Empowering older adults

As a geriatrician and palliative medicine physician based in California, Dr Rebecca Sudore explains how she developed an interest in caring for older vulnerable adults and why she is committed to putting people at the centre of healthcare.

What sparked your primary passion – direct patient care for vulnerable older adults?

My passion has always been to ensure that people have a voice in the healthcare system. I first became interested in vulnerable populations when I helped to create a student-run homeless clinic for women during medical school. It was then that I began my life’s work creating easy-to-read patient health information. I was astounded by the effects that social factors such as homelessness and poverty had on health and healthcare access and by the way these individuals were often disrespected by the healthcare system.

During internal medicine residency at the University of California, San Francisco (UCSF) and at a county hospital in San Francisco, I again witnessed the disastrous effects of longstanding poverty and poor medical care on older adults, as well as the ramifications of not providing easy-to-understand medical information that would allow people to make informed medical decisions. I felt I could have the most impact by caring for these older adults and their families and by creating health education materials that would allow them to make informed medical decisions.

Could you describe what you perceive as the most salient challenges facing the US healthcare system?

A major challenge is maintaining the person’s voice in a healthcare system that has almost limitless options for tests and treatments. Studies show that people want to talk to their clinicians about what is important to them and that clinicians really do want to do what is in the best interest of their patients. However, discussions about patients’ overall values and goals – which would help guide individualised and tailored treatment plans – rarely occur due to lack of time, inadequate clinician training and medical culture.

Without understanding the patient as a person, treatments, tests and medical decisions are at risk for not honouring patients’ values and goals. If the first procedure in a clinic or hospital consultation were a discussion about the patient as a person and their values, rather than a laboratory or radiology test, this would go a long way in improving the quality of care in the US.

You are the site Director for the Medical Student Training in Aging Research (MSTAR) Program at the UCSF. What aspects of this role do you most enjoy?

For the past three years I have directed the UCSF MSTAR Program, sponsored by the American Federation of Aging Research and the National Institutes on Aging. The Program allows medical students to conduct research projects on ageing and matches them with a research mentor during the first summer of medical school. I enormously enjoy meeting students from all over the country, hearing about the amazing projects they complete over the summer and watching many of these students mature into trainees who eventually pursue careers in geriatric medicine.

Mentoring is a key part of your role. Why is it so important to you?

I take mentoring very seriously. I have had the benefit of excellent mentorship myself and have learned that mentoring can occur in many different contexts. For example, through a formal one-to-one relationship with regular meetings over time, through one-off or chance meetings, through higher-level intermittent life coaching or through collaboration with colleagues. I therefore try to make myself available for all types of mentoring encounters and through this have helped others become published, obtain grants, negotiate new jobs and be accepted onto graduate and medical programmes.

Why are you interested in this demographic in particular?

The rich interactions I have with my patients, their families and caregivers, as well as my colleagues, makes my job as a geriatrician and palliative medicine physician incredibly rewarding. Geriatric medicine focuses on care for older adults, while palliative medicine focuses on relieving the symptoms of illness and maximising quality of life for patients of any age and any stage of illness. Both geriatrics and palliative medicine are highly collaborative team efforts; and, as multidisciplinary specialties they allow me to work closely with other clinicians, families, and caregivers in the care of patients. People are much more than their illnesses, and working with older adults in my respective geriatrics and palliative medicine fields allows me to focus on my top priority of understanding the patient as a person.
Helping people understand medical information

In response to a lack of comprehensive and patient-centred advance care planning tools, researchers based in the Division of Geriatrics in the School of Medicine at the University of California, San Francisco, USA, have developed a website that enables patients to make more informed decisions about medical care.

IN A WORLD with a rapidly ageing population, increasing numbers of older people are suffering with severe and chronic illnesses. As a result, individuals from this vulnerable group often face complex choices regarding their current and future medical care and support. Despite the fact that physicians urge older people and their families to engage in planning for future medical care, conversations about values for current and end-of-life care can be difficult and deeply emotive – and are thus avoided by many. Unfortunately, when it comes to making some of the most important decisions in their lives, many elderly people are disempowered and unsupported.

This problem often stems from inadequate healthcare systems that fail to provide older people and their caregivers with a cohesive framework to plan ahead for complex medical scenarios. Additionally, many physicians are not given sufficient training to hold appropriate advance care planning conversations, while many health organisations do not place enough emphasis on advance care planning. All too often the concept of advance care planning is reduced to filling out complicated forms that centre on hypothetical health scenarios and preferences for life-sustaining treatments such as cardiopulmonary resuscitation (CPR). Although such forms are important, and Dr Rebecca Sudore has worked to make these forms easier to understand (see http://bit.ly/ha/health-directive) they fall short of teaching people how to identify their deep-seated values and priorities, how to cope with sudden and frightening medical decisions or how to have meaningful conversations about these issues with their doctors and families.

It is these shortcomings in healthcare that have motivated Sudore – Associate Professor of Medicine at the University of California, San Francisco (UCSF) and the San Francisco VA Medical Center – to focus on empowering patients and their families to engage in meaningful advance care planning. With almost two decades of experience in designing health education materials for adults with limited health literacy, Sudore is passionate about putting patients at the centre of health systems by developing tools that facilitate optimal health communication. “When caring for older adults or individuals with serious illness, I am deeply honoured to connect with people on a personal level and get to know their histories, stories and life experiences,” she affirms.

A CUTTING-EDGE RESOURCE

Most recently, Sudore and her colleagues have focused on developing an advance care planning website called PREPARE – www.prepareforyourcare.org. As a free-of-charge, interactive and user-friendly website, its main aim is to help as many people as possible to proactively engage in advance care planning and to have open, honest discussions about their desires with clinicians and loved ones. Since its inception in 2013, PREPARE has had almost 50,000 unique visitors from 115 countries – and the launch of a Spanish-speaking version in November 2014 means that it now appeals to a broader and more diverse audience. “PREPARE is novel because it is meant to help older adults identify what is most important to them and make informed medical decisions regardless of their stage of life or illness,” Sudore points out. “It walks people through an easy five-step process, including how to identify a potential surrogate or proxy medical decision maker, how to determine what is most important in life and how to communicate decisions to family and clinicians. It shows individuals how to do this through videos and by giving people the exact words they can use to start a conversation.” Importantly, the content on the website was formulated from a series of focus groups with seriously ill patients and their families who shared what would have helped them to make informed medical decisions.

A key feature of PREPARE is its accessibility to an older audience that may not be familiar with the internet or with complex medical concepts. Indeed, the use of large fonts, voiceovers of written text and a simple, easy-to-navigate layout ensures that the content is non-threatening and readily understandable – and in recognition of the diverse needs of different patients, the

WWW.PREPAREFORYOURCARE.ORG

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For nearly 20 years, she has also designed easy-to-communication. In 2012 she was awarded Best Junior palliative care, advance care planning and health of Medicine at UCSF, she is an expert in geriatrics, www.prepareforyourcare.org http://geriatrics.medicine.ucsf.edu E rebecca.sudore@ucsf.edu +1 415 221 4810 x 3475 San Francisco, California 94121, USA T 415 221 4810 x 3475

FUTURE STEPS
At present, Sudore and her team are in the middle of three randomised control trials to determine the efficacy of PREPARE in helping older adults engage in advance care planning. These studies are being conducted in several different locations in the US with both English-speaking and Spanish-speaking cohorts. As the data become available over the course of the next few years, this will enable the researchers to assess the impact of the website on the lives of older people.

Moving forwards, Sudore and her colleagues are currently attempting to obtain additional funding that will allow them to expand the scope of PREPARE. As well as translating the website into additional languages, they are also planning to include specific sections dedicated to providing information about different diseases and for caregivers who may need to make medical decisions on behalf of elderly patients. Additionally, the establishment of research partnerships with several international colleagues could lead to the widespread implementation of similar websites in different countries, thus benefiting the older population on a global scale. “Looking to the future, we are eager to forge additional collaborative research relationships,” Sudore affirms. “In addition, one of our main long-term goals includes finding funds to keep PREPARE up-and-running and free-of-charge for everyone to use.”

http://linkd.in/1xos0KK

• It allows users to create a tailored values summary that can be shared with clinicians and loved ones

Breaking down the end-of-life decisions and priorities

The website PREPARE includes video demonstrations of critical decision making, including information about often complex situations. HDDM’s role in the development of this website was to assist in the workshop and focus groups, and to develop and perform the user interface. To implement the data entry procedure, a web-based application was developed. Depending on the option selected by a patient, a set of information about end-of-life medical care will be presented on the page. A set of questions helps users to determine the type of decision, and then a set of options is presented. After the selection of specific options, another set of questions is presented, so that the user can determine the type of intervention. The information presented on the page is based on the selected option; however, a user can return to the previous page at any time to change or confirm their preferences. The interface was designed for easy navigation and to facilitate the process of making decisions.

PREPARE is a valuable, free resource that focuses on teaching patients the skills they need in order to identify their values and communicate their wishes to loved ones. It is innovative in the following ways:

• It is easy to read and is presented in an easy to follow five-step process
• The content is tailored to each person’s individual needs and preferences
• Rather than asking people to make premature medical decisions, it encourages users to prepare for these decisions in the future and to build their communication skills
• It is based on video demonstrations
• Users are guided to make action plans based on the information they are given
• It is culturally sensitive and features images and videos of people from a variety of ethnic backgrounds
• It allows users to create a tailored values summary that can be shared with clinicians and loved ones

REBECCA SUDORE received her BSc in Microbiology at the University of Washington before completing her MD at UCSF in 1999. Now Associate Professor of Medicine at UCSF, she is an expert in geriatrics, palliative care, advance care planning and health communication. In 2012 she was awarded Best Junior Investigator from the Society for General Medicine. For nearly 20 years, she has also designed easy-to-understand health education materials for older adults.