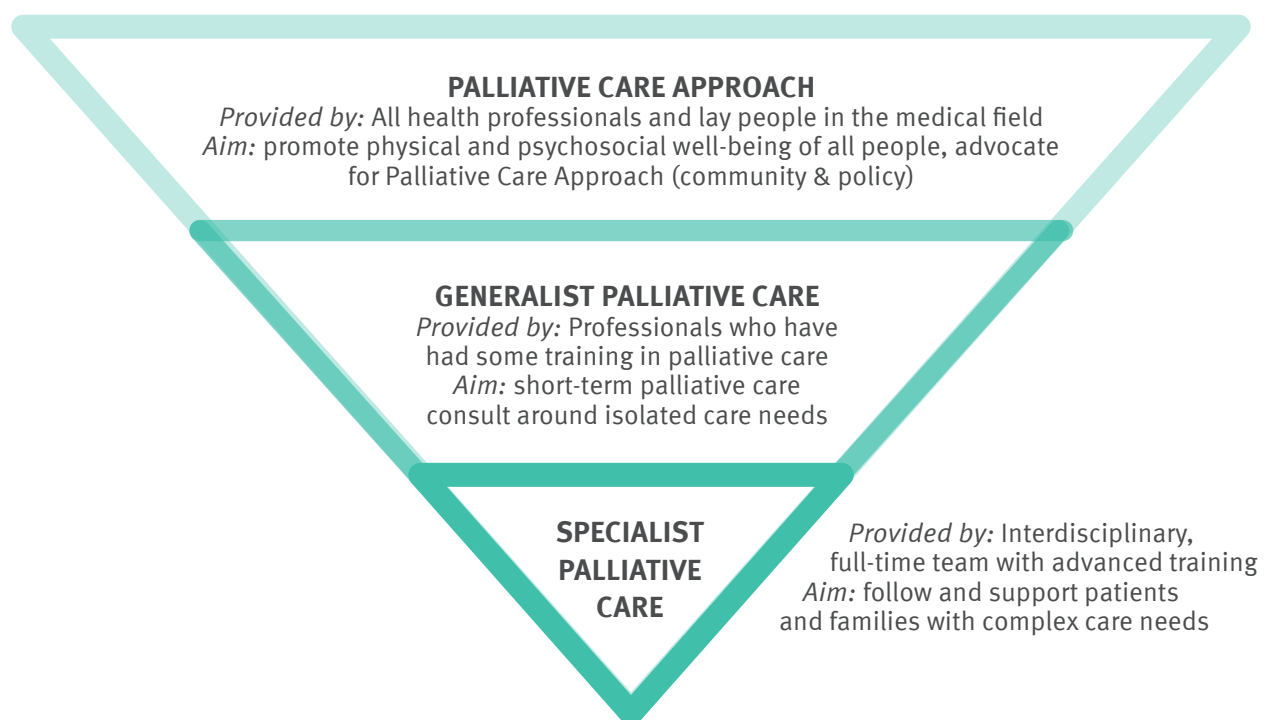
Who Provides Palliative Care?

Approaching the question of “who” should provide palliative care, the Fellows found variation again across different environments, some with substantial shortages of health professionals, education and training resources, and access to treatments and medications. Thus, here too, a continued conversation is needed so as to try to define the roles and levels of education and training within palliative care. This conversation must take into account the varied contexts in which care is being delivered and form an identity of the palliative care provider that is cohesive yet not limited in application to developed, resource-rich settings.

The Palliative Care Approach vs. Generalist Palliative Care vs. Specialist Palliative Care

Fellows discussed a global need to move away from palliative care solely as a specialization and toward a multi-tiered or multi-leveled definition. **FIGURE 7** illustrates a possible framing of this structure, an area of great importance in the Fellows conversations:

FIGURE 7: LEVELS OF PALLIATIVE CARE ¹¹



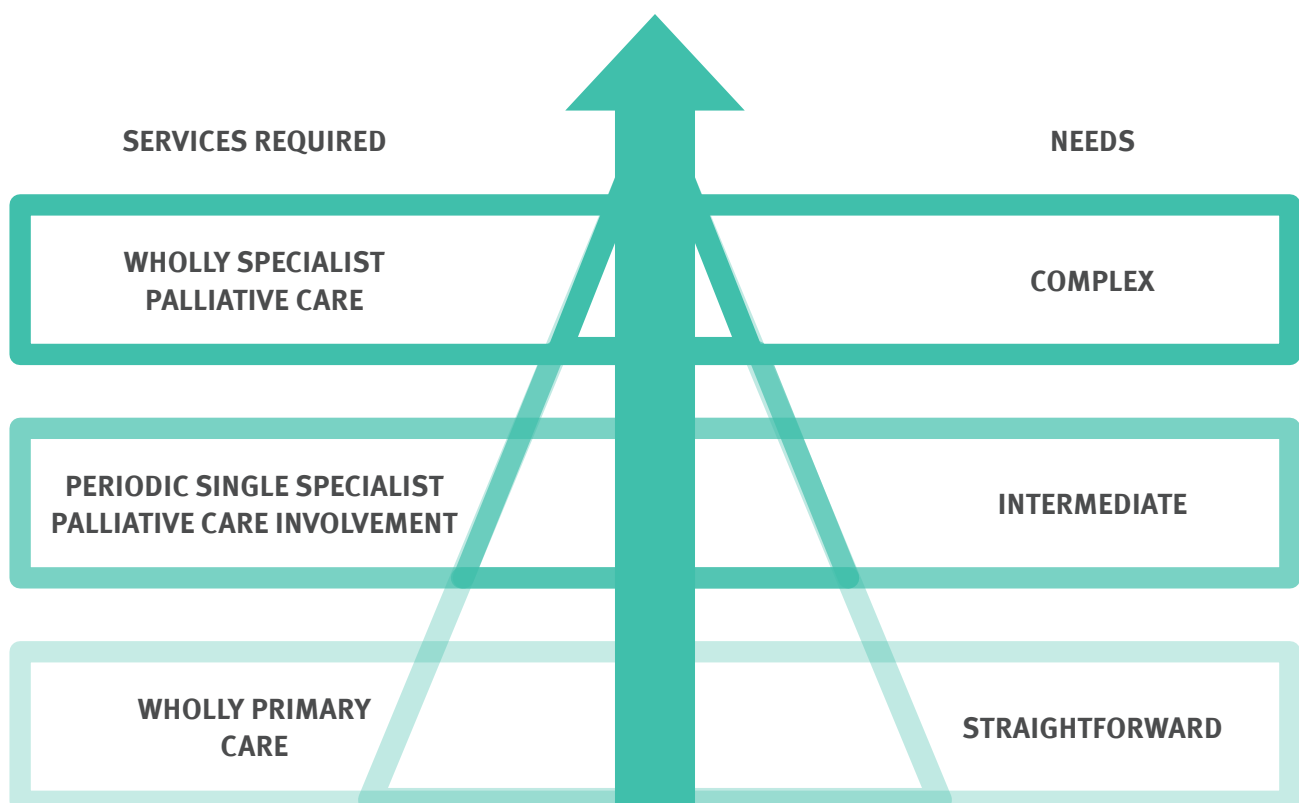
¹¹ Salzburg Session 562 Fellows. (2016). [Levels of Palliative Care]. Unpublished raw data.

Specifically in terms of services, the Fellows encourage a continued conversation around the definition (again cohesive but allowing warranted variation) and a dividing of which services are the responsibilities of the generalist versus the specialist. Fellows identified how palliative care services may be divided within its new overarching Palliative Care Approach and its needs-based levels of services provided by various personnel, again seeking a cohesive strategy but also allowing for warranted variation across our very different global health care contexts.

Considering a Needs-Based Palliative Care Model

FIGURE 8 shows a similar widening and integration of palliative care across medicine, here with specialized care periodically introduced on a needs-based manner and with wholly specialized care provided for those with the most complex needs.

FIGURE 8: NEEDS-BASED PALLIATIVE CARE MODEL ¹²



¹² Mitchell, GK. (2013). *Role of primary care in better supporting older people with cancer*. Geriatric Oncology, 37(3). Retrieved from www.cancerforum.org.au/forum/2013/november/role-of-primary-care-in-better-supporting-older-people-with-cancer

When is Palliative Care Delivered?

Another question was the timing of “when” care is delivered. Currently, “we’re delivering ‘brink of life care,’” one Fellow said, “[palliative care] is still random.”

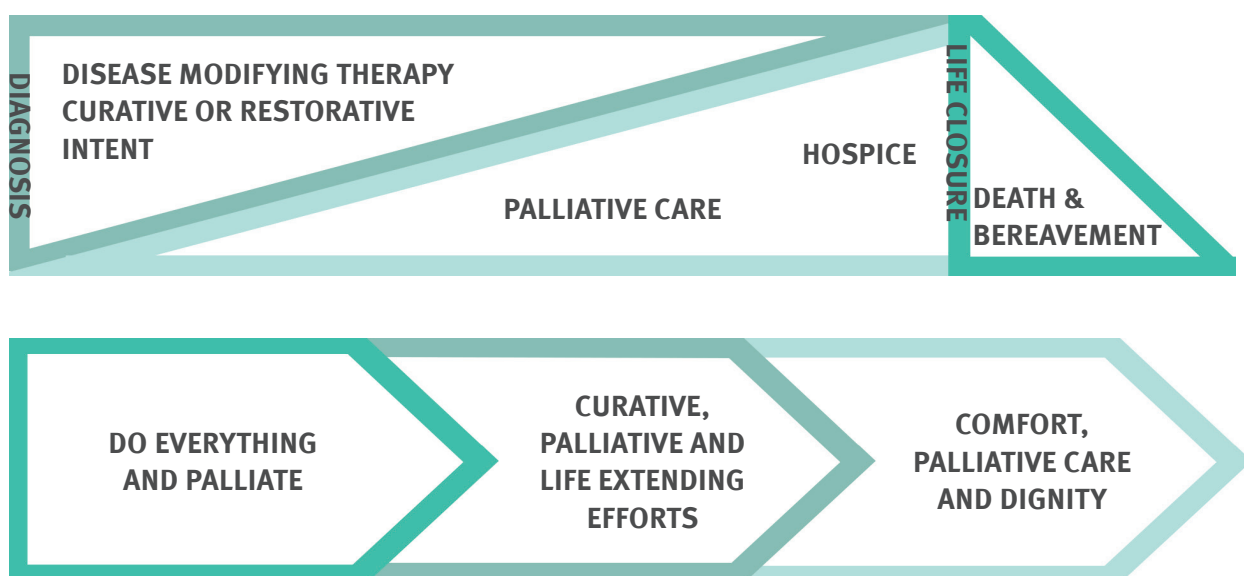
Thus, the Fellows found themselves discussing two important points:

1. When in the illness course is palliative care introduced?
2. How do we ensure that palliative care is being delivered on time for all in need rather than a select, random few?

Integrating and Introducing Palliative Care Early in the Illness Process

“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,” one Fellow said. As **FIGURE 9** represents, an increasingly accepted model of palliative care introduces it at the life-threatening illness’ diagnosis and then concurrently sustains care alongside curative care, through end of life and into bereavement. Rather than a drastic switch from life-prolonging care to palliative or hospice care toward the end of life, palliative care should grow increasingly prominent as the person’s needs dictate through the illness course, shifting forward and becoming more primary as curative care becomes less effective or available.

FIGURE 9: INTEGRATING PALLIATIVE CARE ¹³



¹³ Cote, T. (2015). *Palliative Care at the End of Life*. Online lecture. Retrieved from www.slideplayer.com/slide/3780942

Combining these questions of “what” and “when,” Fellows began to imagine how the Palliative Care Approach could be integrated in various settings – from developed to developing countries, urban to rural communities, adult to pediatric medicine, etc. Through early initiation and gradual increase, time can be freed for relationship building and in-depth conversations between the patient and provider in order to identify the patient’s core values and preferences.



Where is Palliative Care Delivered?

In an attempt to shift away from a medicalized end of life, many developed contexts have strengthened home-based palliative and hospice care services as well as free-standing hospice homes, offering a transition step down from tertiary care settings and home services. With care location options accessible to patients and families, movement can occur as the person's care needs dictate.

In developed countries, barriers such as cost, insurance, time, and location of family can impede this cycle. Even with tertiary levels of care developing, home-based services and hospice homes often remain underdeveloped and under-supported. And across any context, a variety of other factors may support a patient remaining at a high level of care: a person's symptoms may require a higher-intensity level of care; a patient may, true to their values, define themselves by their continued fight to access aggressive therapy to gain even the shortest extension of life; or a family may not have the resources to care for the patient at home or in a lower level of care (e.g. a hospice). Thus, the care location options a patient is faced with toward end of life is highly contingent on the cultural norms and beliefs surrounding care toward the end of life, as well as the health system design, and family resources.

For developing countries in particular, the answer of "where" end of life should occur was challenged by cultural and contextual complexities of care. The Fellows reflected on the societal value attached to location of medical care and end of life care, a value that is shifting as systems develop.

As the Fellows shifted to discussing the idea of a "healthy death" in a home setting though, an important point was made: "Dying at home – and even envisioning a 'healthy death' at home – is still a privilege that many in our world do not, and may never, experience," one Fellow said. "We must use caution not to romanticize dying at home when resources are not available."

For many in developing and developed countries or from marginalized populations (societally and/or geographically), the reality of dying at home can be far from this romantic view of comfort, dignity, and support. Many environments still lack the medical, psychosocial, legal and caregiving frameworks to enable a "healthy death" at home for those nearing the end of life. The importance, Fellows discussed, is not to decide upon one path for patients but, rather, to advocate for the global design of a value-based, "Realistic Medicine"-rooted system that creates integrity and dignity through choice and personal agency. With this framework in mind, developing areas' home-based care and alternative facilities to high-level tertiary hospitals can be designed and implemented according to cultural and contextual aspects of the environment, so that all patients may be increasingly offered the choice of "where" they wish to be at end of life.

“Dying at home – and even envisioning a ‘healthy death’ at home – is still a privilege that many in our world do not, and may never, experience. We must use caution not to romanticize dying at home when resources are not available.”

SPOTLIGHT

Opioids: An Epidemic of Abuse vs. An Epidemic of Deprivation

The discussion of access to resources in the home setting led to a deeper conversation about access to pain medications, including morphine. Globally, dual epidemics exist: 1) growing opioid abuse and 2) historic and still-present deprivation of opioid access.

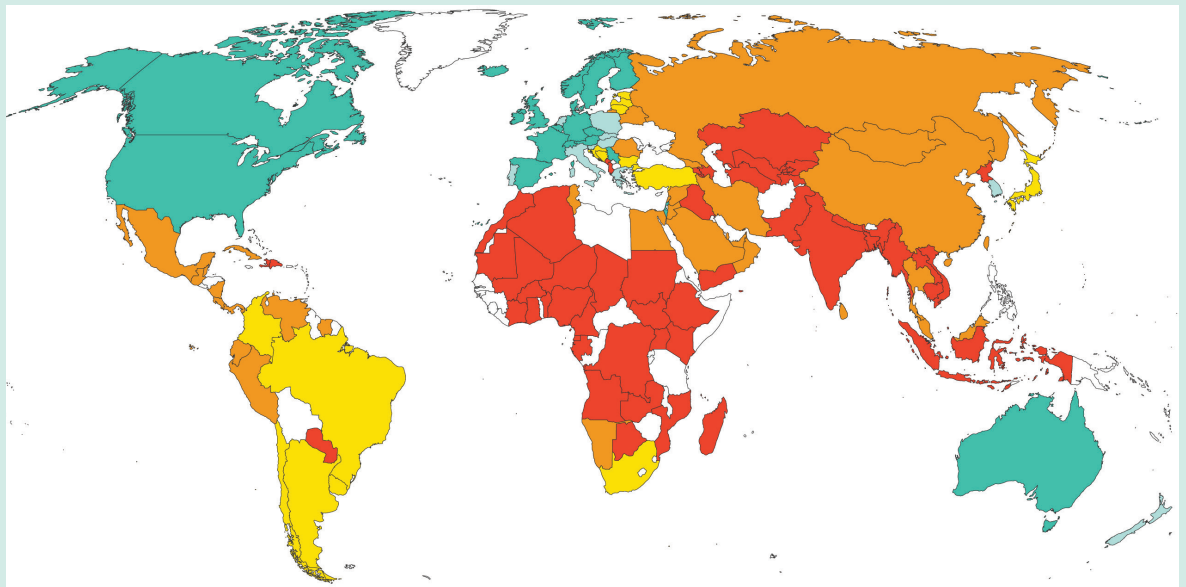
The recent increasing abuse of opioids found in developed countries is challenging the field of palliative care, creating great caution around pain medicines and their potential to bring harm. Between 2008-2015 in the United States, the

number of deaths due to opioid abuse grew by nearly 69%, from 19,582 to 33,091.¹⁴

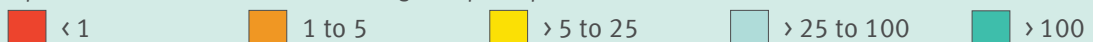
Yet silenced by poverty, inequality, and the still-developing nature of many environments, a historic deprivation of access to opioids is still present in many developing areas. The map below (FIGURE 10) shows the uneven distribution of opioid availability and use worldwide, with countries in red representing <1 mg/capita, a shocking shortage that clearly presides most vastly on the African continent.

¹⁴ National Institute on Drug Abuse. (2017). Overdose death rates. Retrieved from: www.drugabuse.gov/related-topics/trends-statistics/overdose-death-rates

FIGURE 10: GLOBAL OPIOID AVAILABILITY, 2012 ¹⁵

**LEGEND**

Opiod use – minus methadone – milligrams per capita



¹⁵ Worldwide Palliative Care Alliance. (2014). *Global Atlas of Palliative Care at the End of Life*. Retrieved from: www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf

FIGURE 11 gives further detail about the degree of unequal access to opioids experienced by those living in developing areas around the world. From 1975 to 2005, trends in disparity remained similar, showing that Africa used one

percent of the global total mg/capita in opioids in 2005 compared to Europe’s 67 percent and the 25 percent used in Australia, Canada, New Zealand, and the US combined.

FIGURE 11: GLOBAL AND REGIONAL TRENDS IN TOTAL MORPHINE EQUIVALENCE (ME) (MG/CAPITA) ¹⁶

Year	Africa Total ME	Middle East Total ME	Central and South American Total ME	Asia Total ME	Australia, Canada, USA, New Zealand, Total ME	Europe Total ME	Global Total ME
1975	3.21 (2%)	7.66 (6%)	8.29 (6%)	10.08 (8%)	41.58 (34%)	53.10 (43%)	123.92
1986	8.99 (2%)	23.05 (5%)	72.63 (16%)	50.16 (12%)	99.6 (23%)	175.38 (41%)	430.93
2005	31.46 (1%)	141.717 (2%)	97.41 (2%)	212.95 (3%)	1551.66 (25%)	4189.31 (67%)	6218.61

¹⁶ Fisherman, S. (2012). *Bonica’s Management of Pain*. Lippincott Williams & Wilkins.

NOTE: Values in parentheses indicate the region’s percentage of the global total ME for that year. Percentages added across rows may not total 100% due to rounding.

Fellows discussed how developing countries must now, perhaps more than ever before, be strategic and responsible in designing care systems that increase holistic assessment and access to much-needed medications and services, beckoning patients away from the abuse being experienced in some developed areas today.

“ *This Salzburg Global Seminar session supported the importance of holistic end of life care for the patient and family. In palliative care, end of life is not focused on death itself. Rather, it is about a*

health end of life approach – a way to empower the patient to live fully until the end of life or her life. With each care intervention, health providers can give comfort and dignity to patients and cultural sensitivity to the treatment course. And with home-based care that is well supported by skilled providers and accessible pain medications, a person can live these last days of his or her life with dignity and comfort and surrounded by family. **”**

Magnus Gasana, Rwanda

How are the Person and Family Kept at the Center?

Ascertaining Patient Preferences: Potential Tools to Evoke Patient Values

Central to the Palliative Care Approach, for both generalized and specialized services, is the adequate measurement of patient preferences. Fellows discussed a variety of factors that play into the health care system's patient preference seeking and tools that may be helpful, if adapted to local, cultural contexts. The goal of this measurement is to enable the creation of a care plan that marries medicine and social care, joining the care team, the person, and his or her family/caregiver in order to use medicine to help a person live as well as possible for as long as possible.

“When a 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.”

Fellow from Egypt

From shared decision-making tools to legal wills and advanced care-planning documents, recent efforts across cultures and contexts have been made to arm health professionals with the tools to elicit patient preferences. Rather than a document filled out in a singular meeting and placed in the chart, left to influence care even as the medical context may shift, the Fellows agreed on the need for a different aim: an ongoing conversation between health care providers, patients and families seeking to identify the patient's core values.





Listening to and Caring for the Caregiver

“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, Singapore

Fellows in Salzburg included family caregiving researchers, as well as individuals who have been caregivers, have had caregivers, or who work directly with caregivers in their clinical practice. These varying perspectives allowed for a collective agreement on the need to reorient ourselves and our health systems toward integration of the patient as well as the family members and caregivers.

“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, Colombia

“Caregivers do not see themselves as caregivers. The role is in the context of a relationship, not in a label.”

But just as a patient is medicalized, so too is the caregiver and family. Richard Harding of the UK brought up linguistics, highlighting our use of language and labeling with caregivers. “Caregivers do not see themselves as caregivers. The role is in the context of a relationship, not in a label,” one Fellow advocated. Just as the argument was made for returning the partialized patient to a person, so too should we consider reframing caregivers back into the mothers, fathers, siblings, partners, family and friends that they are first and foremost.

As Angela Lunde from the USA discussed, clinicians and health care teams are responsible for ensuring that the caregiver and family understand the end of life care discussions and decisions being made. “If we – as the doctor or medical team – are not normalizing conversations around end of life for the patient, we are not normalizing it for the family either,” she said.

The Fellows considered the question of how caregivers are engaged and embraced in our practice and settings:

“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 conversations 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.”

Anya Humphrey, Canada

Humphrey’s family caregiver voice offered a perspective often overshadowed by that of the health provider and researcher-authored peer-reviewed literature. Caregivers’ views serve as a source of information that should be taken with great weight as we inform ourselves about “best practice” strategies and “evidence-based practice.” Beyond the multitude of lessons Humphrey and her family’s experiences showcase, her caregiver voice reminds us of the most important central theme we must carry forward to inform our practice: that palliative and end of life care are not practices or processes but, rather, experiences felt on a profoundly human level by all whom they touch.

Using Innovation and Technology to Reach the Margins

Fellows recognized the need to be innovative and use different methods to engage with patients, caregivers, families, and communities. “Which are the most promising evidence-based and cost-effective innovations in care toward the end of life?” and “What yields greatest value to patients, especially in low resource settings?” were the questions posed to panelists and all Fellows alike during the latter part of the Salzburg session. Particularly in rural areas, with marginalized populations, and in low-resource settings, traditional means of communication and patient preference tools may not be effective. Through the innovative use of technology though, communities around the world have begun to extend a more equitable reach to those at the margins.

Fellow Shelly Cory from Canada, presented the **Canadian Virtual Hospice**, stressing how interactive online platforms can offer low-cost, innovative ways for patients, caregivers, and health providers to connect, acquire and exchange knowledge, and transcend issues of time, geography and lack of local services.¹⁷ “Technology is not meant to replace people,” she said, “but instead to augment and complement in-person time with providers and re-envision tasks and supports using an online lens.”

A second example of innovative technology use shared was **Project ECHO (Extension for Community Healthcare Outcomes)**, an effort aimed at “democratizing specialist knowledge” by building a community of practice and communication for primary care clinicians in community settings through tele-mentoring (see **FIGURE 12**).¹⁸ Aligning with the need to embrace a Palliative Care Approach with early integration and specialization saved for complex care needs, Max Watson from Ireland invited Fellows to consider how ECHO and similar technologies could be used in various settings to decrease isolation, increase knowledge and communication, and extend higher quality, integrity-rooted care in an equitable fashion.

“Technology is not meant to replace people, but instead to augment and complement in-person time with providers and re-envision tasks and supports using an online lens.”

Shelly Cory, Canada

¹⁷ Canadian Virtual Hospice. (2017). Retrieved from www.virtualhospice.ca

¹⁸ Project ECHO. (2017). *Project ECHO: A Revolution in Medical Education and Care Delivery*. Retrieved from echo.unm.edu

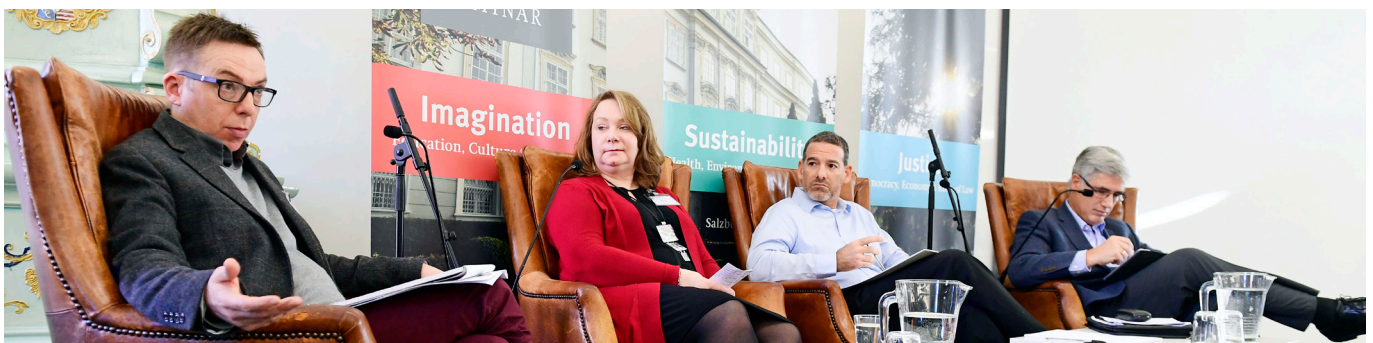


FIGURE 12: PROJECT ECHO: A REVOLUTION IN MEDICAL EDUCATION AND CARE DELIVERY

Project ECHO is a lifelong learning and guided practice model that revolutionizes medical education and exponentially increases workforce capacity to provide best-practice specialty care and reduce health disparities. The heart of the ECHO model™ is its hub-and-spoke knowledge-sharing networks, led by expert teams who use multi-point videoconferencing to conduct virtual clinics with community providers. In this way, primary care doctors, nurses, and other clinicians learn to provide excellent specialty care to patients in their own communities.

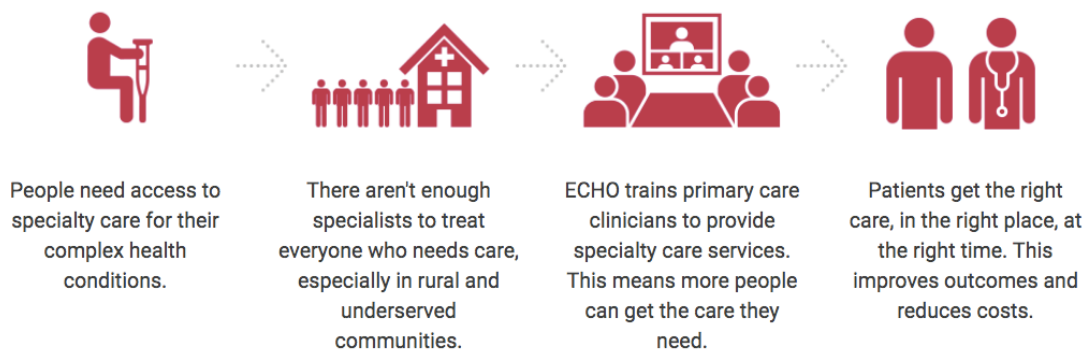


FIGURE 13: ECHO PROGRAMS CURRENTLY IN PLACE INTERNATIONALLY ¹⁹

The following map shows where ECHO Programs are currently in place. Though this approach is still heavily active in Western and Northern contexts,

increased links between developed and developing countries are beginning to be made through the technology as resources allow.



¹⁹ Project ECHO. (2017). ECHO Hubs & Superhubs: Global. Retrieved from: echo.unm.edu/locations-2/echo-hubs-superhubs-global

The Way Forward

Embracing Advancement While Protecting Against Mistakes

In developing contexts around the world, health systems are being built in the wake of historical barriers to medical care access, resources shortages, complex social determinants of health, and limited funding. And still today, despite inspirational pockets of innovation and progress, universal health care and accessible end of life care is not a reality in many countries throughout the world – in developed and developing countries.

As these paralyzing barriers to access are lifted through the advancement of health systems, developing countries are beginning to adopt many developed countries' practices. Yet, too often, palliative care is still built after everything else. Though palliative and end of life care is seen as morally important, many developing contexts are becoming more effective and efficient by growing increasingly medicalized, curative focused, and depersonalized, leaving palliative care as a low priority compared to health systems' other high priorities.

If a thoughtful reorienting toward this does not take place within the developed world, and if developing countries continue forward in an increasingly advanced, medicalized style, developing countries too will soon find their patients in a place far away from the “medicine” of integrity and instead sealed in despair.



“They didn’t ask about faith, family... In my country, a ‘good death’ is to be at peace with God... [This report] was so Western. Maybe that’s why [we] ranked so low.”

Expanding High Quality and Comprehensive Measurement

Beyond the call for an increased conversation guided by patient preference tools (see page 38) Joan Griffin from the UK reminded Fellows of the need beyond this to improve measurement on a greater scale. “How will we measure this revolution?” she asked. “And how do we begin to measure a healthy death?” These nuanced outcomes of care – from dignity, to subtleties in communication, to loneliness – may be more difficult to measure and require innovative uses of qualitative data as outcome- and evidence-based data.

In addition to this, the Fellows reflected on the parameters, definitions, and value judgments used in current assessment and reporting, which often includes value-weighted descriptions described as “best,” “quality,” “highest,” etc. “The questions were only about palliative care [services, practitioners, etc.],” one Salzburg Fellow from a developing country said about a global palliative care report for which information had been gathered. “They didn’t ask about faith, family... In my country, a ‘good death’ is to be at peace with God... [This report] was so Western. Maybe that’s why [we] ranked so low.”

This Fellow’s comment serves as a call for each of us, as a global community, to continue to question the metrics that we use to define value and best practice. Western medicine has great strength in its structure, definition, abundance, and advanced practice, however, such structure may also be a weakness when we allow this framework to define care globally; we may miss crucial contextual pieces that bring great value to people who receive care. As we continue forward as a palliative care field, we must challenge ourselves to use global and locally valid metrics to evaluate, define, and continuously shape care delivery. As many other countries show, spiritual, psychological, and social aspects are deeply tied to the cultural context into which the experience of palliative care and end of life care are woven and must be included in our assessment of “quality” care.



Being Willing to Change Ourselves as Palliative Care Specialists

Medicine is increasingly specialized and value is placed on this refined care. But specialization also takes us away from holistic care – what we need is integration of services and approaches and to see the patient as a person with values, preferences, and wishes far beyond his or her illness.

“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, Philippines

If our true aim is to revolutionize health care by reorienting to a value-based system of care that identifies and bolsters integrity no matter the prognosis, then we must be willing to revolutionize our palliative care roles as well.

“How we view palliative care is also important. Some individuals feel it is so special, that it doesn’t need new knowledge through research. But learning and research is the route to improved care beyond what we do now. Patient and family concerns and their views should drive this research. Palliative care has relied too much in the past on advocacy, and the future needs more advancing of the field and care through truth and knowledge.”

Irene Higginson, UK

We must continue to demand high quality of care and strong standards for practice, both which promise the continuation of specialized palliative care skills across interdisciplinary roles within teams for patients whose biopsychosocial needs require complex support. Being open-minded and flexible toward this revolution does not mean compromising palliative care’s value. But we also must be open to “democratizing” our knowledge and skills, enabling our colleagues across sectors, disease areas, and disciplines to become palliative care generalists so that they may enable patients to access and benefit from a holistic care approach sooner and begin to seek the integrity they deserve toward the end of life; this task-shifting and task-sharing could enable the revolutionary reorientation toward equity on the scale we must reach.

Creating Advocacy: The “Salzburg Questions” #allmylifeQs Twitter Campaign

From a global view, the Palliative Care Approach is spreading across a diverse array of settings. Extremes of excess and medical advancement lay on one side; extremes of lack of access to technical care and deep spiritual and community connection on another. Our challenge as Salzburg Global Fellows is to create a concise, strong, detailed but clear message accompanied by action steps. The message we craft must allow for a degree of warranted variation, shifting and creating innovative steps forward.

To ensure that our broad, overarching concepts, terms, and approach are both representative of palliative care globally and also hold fast despite warranted variations across settings, a continued discussion with expanded audiences is needed. Though the Fellows were originally tasked with creating a “Salzburg Statement,” Fellows requested an alternative action plan: the “Salzburg Questions” Twitter Campaign. Holding ourselves accountable to continue to push forward the topics discussed during Salzburg, the Fellows decided that we will hold a social media campaign through Twitter, supported by blog posts to be authored by Fellows and shared across multiple organizations’ websites.

Using the hashtag #allmylifeQs as well as relevant already-established health care-related hashtags, a year-long debate began on Twitter, spotlighting issues of those facing life-threatening illness or approaching the end of life. Strategically aligned with meaningful global health dates, the monthly Twitter campaign offered the opportunity to engage various, previously untapped online audiences beyond the session’s Fellows to best understand the global perspectives and individualized variations within palliative care.

Each question was led by a volunteer Fellow from the session who both initiated and drove the discussion on Twitter with their lead and sub-questions (listed in **FIGURE 16**) and by drafting a blog post directly addressing their assigned question. Their blogs were published by platforms including the European Association for Palliative Care (EAPC) blog and *ehospice*, as well as Salzburg Global Seminar’s and many of the Fellows’ own websites. Salzburg Global Seminar also shared all blog posts and notice of the upcoming Twitter debate on its other social media platforms and sent regular email updates to all past Fellows who had attended sessions in the *Health and Health Care Innovation* series, helping to spread the Campaign well beyond the 60 Salzburg Global Fellows who attended the December 2016 session.

The hashtag was registered with the Symplur “Health Care Hashtag Project” to facilitate tracking and analysis. Since its initiation on February 20, 2017, the World Day of Social Justice, people from all across the globe have taken part in this “Salzburg Questions” Twitter Campaign, answering questions related to palliative care using the #allmylifeQs hashtag. As of December 12, 2017, the Campaign has had an impressive online impact, shown here in **FIGURES 14** and **15**. In total, the “Salzburg Questions” Twitter Campaign generated almost 11.5 million Twitter impressions (the number of times the hashtag #allmylifeQs appeared in the feed of Twitter users) through the engagement of over 500 users²⁰, producing a total of 3692 Tweets addressing the nine questions. EPAC reported an average of nearly 500 views per blog post. Total engagement has reached 182 countries.

²⁰ It is not possible to discern how many of the 291 users who Tweeted in the latter stage of the Campaign are unique to the 521 users who Tweeted in the earlier stage of the Campaign.

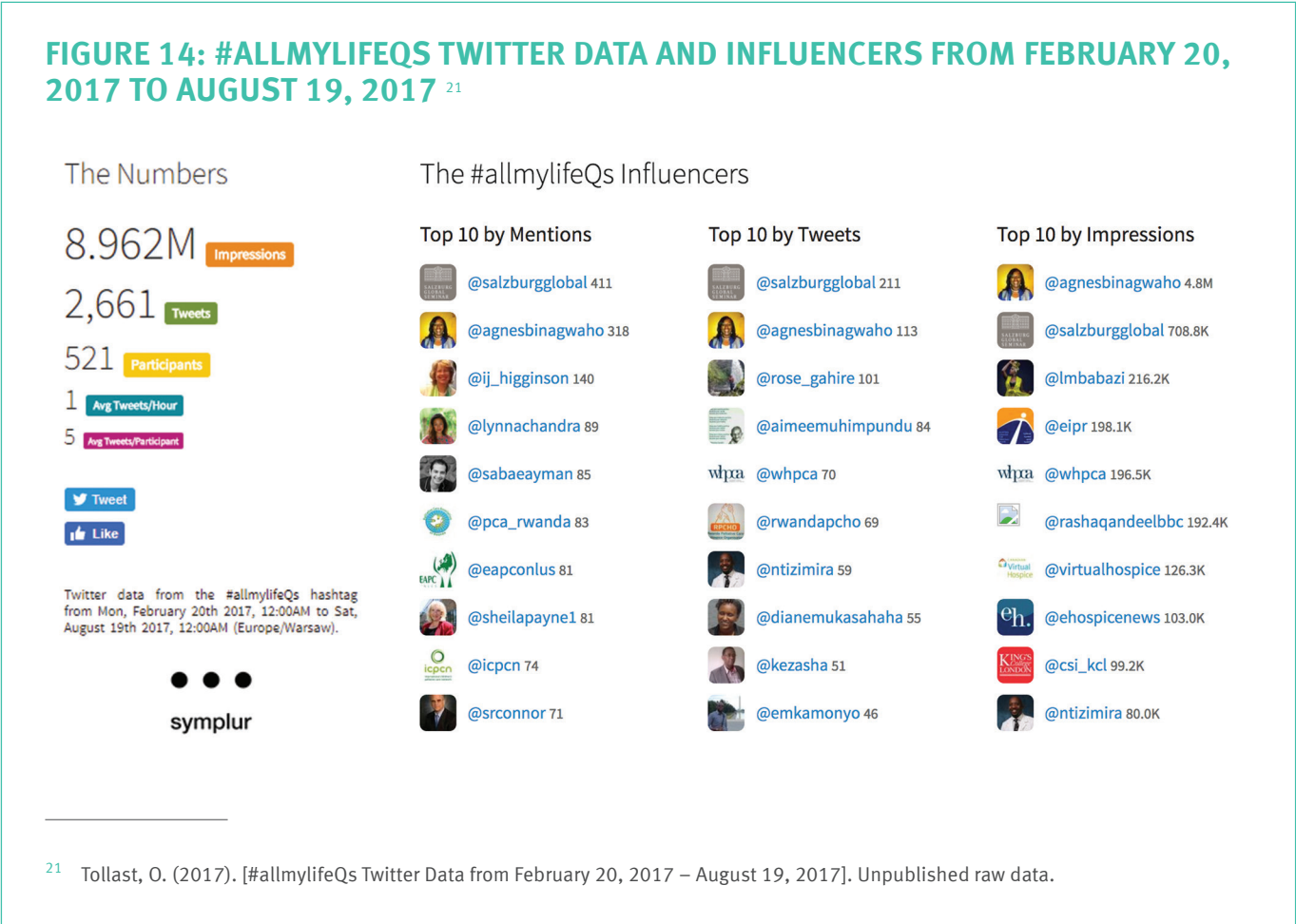


FIGURE 15: #ALLMYLIFEQS TWITTER DATA AND INFLUENCERS FROM AUGUST 20 TO DECEMBER 12, 2017 ²²

The Numbers

2.498M Impressions

1,031 Tweets

291 Participants

0 Avg Tweets/Hour

4 Avg Tweets/Participant

Tweet

Like

Twitter data from the #allmylifeQs hashtag from Sun, August 20th 2017, 12:00AM to Tue, December 12th 2017, 12:00AM (Europe/Berlin).

● ● ●
symplur

The #allmylifeQs Influencers

Top 10 by Mentions

	@ij_higginson 193
	@whpca 164
	@apcassociation 161
	@who 100
	@un 94
	@csi_kcl 88
	@salzburgglobal 80
	@drluyirika 76
	@drbruce_tsf 39
	@kehpc 36

Top 10 by Tweets

	@salzburgglobal 87
	@whpca 84
	@drluyirika 63
	@apcassociation 42
	@srconnor 39
	@julia_downing 35
	@kate_ehospice 29
	@ehospicenews 25
	@worldhospiceday 23
	@drrhoira 23

Top 10 by Impressions

	@agnesbinagwaho 375.1K
	@salzburgglobal 322.2K
	@whpca 284.8K
	@ehospicenews 174.2K
	@virtualhospice 128.7K
	@csi_kcl 108.2K
	@apcassociation 107.2K
	@worldhospiceday 76.9K
	@srconnor 63.4K
	@ij_higginson 62.6K

²² Tollast, O. (2017). [allmylifeQs Twitter Data from August 20 to December 12, 2017]. Unpublished raw data.

“From tiny seeds, tall oaks can grow, and we hope that the roots that were laid over the course of the campaign will continue to flourish.”

Katie Witcombe, UK

As Katie Witcombe, outreach administrator for the Cicely Saunders Institute in the UK and one of the facilitators of the “Salzburg Questions” series wrote at the conclusion of the Campaign: “The series has given project teams and researchers from world-leading institutions the opportunity to showcase their most recent research into global healthcare trends, place of death, how to support an aging population and treatment for non-cancer conditions... Ultimately, the Salzburg Questions series has highlighted the appetite that exists for discussions about the issues affecting palliative care, and the role that online platforms such as Twitter have to play in these global conversations... Twitter discourse is a democratization of the decision-making processes which have governed research for so long; people from all demographics and backgrounds can now help to shape the direction of future work by signposting the areas which they feel need the most investment. From tiny seeds, tall oaks can grow, and we hope that the roots that were laid over the course of the campaign will continue to flourish. The enthusiasm and engagement with which this series of questions has been met is a clear signifier of the conversations which people from all over the world are ready to have about the lasting need for high quality, effective and accessible palliative care.”

FIGURE 16: SALZBURG QUESTIONS AND SUB-QUESTIONS

Question Number	Theme & Lead Fellow	Date & Importance of Date	Lead and Sub Questions
Question #1	Accountable Countries Agnes Binagwaho, Rwanda	February 20, 2017 World Day of Social Justice	Why aren't countries accountable to commitment on #EOL care for vulnerable people? #allmylifeQs Govt, health workers & family: what is your role in supporting voiceless children in their needs of care at #EOL? #allmylifeQs Govt, health workers & families: what is your role in supporting older people in their #palliative care needs? #allmylifeQs
#2	Wider public engagement Lynna Chandra, Singapore	March 20, 2017 International Day of Happiness	Is dying well as important as living well? #allmylifeQs End of life (#EOL) care matters for all of us because we will need it and we need to support it for our beloved #allmylifeQs Cicely Saunders said: "You matter because you are you, and you matter all the days of your life." What does this mean to you? #allmylifeQs
#3	Preparation & dialogue Suresh Kumar	April 7, 2017 World Health Day	How have you prepared for your death? #allmylifeQs Who have you told about how and where you would like to be cared for toward the end of your life? #allmylifeQs

Continued on next page

Question Number	Theme & Lead Fellow	Date & Importance of Date	Lead and Sub Questions
#4	Family Caregivers Sheila Payne, UK	May 15, 2017 World Family Day	Will caring for your dying loved one bankrupt you emotionally & financially? #allmylifeQs Govt, health workers & family: what is your role in supporting voiceless children in their needs of care at #EOL? #allmylifeQs Govt, health workers & families: what is your role in supporting older people in their #palliative care needs? #allmylifeQs
#5	Refugees Emmanuel Luyirika, Uganda	June 20, 2017 World Refugee Day	145 countries signed http://bit.ly/2ah31bH why do refugees have limited access to quality health care and #EOL care? #allmylifeQs Why aren't countries accountable to commitment on #EOL care for vulnerable people?
#6	Measurement Richard Harding, UK	July 11, 2017 World Population Day	How and what do you measure to ensure quality palliative & #EOL care? #allmylifeQs What matters to you in your care in advanced illness & toward the end of life? #EOL #allmylifeQs
#7	Education Bruce Chernof, USA	September 28, 2017 International Right to Know Day	Doctors & nurses: do you want to die the way your patients die? #allmylifeQs What are you teaching about #palliative or #eol care? For whom? Where? How? #allmylifeQs

Continued on next page

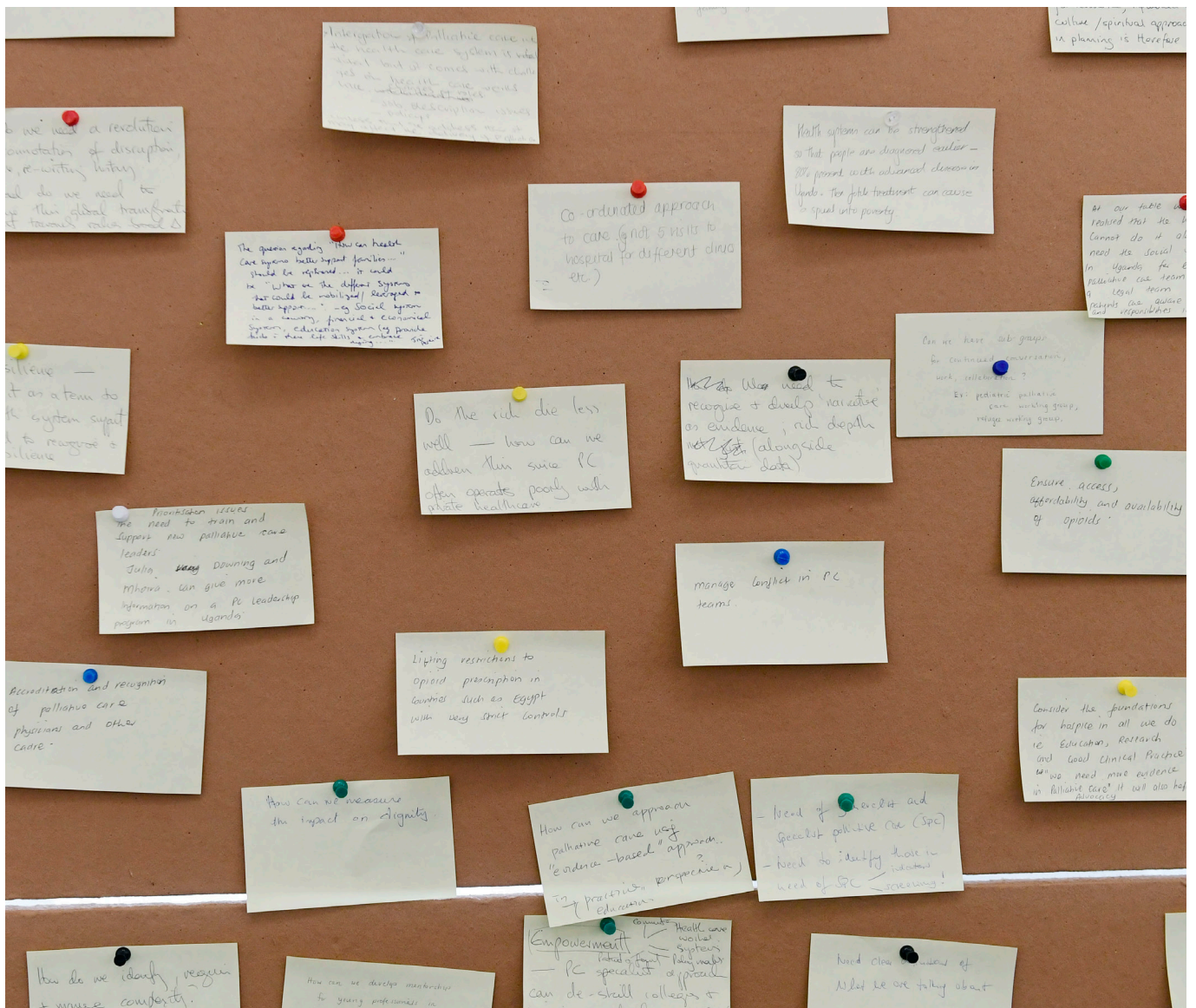
Question Number	Theme & Lead Fellow	Date & Importance of Date	Lead and Sub Questions
#8	Universal Coverage / Access Stephen Connor, USA	October 13, 2017 World Hospice and Palliative Care Day (launched one day prior to October 14)	<p>Do you know how to access #palliative care when you need it? #allmylifeQs</p> <p>How do we make #palliative care available for all within 10 years? #allmylifeQs</p> <p>Have you identified geographical areas or population groups missing access to #palliative care? #allmylifeQs</p> <p>Why aren't countries accountable to commitment on #EOL care for vulnerable elderly people? #allmylifeQs</p> <p>What policy changes are needed to insure universal access to #palliative care? #allmylifeQs</p>
#9	Research Irene Higginson , UK	November 10, 2017 World Science Day for Peace and Development	<p>What future research is needed to improve care for people w advanced illness & toward the end of life? #allmylifeQs</p> <p>Are there evidence-based innovate #palliative care models that could be scaled up? #allmylifeQs</p>



A Closing Note

It is the hope of the Fellows that these continued discussions through multiple platforms catalyze global, cross-cultural discussion on the importance of returning wisdom and integrity to the care we provide the people we call patients.

The advancement of medicine need not bring with it a loss of this integrity; rather, a thoughtful advancement of the medical field through high-integrity systems and a preference-focused, palliative care approach toward the end of life can shape our care more deeply for each person before us and his or her wishes in the face of illness.



Salzburg Global Seminar and the Health and Health Care Innovation Series

Salzburg Global Seminar has long been a leading forum for the exchange of ideas on issues in health and health care affecting countries throughout the world. At these sessions agendas have been re-set affecting policy and practice in crucial areas, such as patient safety and the engagement of patients in medical decision-making. In 2010, Salzburg Global Seminar launched its multi-year series – *Health and Health Care Innovation in the 21st Century* – to crystallize new approaches to global health and health care in the face of emerging challenges affecting us now and set to continue on through the coming generation. The session, *Rethinking Care Toward the End of Life*, formed part of this series.

Since December 2016, Salzburg Global Seminar has built upon the learnings from this session, incorporating them into its subsequent sessions, *Toward a Shared Culture of Health: Enriching and Charting the Patient-Clinician Relationship* (March 2017), *Building Healthy Communities: The Role of Hospitals* (December 2017), and *Changing Minds: Innovations in Dementia Care and Dementia-Friendly Communities*, the latter of which was held again in partnership with the Dartmouth Institute for Health Policy and Clinical Practice and The Mayo Clinic.

Topics for future sessions in the *Health and Health Care Innovation in the 21st Century* series include inclusive place-making for health communities (Spring 2018), children's health (Fall 2018), and metrics for patient safety (2019). Salzburg Global Seminar is also the convening host of the recently established *Sciana: The Health Leaders Network*, a new initiative between the Health Foundation (UK), Careum Stiftung (Switzerland) and the Robert Bosch Stiftung (Germany), bringing together outstanding leaders in health and health care policy and innovation across Europe. A select number of Salzburg Global Fellows will be invited to return to future *Health and Health Care Innovation* sessions and to present at meetings and conferences of *Sciana*, to further facilitate cross-border, cross-sector and indeed cross-session learning,

The “Salzburg Questions” social media campaign is to be adopted and implemented for other topics at upcoming Salzburg Global Seminar sessions, including *Springboard for Talent: Language Learning and Integration in a Globalized World* (December 2017) and *Climate Change, Conflict, Health, and Education: Targeting Interdisciplinary Research to Meet the Sustainability Development Goals* (March 2018).





APPENDIX

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