YANKEE DOODLING Douglas Kamerow

Lessons from a fallen hero

What I learnt about patient engagement from Jessie Gruman

One definition of a hero is a person who displays courage in the face of danger. Another is one who is admired and seen as a role model. Jessie Gruman, a patient and patient advocate extraordinaire, who died on 14 July, fitted both perfectly. While dealing with four serious cancers throughout her life she kept a laser focus on discovering and describing the process that she and many other patients with serious illnesses go through, to create useful tools for all patients. She did it with admirable grace, humor, wit, and wisdom.

Gruman founded the Center for Advancing Health (CFAH) in Washington, DC, in 1992, with support from several foundations. During its early years CFAH focused on the importance of health related behaviors, raising the visibility of the role of behavior in health and advocating for the importance of health behavior research.[1] One extraordinarily important achievement during that period was the creation of the Health Behavior News Service in 1995. The service prepares news accounts of research and systematic reviews on important behavioral health topics for journalists. For years it was a free subscription wire service for science and medical reporters; now it is available to all on the web.[2] The service has facilitated broad dissemination of behavioral research that otherwise would have been relegated to dusty library shelves.

Influenced by her personal history of numerous contacts with doctors and hospitals for cancer care, Gruman could have been content to be what she once described to me as a "professional patient," serving on boards, giving speeches, and writing about her healthcare experiences and the lessons she learnt from them. She did do some of that, and she wrote especially movingly and perceptively about her most recent (and ultimately fatal) cancer.[3,4] From her writings I learnt a lot about serious illness, such as that you ultimately cannot hurry healing, even if you work hard at it; that health information technology has improved access to care and information, but when you are seriously ill you may not have the energy to take advantage of it; and that serious physical illness impairs judgment and decision making.

But, early on, Gruman moved beyond her individual experiences to search out and categorize lessons learnt by others. For her seminal book *AfterShock*, first published in 2007 and subsequently revised, she interviewed dozens of patients with serious diseases, sought out and reviewed community and national health and patient resources, and organized it all into a semi-chronological guide for people who receive a devastating diagnosis such as a serious cancer.[5] She starts the book by relating how it feels to receive such a diagnosis: "like a healthy person who has been accidentally drop-kicked into a foreign country . . . where you don't know the language, don't know what is expected of you, and don't have a map." Then Gruman intersperses affecting and useful quotations from patients with the very language and maps that patients need in this most foreign of lands. *AfterShock* is now a smartphone and tablet app as well as a book.

Gruman then collaborated with CFAH and academic colleagues to broaden the scope and deepen the evidence behind her writings about patient engagement, moving beyond patients with serious diseases. They conducted literature reviews and over 250 interviews with caregivers, patients, and expert key informants. The goal was to create a qualitative description of the behaviors that all patients need to perform to optimally benefit from their healthcare.

What emerged from this in 2010 was an "engagement behavior framework," a bulleted list of 42 measurable behaviors in 10 categories.[6,7] They range from basics, such as finding safe, decent care and organizing that care, through typical health education topics like communicating with healthcare professionals and participating in treatment, to specific types of care, including getting preventive care and planning for care at the end of life. As the authors point out, this framework can be useful in assessing the size and scope of what patients face, as a guide to planning engagement programs and research, and as an aid in assessing patients' competencies and need for assistance.

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To help patients implement the engagement framework behaviors, CFAH's website has a section on the "prepared patient" devoted to it.[8] It offers guidance in achieving each of the behaviors of the framework as well as links to details and resources found elsewhere. It is updated regularly as new material becomes available.

The CFAH's engagement behavior framework and Gruman's work in general complement *The BMJ*'s increasing interest in and focus on patient partnerships. Groups such as the UK National Institute for Health and Care Excellence and the US Patient-Centered Outcomes Research Institute have taken the lead in finding ways to incorporate patients' input into every stage of healthcare research. Although, as *The BMJ* editors Tessa Richards and Fiona Godlee recently pointed out,[9] patient partnership is a lot easier to talk about than to realize, it is heartening to see these two institutes, *The BMJ*, and others working to make this happen from the professional and research perspective.

Combining that work with the patient resources available from CFAH and many others, maybe Jessie Gruman's legacy will ultimately be more patients benefitting from the goals she selected as a tagline for the center she founded: Evidence. Engagement. Equity.

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