

**Writing Medicine:**

Narrative and literature helps community members express personal stories of chronic illness

*The Voice of the Physician as Patient and Participant*

Seema Shah MD, MSPH

I attended the first “The Examined Life: Writing and the Art of Medicine” conference at the University of Iowa in 2007. I have received much benefit from the reading and writing of literary illness narratives as a patient; therefore, I went to learn about the ways these modalities could be used in patient care. Interestingly, I was also introduced to a concept that was completely new to me: the use of literature and reflective writing in medical education. It was also the first time I heard the term “narrative medicine.”

Physician and literary scholar Rita Charon, a pioneer of narrative medicine, refers to the emerging field as “a clinical cousin of literature-and-medicine” (Charon, 2006, p.vii). The field of literature-and-medicine was introduced to U.S. medical schools in the early 1970’s to “humanize” the largely biomedical science-based curriculum. Since then other rationales have emerged, including the application of literary theory and skills to the practice of medicine, understanding the patient’s perspective, and the teaching of medical ethics (Wear, 2004). Charon first used the phrase “narrative medicine” in 2000 to capture the hands-on use of literature in medicine, describing it as “medicine practiced by someone who knows what to do with stories” (Charon, 2007, p.1265).

There is strong evidence that the arts and humanities in general, and literature specifically, can be used effectively in health professional education to hone observational, reflective, and interpretive skills, as well as to promote better provider-patient relationships through the fostering of compassion and empathy (Brett-MacLean, 2007; Staricoff, 2004). For example, literature can stimulate insight and understanding by portraying different perspectives and complex situations.

My first foray into the use of literature in health professional education was in 2008, when I became involved in the “University of British Columbia Community Partnerships for Health Professional Education” initiative. The initiative is a campus-community collaboration to teach students about the lived experience of illness through the development and implementation of patient-led workshops.

I became involved in this project in the capacity of a community member living with chronic illness. I wanted to share some of my first hand knowledge about being a patient; however, I also thought my experience from the perspectives of physician and patient would lend a unique perspective to the project. I was hoping to be able to apply some of what I had learned about narrative medicine.

Though in-person sharing of patient stories alone has been found to be effective in teaching about the patient's experience of illness (Kumagai, 2008), I wanted to add the use of a literary narrative to sharing my story. Although I had not encountered this dual approach to sharing in the literature, I thought combining the in-person sharing of my personal story with a literary narrative of illness had the potential to be particularly effective.

Reasons for my view include the fact that literary narratives are expertly crafted to engage the reader/audience and to effectively convey emotion and meaning, which can be particularly challenging when sharing the difficult stories of illness (Alcauskas & Charon, 2008; Neimi & Ellis, 2001, Raoul et al., 2007). In addition, literary illness narratives can minimize the chance of personal sharing becoming self-indulgent, a risk associated with this type of public sharing about illness (Hawkins, 2007; Neimi & Ellis, 2001).

To achieve my aims, I combined the sharing of my own experience with a fictional short story about a woman living with chronic depression (Krahn, 1999). I chose a story that I felt addressed the workshop objectives for students and accurately reflected important aspects of my own experience with illness, as well as speaking to me at an emotional level. In the context of the workshop, the students did a role-play using the story, followed by a brief reflective writing exercise. After this, there was a group discussion, during which I was able to share my personal insight and experience.

Based on results and observations from two workshops we have facilitated, the use of a literary illness narrative seemed to help students better understand the lived experience of illness. By portraying a complex scenario – including a phone conversation between a chronically depressed woman and her adult daughter – the short story gave students the opportunity to consider different perspectives. Through additional conversations the woman had with the reader/audience and with 'depression' itself, the importance of context when interpreting a situation was made clear and the actual experience of the depressed woman was better understood.

The combination of personal and literary narratives seemed to provide a good balance, each method building on the other. For instance, I believe the insight I shared from the perspective of a patient added to the interpretation of the story, while the story acted as a springboard for the sharing of my own stories of illness.

By sharing insight and specific examples from my life, I was able to help students see how some of the comments made by the daughter may have been interpreted as judgemental or condescending and affected how the depressed woman chose to respond. This was especially valuable since some of the students identified with the daughter and thought they would act similarly to her. Seeing the impact their responses could have on a patient assisted them to move from judging the mother's reaction towards

understanding; they realized there may have been logical reasons to explain why the mother didn't always feel like she could be forthcoming.

Focusing on fictional characters and emphasizing there were no "right" and "wrong" answers seemed to put the students at ease to express their feelings. Commenting on "characters" allowed a level of honesty I don't think they would have demonstrated if only focusing on my personal story. In the same way, I could respond honestly to their comments, from the perspective of a patient, *through the text* without putting students on the defensive or making them feel like they said the "wrong" thing.

Along with lending support to the use of literature in medical education, from my experience with the workshops, I would argue there may be a role for the combined use of in-person patient narratives and literary narratives of illness to teach students about the lived experience of illness and complement their required biomedical textbook learning.

### **Acknowledgements**

I would like to thank the Advisory Board for the project entitled "UBC Community Partnerships for Health Professional Education" for collaborating with me so that I was able to submit this commentary describing my workshop experience for publication. I'm very appreciative that the Advisory Board and the workshop planning team supported my efforts to develop my contribution. I also want to acknowledge the UBC Teaching and Learning Enhancement Fund for providing funding to make this project possible. I specifically want to acknowledge the planning team: Ms. Stacey Creak, Dr. Wendy Hall, Ms. Andrea Harstone, Ms. Sue Macdonald, Ms. Lisa Marie Sterr, Mr. Justin Wallace, and the third community educator for their contributions to workshop development. I also want to thank the research team: Dr. Angela Towle (principal investigator) and Lesley Bainbridge, Grant Charles, Marion Clauson, David Fielding, William Godolphin, Wendy Hall, Sue Murphy, and Michael Lee (co-investigators) as well as the project's research coordinator, Cathy Kline and the former project coordinator, Ms. Stacey Creak, for sharing the project-specific information required for me to write this paper. In addition, I'd like to express my appreciation to Dr. Wendy Hall from the UBC School of Nursing and Dr. Angela Towle from the Division of Health Care Communication for reviewing this commentary and providing valuable feedback.

## References

Alcauskas, M & Charon, R. (2008). Right brain: Reading, writing, and reflecting: Making a case for narrative medicine in neurology. *Neurology*, 70, 891-894.

Brett-MacLean, P. (2007). Use of the arts in medical and health professional education. *University of Alberta Health Sciences Journal*, 4(1), 26-29.

Charon, R. (2006). *Narrative medicine: Honoring the stories of illness*. New York: Oxford University Press, Inc.

Charon, R. (2007). What to do with stories: The sciences of narrative medicine. *Canadian Family Physician*, 53(8), 1265-1267.

Hawkins, A. H. (2007). Writing about illness: Therapy? Or testimony? In Raoul, V., Canam, C., Henderson, A.D., & Paterson, C. (Eds.), *Unfitting stories: Narrative approaches to disease, disability, and trauma* (pp. 113-127). Waterloo, ON: Wilfred Laurier University Press.

Krahn, R. (1999). Unwanted companion. In Edwards, W. M. & Serviss, S. A. (Eds.), *Study in grey: Women writing about depression*. Edmonton, AB: Rowan Books, Inc.

Kumagai, A. K. (2008). A conceptual framework for the use of illness narratives in medical education. *Academic Medicine*, 83(7), 653-658.

Neimi, L. & Ellis, E. (2001). *Inviting the wolf in: Thinking about difficult stories*. Little Rock, AR: August House Publishers, Inc.

Raoul, V., Canam, C., Henderson, A.D., & Paterson, C. (2007). Introduction: Aesthetics, authenticity, and audience. In Raoul, V., Canam, C., Henderson, A.D., & Paterson, C. (Eds.), *Unfitting stories: Narrative approaches to disease, disability, and trauma* (pp. 25-32). Waterloo, ON: Wilfred Laurier University Press.

Staricoff, R. L. (2004). *Arts in health: a review of the medical literature*. Abingdon, UK: Arts Council of England.

Wear, D. (2004). Toward negative capability: Literature in medical curriculum. *Curriculum Inquiry*, 34(2), 169-184. Abstract retrieved from Wiley InterScience website

**Bio:**

Seema Shah, is a physician who has completed a residency in preventive medicine and has a master's degree in public health. She left general practice in 2004 due to chronic illness. Since then she has facilitated workshops using creative writing and literature for people living with chronic illness and for health professional students. Creative writing about her experience with illness was published in Portfolio milieu 2004, an anthology of Canadian women's writing and is forthcoming in *Blood and Thunder: Musings on the Art of Medicine*.