

Patient-Inspired Research: A Better Way to Go?

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Are clinicians even able to identify what is important to our patients? Or are we potentially meeting the needs of our own intellectual curiosity rather than the experiential needs of our patients?

Recently, I attended a meeting of the Oncofertility Consortium and had one of those “a-ha” moments that change one’s perspective in a very real way. A surgeon from Sweden was talking about uterus transplantations, and she described how these came about. She told a story about one of her colleagues, who was talking to a young woman who had cervical cancer and had a hysterectomy. The patient asked the physician if they could give her a “new” uterus

so that one day she could have a biological child. The physician told her that was not possible and the patient responded, “Why not?” That prompted the physician to start a new

field of research, uterine transplantation, that has had some early successes, as well as many failures. Sweden is a leader in this area of research, and, in time, I have no doubt that this will become more common for a select population of cancer survivors who want to bear children.

I am reminded of the work of the Patient-Centered Outcomes Research Institute (PCORI), a non-profit funding organization that has been in existence since 2010 (www.pcori.org). During the past six years, this organization has funded comparative clinical effectiveness research on many topics, including cancer. Sixty-five studies have been

funded, for a total of \$194 million, with the majority of funding going toward studies on breast cancer, followed by colorectal, lung, prostate, and cervical cancer. Of note, the majority of studies have focused on racial or ethnic minority populations as well as women, older adults, and low-income populations. PCORI-funded research projects are intended to address the questions and concerns that are most relevant to patients. They involve patients and their caregivers, as well as clinicians and researchers, in deciding what should be funded and how.

What struck me most about the story of the patient who asked, “Why not?” was that the patient and her need or desire was the impetus for a new field of research that has the potential to affect many. This is patient-inspired research rather than patient-focused research, or, as we more often see, investigator-initiated research. How often does this happen? I know that many of us have been moved by something a patient or family member has said in conversation that led to a study or practice change. Is that patient-inspired research? Do we need to be asking our patients what they think is important for us to study, as Cox, Arber, Gallagher, MacKenzie, and Ream (2017) did in their Delphi survey? How do we ensure that the research we conduct is inspired by the people who will most benefit from the results, regardless of whether they are positive?

Should we be encouraging, or even requiring, researchers to spend time in clinical practice so

that the voices of the patients can be heard and lead to inspired research? This is an old argument that does not seem to go away, despite years of debate. However, in the Cox et al. (2017) study, consensus between nurses and patients was reached in less than 50% of the research priorities. So, are clinicians even able to identify what is important to our patients? Or are we potentially meeting the needs of our own intellectual curiosity rather than the experiential needs of our patients? Can patient-inspired, patient-centered, or patient-focused research that is relevant to many be conducted, or is that merely an illusion? Can we even think of patients as a whole when, in reality, each and every patient is an individual with unique needs and experiences?

I do not believe that these questions have right answers. Certainly, the PCORI model that involves a team approach is important. Intellectual curiosity and clinical observations are relevant, too. If clinicians are listening to their patients, they will hear the “whys” and “why nots” that can inspire scholarly inquiry. Perhaps a solution is for nurse scientists to talk to clinicians more directly and more often. If the most relevant arena for identifying patient priorities for research is at the bed- or chairside, let us find a way to bring scientists and clinicians together to identify research priorities. We certainly are seeing examples of this in larger cancer centers where nurse scientists have a presence and connection to the bed- and chairside, and this is a good start.

But clinicians also need to start seeing themselves as partners in the research process; even without advanced degrees, staff nurses have a role to play in listening to the questions and observations of our patients and communicating those to nurse scientists who can translate those questions into research studies that, ultimately, will have an impact on individual patients. Although no one-size-fits-all answer to these questions exists, communication is always the place to start.

Reference

Cox, A., Arber, A., Gallagher, A., MacKenzie, M., & Ream, E. (2017). Establishing priorities for cancer nursing research: Nurse and patient collaboration. *Oncology Nursing Forum*, 44, 192–203. doi:10.1188/17.ONF.192-203