

Rethinking patient-oriented research

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In my late teens, I worked in a foreign country with a community very different from my own. It was challenging, but I came to love and appreciate the richness of the culture. This experience of immersion in a new culture led me to pursue a research-based master's degree in medical anthropology, where I learned to think deeply and critically about power structures inherent in health care delivery and came to value each individual's subjective experiences. As an ethnographer, I learned the importance of human-to-human interaction and the nuances of cultural humility.

I went on to pursue my goal of becoming a physician. In medical school, I was re-educated in the tradition and culture of evidence-based medicine (EBM), which often clashed with my previous training in anthropology. In the traditional hierarchy of evidence as conceived by EBM, quantitative evidence like randomized controlled trials and cohort studies trump experiential knowledge conveyed through methods like ethnography, which are often derided as anecdotal. I came to appreciate the value in both forms of knowledge and sought to marry them as I subsequently pursued a doctorate in health services research.

Around the time I started my doctoral research training, the Canadian Institutes of Health Research launched its Strategy for Patient-Oriented Research (SPOR).¹ This became a hot topic in health research circles, as targeted funding competitions were launched. I fully agreed with the need for such a strategy, but the practice was often somewhat disappointing. It seemed to me that an investigator, including me, could turn any project into patient-oriented research with a few patient signatures and maybe a consultation or two.

However, the anthropologist in me yearned for more authentic, meaningful dialogue with people who had lived experience. I recognized the need for a fundamental shift in the power dynamics of the research enterprise.

During my postdoctoral fellowship, I set out to empower patients more fully in a research project, as partners rather than as participants or subjects. Research participants contribute data to projects, but patient partners contribute to the research questions, design, conduct, interpretation and dissemination. In community-based participatory research (CBPR), the patient partners who do this work are referred to as co-researchers. I chose to conduct a CBPR study, as it seemed to me that these often-underutilized approaches would be more in keeping with the values behind SPOR than much of what I had seen and done previously.

We faced a lot of adversity at the beginning. Many external agencies are not keen to fund a project that doesn't have a research question; nevertheless, we secured a small local grant from our institution. We then faced an ethics board that had never seen such an open-ended proposal and weren't quite sure what to do with our protocol. This required lots of back and forth and several modifications. Finally, some of our collaborators decided that the study was not feasible within the time frames and resources at our disposal. However, others were willing to take the chance of joining us on this atypical journey.

After funding, ethics approval and collaborators were secured, logistical

problems remained. Challenges included finding a friendly community space to host our group, sourcing food to share with co-researchers and figuring out how to compensate people for their time, as well as questions of where to recruit potential co-researchers, how to train them, which methodologies to undertake and what issues to study.

Our efforts brought together a group of eight diverse, experienced and engaged individuals who each had lived experience of diabetes and homelessness. We met with them every week or two, to provide both diabetes education and research training. Over time, these individuals evolved from study participants into full-fledged co-researchers, who formed the Clients with Diabetes Action Committee (CDAC). Through respectful communication and deliberation, we found common ground and were able to work collaboratively with a shared purpose: to improve the experience of those living with homelessness and diabetes.

In my research training, I had learned that success depended upon meticulous planning and systematic research implementation. Ceding control did not come naturally and was very unsettling for me. At several points, I was concerned that our efforts might fail to coalesce into a tangible product. I was afraid that I might not produce academic deliverables or satisfy our funders' requirements. I even contemplated intervening. Over time, however, I learned to trust the process and the co-researchers. They showed me that their lived experience is as valuable as my own knowledge of theory, methods, physiology and pharmacotherapy.

During our priority-setting process, the group conveyed that their top priority with respect to diabetes management was the daily problem of how to access, afford and prepare healthy food.² This was initially quite a blow to my ego, as I had naively expected that group members would prioritize their interactions with health care providers and the services we provide. It dawned on me that maybe we're not as important as we think.

The group completed a photovoice project where each co-researcher highlighted their experience managing diabetes and homelessness, using a photograph and an accompanying narrative.³ It was humbling to witness their personal and nuanced experiences, conveyed more powerfully than I could have even with years of clinical and research training. This unique approach to research had more value than anything I could provide on my own.

The CDAC's work was highly successful, resulting in peer-reviewed publications, media attention and presentations at national and international conferences; co-researchers have been recognized as authors and presenters.⁴ However, the impact that the project had on those who participated seemed to be the greatest success of all. Former CDAC members said they were not used to being treated as experts

and that the experience in the CDAC was deeply meaningful. These stories, more than anything else, make this kind of academic work worth my effort and stress.

My fellowship has ended and the work of the CDAC is now complete, but the experience has cemented my commitment to true patient-oriented research, and the need to meaningfully give people with lived experience a voice in our academic work. Building on the work we did together, we have now established a similar group in Calgary to inform and guide our ongoing program of research.

Although there are inherent challenges with CBPR, I have made a commitment to continue prioritizing the application of these approaches in each of my research projects and to elevating the voices of patients, from participants to co-researchers. I look forward to the many things that co-researchers, like those from the CDAC, will yet teach me.

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