Toward a Shared Culture of Health: Enriching and Charting the Patient-Clinician Relationship

SALZBURG GLOBAL SEMINAR

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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 of the panels and interviews with our Fellows, all of which you can find on the session page: www.SalzburgGlobal.org/go/553

You can also join in the conversation on Twitter with the hashtag #SGShealth and see all your fellow Fellows and their organizations on Twitter via the list www.twitter.com/salzburgglobal/lists/SGS-553

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, and we might feature your photos in the newsletter!

@SaraRiggare Best warning sign EVER! #sgshealth

Participants and faculty members involved in Session 553 | Toward a Shared Culture of Health

Care in communities and families

Oscar Tollast

During the session *Toward a Shared Culture of Health: Enriching and Charting the Patient-Clinician Relationship*, participants have learned knowledge is not enough when it comes to tackling issues and creating pathways forward. A successful patient-clinician relationship is not only built on facts and figures. It should also be based on trust, understanding, and taking into consideration the patient's motivation. These factors take on a further degree of importance when it comes to providing care in the communities and supporting family members.

In between plenary sessions held on Saturday, participants learned about motivation in health care, and what changes for families, friends, and communities.

Session co-chair Professor Tobias Esch discussed the neuroscience of motivation and self-care.

The word motivation comes from the Latin word "movere" - to move. Building on this, Esch said there were three types of motivation. Type A concerns moving toward something or wanting something. Type B is about avoiding or escaping something. Type C, meanwhile, is about staying and attaching yourself to something.

Type A is associated with pleasure, which you can obtain after passing through stages of creativity and learning. Type B, on the other hand, is linked to a state of relief, which can stem from protection and survival. Type C, simply put, is associated with happiness.

All three types of motivation can be linked with patients at different stages of their lives, according to Esch. He suggested Type A was often found in young people, while Type C involved those aged 65 and over. The majority of people in between these age groups are linked to Type B.

Esch cited research which suggested humans had three basic needs: existence, relatedness, and growth. Existence is a concern for those with a Type B form of motivation, while relatedness is closer to those experiencing Type C. Growth, meanwhile, has a closer match with Type A, as young people look to grow and move toward something.

Insights from behavioral economics
Following this talk from Esch, participants received new insights from behavioral economics and how this could affect decisions made by health care professionals.

To begin with, the speaker discussed the shaky foundations of health policy. These foundations included shared decision making, nutrition and calories labeling, *Continues on page three*

Liz Salmi: "I hope to keep growing as a patient with the goal of doing something that will be respected by the whole profession"

Patient advocate discusses her experience blogging and the e-Patients movement

Andrea Abellan

Liz Salmi is attending *Toward a Shared Culture of Health: Enriching and Charting the Patient-Clinician Relationship* **as an advocate for patient access to complete medical records.**

Salmi was diagnosed with a brain tumor eight years ago. Since then, she has overcome two surgeries and the consequent challenges of being affected by a serious disease.

Through her high participation in digital platforms, Ms. Salmi has become a voice of patients seeking greater accesses to their own health information. She spoke with Salzburg Global's Andrea Abellan about her experiences.

AA: With more than 30,000 visits each year your blog, thelizarmy.com **is a reference on patient-focused websites. What prompted you to start blogging about your illness?**

LS: Before my cancer diagnosis, I was working in Marketing and Communications. When I first ended up in hospital, it came naturally to me to start writing about my situation. Eventually, I had to leave my job for a time to focus on my health, but I still felt that my ability to communicate was my strongest skill.

I started blogging about brain cancer and my health condition immediately became well-known by not only my closest friends and family, but also by people I didn't know. In time I realized that the information I was sharing could be interesting because the number of comments kept growing. The decision to make my blog open was in hopes others could benefit from the information.

AA: How has your experience of blogging evolved over time?

LS: The topics I have chosen to blog about has changed a lot since I first started posting. In the beginning, as a newly diagnosed person, the blog was mostly focused on the uncertainties of my daily life. The content was very self-centered.

After the treatment, I started to get more interested in other things, such as disease-specific research and public policies. Over time, I became more informed on health technology and on the idea of patients

Patient advocate Liz Salmi speaking during a group session

engaging more with the information in their electronic medical records. I have grown as a patient blogger just as I could have grown in any other professional "career".

AA: How are you involved in the e-Patients' movement? What activities do you carry out as part of this group?

LS: There are 40,000 searches made in Google every second, 2,000 of which are related to health issues. The Internet gives people access to information that make it possible for our doctors to be better.

"e-Patient" is a person who is enabled, empowered, engaged in their health care. If you are engaged in your self-care and research about your health, then you might be an e-Patient. For now we need specific terms to describe this kind of active patient participation, but in the future, I hope this will become a standard attitude.

AA: You also co-founded Brain Tumor Social Media (#BTSM), a hashtag community helping to connect people diagnosed with brain tumors. How is this group working?

LS: Twitter has an amazing power to spread information. Health care professionals have realized the potential of

the platform to reach their specific target audience. The use of acronyms as hashtags is making it easier to aggregate patients, caregivers, and care providers in the same conversation.

Charlie Blotner and I were inspired by the online breast cancer social media (#BCSM) community to create something similar for people affected by brain tumors. We host a live tweet chat every first Sunday [of the month] at 6pm PT. These virtual gatherings have become a great opportunity to exchange support and learn about the latest developments in brain tumor research.

AA: What do you expect from your participation in this session?

LS: It is exciting to engage with Fellows who are facing the same challenges around the world. This [session] gives us the opportunity to learn how things are working in different parts of the world.

For years, a complete medical record has been hidden from patients. I think these discussions around transparency and "open access" to information will be a catalyst for increased engagement by patients and lead to satisfaction in healthcare decisions.

Sunday Highlights

A selection of photos from Sunday's activities, taken by Denise Macalino. These and more will be made available on Facebook and Flickr.

Continued from page one pay for performance incentives, informed consent, health care cost or quality transparency, and health insurance deductibles and copayments. These approaches are based on the view that given enough information, people will make decisions most likely to achieve self-interest.

By bypassing cognition, however, the speaker suggested health care professionals could obtain more positive results using behavioral reflexes. He claimed the science of motivation had evolved. Participants heard, "Once you recognize that people are irrational, you are in a better position to help them." The speaker provided a list of examples of where this irrationality could be used for good. For example, a solution to regret aversion is alerting people to what might have happened.

Discussing life in the US, the speaker remarked upon health insurance choices, which can be presented in a fashion difficult to understand. He said an incentive you cannot understand could not work, and in designing complex incentives, you are giving up some value.

Participants were asked to consider what they heard through the lens of a patient and that of a clinician. One responded, "If you want to change a behavior, the new behavior has to feel as good as the one you change."

What changes for families, friends, and communities?

On Saturday afternoon, participants were also asked to consider certain scenarios and how they might play out. They broke off into six groups and were given individual topics to develop a presentation around. These topics included chronic condition, elder care, the personal experience of using OpenNotes, the family caregiver, the problem patient and the problem clinician, end of life care, and sexual health.

In this interactive plenary session, participants considered how private, and secure AI tools similar to Siri could tackle the taboo of discussing sexual health. An idea for an online platform called "Check-in Now" was also put forward, which would allow patients with a chronic condition, their family members, and doctors to have access to data in one place.

Participants heard family caregivers want to be able to communicate with health providers quickly, and should receive more tools and support. One participant said caregivers would like a seat at the table, one as important as the patient's and the health care professional's.

Transparency with socially at-risk and culturally diverse patient populations

Participants also looked at transparency with socially at-risk and culturally diverse patient populations. The speaker leading the event talked about the origins of mistrust in medical care found in socially at-risk groups. This mistrust can stem from a legacy of discrimination, disparities in access and quality of care, and disparities in interpersonal treatment.

She said those at risk included ethnic minorities, religious cultural minorities, low-income groups, people with low health literacy, people with disabilities, and people from the LGBTQ community.

The speaker said to enhance transparency there should be a focus on disclosure, clarity, and accuracy. To engage patients, health providers should consider one-on-one coaching, group-based classes, web-based interventions, patient portals, and mobile apps. What's important to remember, she claimed, is that cultural, social, language and literacy adaptation remains critical in this process.
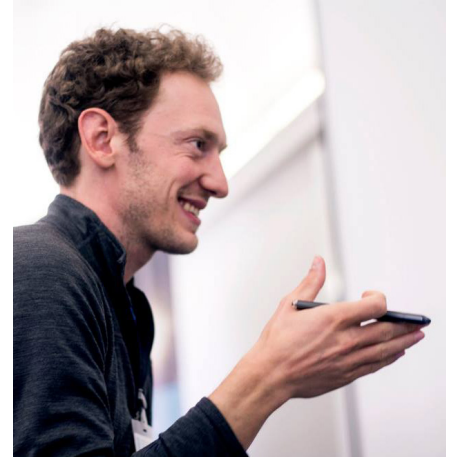
Hot Topic:
"How will greater patient agency affect health care in your country?"

Denise Macalino

"In many ways, I think nowadays, what I see in Chile, is kind of a division between the patient and the physician. There is a mistrust, I think, from both sides. The new and empowered patient is demanding more attention from the physician. The physicians today just don't know how to relate to that, how to answer to that. I think that transparency and agency create paths to develop a new relationship, that will result in more efficiency and better care... Today we have a kind of crisis with the relationship between the doctor and the patient. So somehow there has to be a solution for this crisis. And I think that this solution comes from better agency, patient agency, better involvement. Institutions and doctors should change a lot to achieve that."
Ricardo Zisis
CEO of AméricaEconomía Media Group, Chile

"[Australia Digital Health Agency]'s agreement is to make health information move seamlessly around the country, to support better health outcomes, and giving people a happier and healthier life, and a better deal out of the healthcare services. That is essentially what we're there to do... I think that patient empowerment is one of the fundamental principles that should underpin an enlightened healthcare system in the modern age. My organization has a role to digitally enable health care services and technology, and make them accessible to people. And in that way, we are empowering people by providing them with access to their own health information. And we know that people who have an understanding of, and better access to their own health information in many different disease models have better health outcomes with those conditions. So it's really vitally important."
Meredith Makeham
Chief Medical Advisor for the Australian Digital Health Agency, Australia

"Both before I came here and during the course of our discussions, I think we're trying to define how to share the roles and responsibilities of patient empowerment with the clinicians and their teams, and with the patient. An informed patient, a patient who is actively a part of their care giving and a patient who asks active questions, I think, is more engaged in their care. And I think that's critical. It's not just the doctor's and their team's responsibility. The patient also has a role and responsibility, and the more you know, the more you can play a major role and a positive role in that care. And I think that the discussions we've been having really point that out. I mean, I think it's good."
Jacqueline Woods
Senior Consultant for Academic Search, Inc., USA

"Medicine has always consisted of three elements of doctors doing something with the patient, and then providing care for the patient. But the third part is what the patient himself or herself can actually add to really resource-oriented, patient-centered medicine. And this part is completely missing, I would, say in the German health care system. We expect from this seminar, and from the idea of patient empowerment and engagement, that this third leg, from the three-legged stool of patients: self-help, self-care, and patient activation is really becoming healthcare again."
Tobias Esch
Dean for Organizational Development and Professor of Integrative Health Care at Witten/Herdecke University, School of Medicine, Faculty of Health, Germany
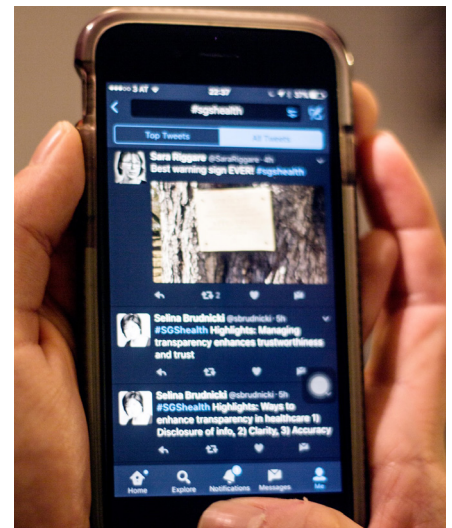

Want to join the conversation?
Tweet @SalzburgGlobal using the hashtag #SGShealth

Have an opinion on any of our hot topics this week?
Email Salzburg Global Seminar Editor Louise Hallman
(lhallman@salzburgglobal.org)
with either a short 50-100 word response or a 500-750 word article and we will consider it for publication in the report to be published in mid-2017!

#SGShealth

#SGShealth Interesting to know doctor's notes are usually written in prescriptions in India. Wondering why they are not written in Japan.

Maho Isono
@mahoisono

Patients seek a revolution in healthcare. So do clinicians working in its #burnoutshops. Debating how to join forces at #SGSHealth.

Tessa Richards
@tessajlrichards

Thought provoking days @SalzburgGlobal #sgshealth so far - we have not designed systems with patients in mind & gaps in how trained as docs

Harpreet S Sood
@hssood

#SGShealth Highlights: We need to look to patients as teachers, co-designers, and innovators

Selina Brudnicki
@sbrudnicki

#SGSHealth Patients can be teachers for other patients, clinicians, and decision makers

Cecilia Rodriguez
@ceciliarod

To view a list of participants at this session with Twitter accounts, please visit: twitter.com/SalzburgGlobal/lists/sgs-553