

Patient Stories and Health Research

Below are some thoughts and suggestions intended principally for patients, caregivers, and family members—hereafter all included in a single term, patients—about the use of patient stories in health research. I offer them not as conclusions or even guidelines but as “thoughts in progress” that I hope help to prompt and inform discussion and debate.

Lived Experience and Patient Stories: These terms are sometimes used interchangeably, but this seems mistaken. Lived experience, the redundancy (there being no “unlived experience”) perhaps deliberate to underscore the “first handedness” of the experience and the fact that it belongs entirely to the person who had it, exists whether or not a story is made out of it. Stories, on the other hand, are created, often quite deliberately and sometimes as much from other stories as from the teller’s experience. Patient stories can have immense power, and they can be harmful as well as helpful. Once shared, they no longer belong entirely to the individuals or groups who created them.

The Patient Story: This is a term probably best avoided if not discarded. Researchers know there are at least as many patient stories as there are patients, and most patients must know this even better. Still, the term keeps turning up. There is real danger in regarding a single story as representative of all patients’ experience (as if their lived experience was generic) or even of the experiences of a particular group of patients who share a diagnosis or a specific trait. Patient members of research teams may feel tempted—perhaps having been encouraged by other team members—to depict “their” stories as “the” story, but it would probably relieve patients to know that the stories they tell are not being expected to be any more representative than other patients’ stories. Not feeling any pressure to tell “the patient story” might well yield a richer, more authentic story.

The Purpose(s) of Patient Stories: Since patient stories can be told and used for many purposes, it is always good to ask anyone asking you to share your story—even a small part of it—why you are being asked to do so and how the story will be used. (This should always be done, but sometimes it isn’t.) And if the impetus to tell the story is coming from you, consider carefully why you want to tell the story, what you want or expect to result from the telling, and if there is potential for unintended consequences—for anyone referred to in the story or for yourself.

Only Patient Stories?: Restricting the telling of stories within the research team to patient members of research teams can, perhaps unintentionally, too narrowly define their roles and make it harder for them to be equal members of the team. Clinicians, researchers, policy makers, and even administrators also have healthcare stories—and are often eager to share them. If many members of the team do so, a greater degree of equality can result—and there will be a deeper pool of stories from which to draw.

Advocacy Stories (Close-Ended) and Research Stories (Open-Ended): Consider the difference between stories used in advocacy (for better services, easier or quicker access, etc.) and stories most useful in research. In the former patients typically select the content and shape the structure to maximize their impact in helping to effect a particular desired result. They may focus on particular negative effects of the disease and omit any mention of strategies they have found helpful in mitigating the disease’s impact. In the latter patients provide as complete and accurate a picture as possible of that part of their experience that is most relevant to the research question. Advocacy stories end with a call to certain action; stories most helpful to research often raise new questions or add further complexity. Stories used in advocacy are designed to narrow the scope of potential interpretation; stories researchers prize

lend themselves to several, sometimes conflicting, interpretations. A patient's story, due largely to its intrinsic richness, may be understood and used by researchers in ways the patient never imagined,

Anecdotes and the Anecdotal: Take particular care in calling something you or someone else shares “an anecdote” or “anecdotal information.” There's not always a clear distinction between an anecdote and a story, but in research contexts calling something anecdotal is often a way of dismissing it or of minimizing its relevance, its importance, or its status as evidence. Sometimes anecdotes are regarded as having no evidentiary value at all. The same views can apply to anything called a story, but the unique value of patient stories within healthcare generally and health research particularly appears to be gaining wider recognition.

Recently there have been attempts to promote the use of “colloquial information” and “colloquial evidence” as less loaded terms than “anecdotal information” and “anecdotal evidence.” Patients should attend to these changes and distinctions and ask questions about the relative values, often assumed rather than stated, that are attached to all these terms.

Stories as Evidence, Stories and Evidence: Patient stories collected systematically in the course of research are regarded by almost everyone as evidence--qualitative evidence, which is sometimes regarded as less valuable or as less reliable and trustworthy than quantitative evidence. In some instances it may be more appropriate and useful to look upon these stories less as lower quality evidence than as sources of key insights into the meaning, significance, and limitations of the quantitative data that have emerged from a trial. The stories of patient members of the research teams can also shed light on the meaning and implications of the trial data, though, again, caution must be applied when thinking of how generally a relative handful of stories can be applied. What's important is that all members of a research team, including patient members, candidly discuss the degree to which and the ways in which they regard patient stories as evidence.

Revisiting Stories: Stories sometimes yield more when they are recalled or retold than when they were first articulated or heard. Especially given the length of many research projects, it can be especially useful—whether in a fortifying or a corrective way—to revisit stories shared and considered at earlier stages.

A Final Thought: No one has the whole story.

Frank Gavin

National Liaison, Canadian Family Advisory Network

Member, Ontario SPOR Support Unit Board