The practice of qualitative inquiry in illness narrative scholarship

Warren Bareiss

Department of Fine Arts & Communication Studies, University of South Carolina Upstate, Spartanburg, South Carolina, USA

It has been more than 30 years since Arthur Kleinman first published *The Illness Narratives; Suffering, Healing & the Human Condition*.[1] In his preface, Kleinman referred to the case of a young burn victim:

> She taught me a grand lesson in patient care: that it is possible to talk with patients, even those who are most distressed, about the actual experience of illness, and the witnessing and helping to order that experience can be of therapeutic value. (p. xii)

He also describes an older patient who suffered from cardiovascular symptoms associated with syphilis, stating that "This patient, like her much younger counterpart, edified me about the difference between the patient's experience of illness and the doctor's attention to disease" (ibid.). Elaborating further, Kleinman argued that

> …to evaluate suffering requires more than the addition of a few questions to a self-report form or a standardized interview; it can only emerge from an entirely different way of obtaining valid information from illness narratives. (p. 28)

Kleinman's work thus demonstrated a phenomenological gap between patient and healthcare provider that can be bridged through understanding of how patients describe their struggles, losses, and victories through storytelling. Paying attention to illness narratives is a means of getting up close to the illness *experience*.[1]

A few years later, Rita Charon[2] similarly began exploring the functions and significance of medical narratives in work that would blossom into dozens of highly influential books, chapters, and articles that she continues publishing to this day. And it's been nearly as long since Arthur W. Frank first published *The Wounded Storyteller*,[3] a concise, clearly written monograph explaining how patients come to terms with the ways that their bodies and lives are transfigured by telling stories about their struggles with illness.

Of course, phenomenology of storytelling has a much longer history with respect to treatment and understanding of mental health and arguably neither Kleinman, Charon, nor Frank were the first to apply narrative analysis methodologies to patients' stories. Nevertheless, it wasn't until the work of these three scholar/practitioners was widely read that the importance of what stories are told, how stories are told, and who tells stories with respect to healthcare coalesced into what we now called the scholarship of "illness narratives."

Indeed, in preparing this editorial, I ran a quick database search for "illness narrative" from 1900 to 1987 and found five publications; however, a subsequent search from 1988 to the present led me to over 10,000 publications.

Perhaps one of the reasons that so much attention is placed on storytelling in healthcare contexts is that stories can be analyzed from many academic directions, including rhetorical and literary studies (e.g., discourse analysis, thematic analysis, and narrative analysis), ethnography, sociology, and psychotherapy to name a few.

Furthermore, illness narratives in no way need to be limited to patients' stories. Indeed, healthcare providers' stories are just as important in understanding how illness shapes people's lives. And the same can be said for stories

Correspondence: Warren Bareiss, Department of Fine Arts & Communication Studies, University of South Carolina Upstate, Spartanburg, South Carolina, USA.
E-mail: bareiss@uscupstate.edu

Key words: Qualitative inquiry; illness narrative scholarship; patient and healthcare provider; storytelling.

Received for publication: 30 September 2022.
Accepted for publication: 30 September 2022.

Qualitative Research in Medicine & Healthcare 2022; 6:10898
doi:10.4081/qrmh.2022.10898

told by caregivers who provide rich accounts of how they, too, adapt (or not) to illness experienced by loved ones.

I suppose that illness narratives could be analyzed using quantitative methodologies, but it strains my imagination to think how or why anyone would want to do that. In contrast, I can't think of a better application of qualitative methodologies than the exploration of human experience of illness by way of narrative analysis. Qualitative narrative analysis examines not only *what* is said, but *how* it is said within specific contexts to real or imagined listeners. Meaning (or more accurately, meanings), is/are fluid—changing from telling to telling, shaped by not only the storyteller, but by contextual conditions and by conceptual filters in the minds of listeners. Thus, even those who tell stories have no proprietary hold on meanings implied by the tales they construct.

The role of the qualitative analyst is to understand meanings on at least two different conceptual plains. First, qualitative scholars ask what stories and their narrative elements (characters, settings, motivations, and so forth) mean to the storytellers. But that is only part of qualitative researchers' task. To stop there would be good reporting, but not good analysis. Instead, qualitative researchers immerse themselves in many stories, usually told by many people, looking for patterns to, as Kleinman said, "emerge."[1]

Sometimes, narrative analysis is a waiting game, as scholars sift through story after story, hoping and waiting for that moment when one or more patterns become manifest. Having done that kind of work, I can attest to the worry one might feel that a pattern might never be evident—and the mixed feeling of accomplishment and relief when it finally becomes clear.

And, of course, true to qualitative tradition, no two scholars would be expected to perceive the same patterns. Stories speak to everyone in different ways, conditioned by the unique baggage that each of us brings with us as audience members in the narrative process.

Storytelling is central to all three articles in this issue of *QRMH*. MacDougall et al.[4] report on personal videos produced by outpatients in a psychosis intervention program. Rather than assess the content of the videos, MacDougall et al. examine the value of the story *telling* to the participants. Here, the channel of storytelling is front and center. Video production is a collaborative process, so the experience of telling a story is a group effort. The finished videos were, thus, not only an expression of self, but also the outcome of a shared process of meaning making.

Tullis[5] approaches storytelling in a very different way through analysis of discourse among healthcare providers in the context of tumor board meetings. In comparing different types of tumor board discussions, Tullis finds that patients' stories are emphasized much more in some scenarios than in others. Specifically, Tullis explains that blood and bone marrow tumor board discourse tends to delve deeply into patients' stories (i.e., taking a more holistic approach to the patient) because those forms of cancer are "inherently relational." In other words, those patients are more often perceived within the context of family caregivers who are often transplant donors. Tumor board discourses in those situations, therefore, are performative contexts wherein stories provide Kleinman's aforementioned bridge "between the patient's experience of illness and the doctor's attention to disease."

The final article, from Fischer et al.,[6] is peppered throughout with dozens of stories. Although the stories are brief—often just a sentence or two—they are nonetheless deeply revealing in their totality. A better instance of emerging patterns would be hard to find as the authors demonstrate common themes among healthcare providers' descriptions of their best efforts during the early days of COVID-19. Brief quotes provided by more than 20 family physicians blend eloquence with emotion, demonstrating providers' anxiety, frustration, and burnout, often (though not always) balanced by hope, resiliency, coping, and determination to serve.

We at *QRMH* hope that you will enjoy reading each of these three articles and learn not only about the experiences of the people whose stories are represented, but also about how qualitative analysis of patients' and providers' stories can forge better understanding among patients, caregiving family members, and healthcare providers.

References

1. Kleinman A. The illness narratives; Suffering, healing & the human condition. Basic Books; 1988.
2. Charon R. To build a case: Medical histories as traditions in conflict. Lit Med 1992;11:115-32.
3. Frank AW. The wounded storyteller; Body, illness & ethics. The University of Chicago Press; 1995.
4. MacDougall AG, Price E, Glen S, et al. A pilot study of participatory video in early psychosis: Qualitative findings. Qual Res Med Healthc 2022;6:10438.
5. Tullis JA. Tumor talk: A descriptive study of communication about tumor board meetings. Qual Res Med Healthc 2022;6:10717.
6. Fischer A, Shapiro J, Nguyen T, et al. Views from the trenches: California family physicians' challenges and resilience factors while providing patient care during the initial wave of COVID-19. Qual Res Med Healthc 2022;6:10296.