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Commentary: Using patients’ narratives in complex research

Ross E G Upshur

The use of narratives is attracting attention in health care as a means of exploring and sharing experiences of health, interactions with the health care system, and as a research method, in and of itself. How narratives function as part of a complex research programme is a less explored terrain. Greenhalgh and colleagues are to be commended for their innovative and novel approach to creating an intervention for diabetes education with the specific aim of engaging bilingual health advocates to facilitate narrative or story telling approaches as a part of a programme to improve diabetes management for a vulnerable and neglected population.1

The study is itself part of a story. Like an early chapter in a book, what we see before us is only an indication of what is to come, and as with all good stories it clarifies some dimensions of the plot but leaves others untold. Greenhalgh and colleagues clearly show the difficulties and describe the barriers required to get an action oriented research programme functioning, and they are candid in both their successes and failures. It seems that a user group led by a bilingual health advocate can be successfully implemented in some circumstances, but not in all. Considerable effort is required to ensure the acceptability and sustainability of the programme.

I wonder whether the authors have explored the possible harms associated with this type of research. One of the important findings was that participants did not compare their blood glucose results to previous results, but compared their results to each other’s: “She didn’t have a second helping and, look, her result is better than yours.” Considerable trust and support is required for this kind of disclosure and public discussion of a personal narrative in a public or group setting. I hope that victim blaming didn’t have an important role and that surveillance, patronising, and intrusiveness did not become a part of the lives of the people who shared information about their diabetes. An example would be a social occasion when people say “You can’t eat that, you’re diabetic.” The ethical demands of action research are relevant but are rarely discussed.

The story of this study is not yet completed. This report will leave readers anxious for the next installment. Greenhalgh and colleagues have established the feasibility of establishing diabetes support and education groups with bilingual health advocates and service users, revealing novel insights. They now propose a randomised control trial. Will they engage their study communities in the creation of this randomised trial, particularly seeking input from the group on the desired outcome measures and the magnitude of effect expected by such an intervention? The importance placed on outcomes by different participants in the research process varies greatly. Narrative approaches are ideally suited to capturing this diversity and I hope that, true to the researchers’ methods, the community has as much input in the conception of the randomised trial as it has had into the development of this important study.

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