SESSION OVERVIEW

The care they need and no less, want and no more
Patients and transparency in shared decision making

By: Louise Hallman

Individuals often delegate decision making power to others – we trust mechanics to fix cars without needing all info, so why don’t we expect the same of our doctors?

World Bank Institute senior health economist Roberto Iunes’s comment might have raised a wry laugh in Parker Hall with the participants of the session ‘Realizing the Right to Health’ at Salzburg Global Seminar, but it also raises a fair question for those not already familiar with the concept of shared decision making. After all, doctors are experts in medicine, no?

“Shared decision making is not just informed consent,” clarified fellow panelist Al Mulley, director of the Dartmouth Center for Health Care Delivery Science. Rather, shared decision making recognizes the patient’s own expertise – how they feel about their own treatment and condition. Just because a particular treatment, medicine or surgery works for one person does not mean that it will be the best course for all patients. Shared decision making also recognizes the patient’s possible alternative health futures.

“You have to recognize that different patients have different risk attitudes,” said Mulley. What works for one patient, won’t necessarily be what another wants owing to their own circumstances. This is particularly stark when dealing with critical patients; one may choose to exhaust all medical options, taking drugs with dire side effects in the hope they will prolong life. Others may simply choose to spend the time they have left with their families rather than a hospital.

“A doctor’s job is only half done with the diagnosis,” added Mulley. As he explained, the huge range of treatments available means that the doctor’s job is further complicated, in some cases essentially asking their patient ‘which side effect would you like to deal with?’ and ‘what trade-offs are you willing to make?’

But whilst many are starting to agree that shared decision making – giving the patient “the care they need and no less, the care they want and no more” – is important, doctors and patients must both recognize that a patient’s capacity to make an informed decision might be impaired, regardless of the amount of information available to them. Put simply, patients are by definition not in their best health. Shared decision making needs more than just a strong ethical relationship between a doctor and patient, it also requires a social contract between the government and the patient, added Iunes.

Shared decision making brings transparency between the doctor and the patient, and the patient also needs transparency from government. In order to make a well informed decision, patients need reliable and accurate information. But simply providing the information and claiming transparency it is no panacea; the information must be easily understood and not misrepresented – which can often not be the case in the media.

Highlighting the MMR-autism case in the UK (which saw the publication of a since-disproved study relating the MMR vaccination with a higher rate of autism and led to many parents choosing to boycott the vaccination), panellist interviewer SGS program director John Lotherington exclaimed: “You can’t just dispense transparency – you must consider reception of the information!”

Doctors and governments have the responsibility to ensure patients are well informed.

“It’s not just about doing things right, it’s about doing the right things,” concluded Mulley, and ultimately trusting that the patient knows what’s right for them.

Calling all bloggers!

Salzburg Global Seminar has teamed up with the British Medical Journal to give you all the opportunity to share your opinions on the issues raised at this seminar. If you would like to be considered for publication in the BMJ and on SalzburgGlobal.org, submit your articles to SGS Editor Louise Hallman (maximum 500 words).

You can follow this session online on our website and via Facebook and Twitter, using the hashtag #right2health. Need help with Twitter? Ask Louise!
Panthers are usually found in the jungle or the zoo, but as Fellows of the Salzburg Global Seminar on 'Realizing the Right to Health' heard on Saturday morning, they also belong in the rights-based approach to health care delivery.

Speaking in the opening session of the day, Margot Skarpeteig, senior advisor at the Norwegian Agency for Development Co-operation, Norad, explained the seven components to a rights-based approach to development, which can also be applied to health:

- **Participation** – ensuring patients have a role in their own health care;
- **Accountability** for both governments and doctors;
- **Non-discrimination** – ensuring the delivery of health care to all, including the vulnerable;
- **Transparency** in the decision-making process;
- **Human dignity** – ensuring everyone is treated with respect of their cultural differences;
- **Empowerment** – ensuring patients are informed about their health care systems;
- **Rule of law** – ensuring all participants in the health care system deliver the right to health in accordance to legislation.

A human rights approach to health care gives clear focus on the individual, not just the provision of medicine and hospitals, explained Skarpeteig. And a rights-based approach to health care also puts the focus on governments and their role. Are they actively working against people accessing their right to health, such as in the case of HIV-positive women in Kenya being forcibly sterilized? Are they just passive, such as failing to encourage girls’ education in Pakistan? Or do they simply not have enough resources?

To ensure their citizens can exercise their right to health, governments are obliged to ensure that health services and medicines are **available** – exist in sufficient quantity; **accessible** – affordable and offered to everyone; **acceptable** – taking into account cultural preferences; and of good **quality**.

Fulfill these criteria, and citizens will not only have their rights respected and protected, but fulfilled also.