

R_x Storysharing, prn: Stories as Medicine Prologue to the Special Healing Issue

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The story of narrative medicine is dynamic and is examined here, exploring specific cross-disciplinary research involving both storytelling and storylistening in the context of health care. Specific findings concerning storysharing in a variety of health communities are described, and a functional model is offered for understanding the effects of storied communication for both caregivers and carereceivers. The current challenges of research into storytelling and healing are explored, positioning the special issue articles into future directions for scholarship on stories as medicine.

In West Africa, when a person in the village becomes sick, the Healer will ask, "When was the last time that you sang? When was the last time that you danced? When was the last time that you shared a story?"

— Cox (2000, p. 10)

Now God sometimes tires of making people happy and always mixes some misfortune with good luck, like rain with sun. The queen fell ill, and neither the learned doctors nor even the quacks could do anything for her.

— Excerpt from *Donkeyskin*, an oral folktale

*T*he magical words "Once upon a time . . ." that often start a traditionally structured folktale can induce a soothing, healing light trance state in listeners. Indeed, "holding an audience spellbound" is often used to describe an audience's altered state of listening to a great tale told well, while therapists have claimed that storytelling performances contain many of the conditions necessary for inducing trances. A psychotherapist-storyteller from Boulder, Colorado, described such healing listening trances as *inner-directed* states of consciousness, such that although listeners' eyes may be on the storyteller, their consciousness is turned inward (Martin, 1993).

Beyond the Storied Listening Trance

This hypnotic effect alone might be enough to recommend that listening to stories can be healing. There is evidence, however, that listening to oral tales can meaningfully penetrate even organic brain disorders, producing significant moments in people's lives. Olga Loya described one powerful experience of a storytelling troupe of middle-school students (sponsored by the California Arts Council) that was giving weekly performances at a daycare center for senior citizens (Loya, 1997). Loya recounted the effects of those story performances on one of the senior citizens:

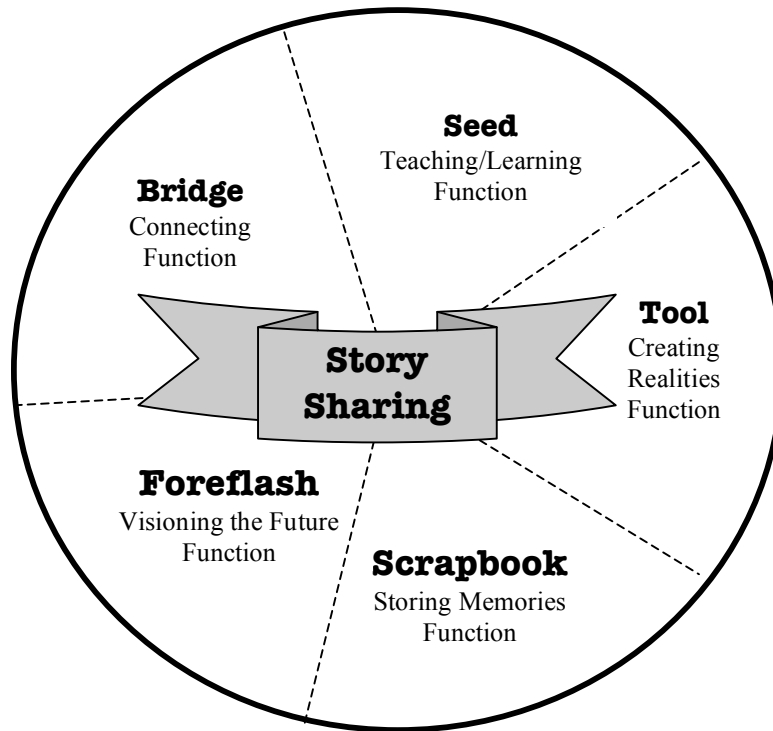
Frank told amazing stories. With each passing year, however, his personality deteriorated, ravaged by Alzheimer's disease. By the third year he barely talked and never told stories. One day a young teller, Yarra, told about dancing. When she finished, Frank spoke for the first time in months. He had been a champion dancer, had won lots of competitions. Would Yarra like to dance? She accepted. They moved gracefully about the room in a wonderful dance, then he brought her back to her chair. As he sat down, the light left his eyes for the last time. He never spoke again after that (p. 10).

The beneficial effects for those who are ill of telling their story has long been recognized in many cultures and has received attention from philosophers, social scientists, and medical practitioners alike. Illness, treatment, and/or death challenge those who are affected to construct meanings that create a tolerable narrative for what appears to be inexplicable; in such a context, storytelling is viewed as a form of communication that can help people to successfully cope with and reframe illnesses and, thereby, create the paradoxical possibility of being "successfully ill." Frank (1995, 1997, 2004), a sociologist at the University of Calgary, has argued that illness may be thought of as a call for stories, in that becoming ill often triggers narratives that help affected individuals to redraw their self-maps, in light of changed circumstances.

My colleagues and I have recently offered a model that demonstrates the interdependent effects of storysharing in medical contexts (Sunwolf, Frey, & Lesko, in press). This model focuses on five dynamic, nonexclusive, functional categories that shared stories may serve: as a seed, tool, scrapbook, foreflash, or bridge. This model offers a useful framework both for analyzing research findings about storied medicine as well as framing new areas for scholarship, suggesting how narrative in health-care contexts may function to seed learning, as a tool to create new healing realities, as a scrapbook to hold memories, as a foreflash to vision future healing possibilities, and as a bridge to connect

people (e.g., health-care practitioners, recipients, family, and friends) along the healing journey.

Figure 1. A functional model of the healing effects of sharing stories.



Storytellers have long recognized the power of narratives to move listeners from the pain of the moment to a happier-ever-after (Sunwolf, 1999), with powerful narratives provoking intense flashes of insight for listeners who are ill (insights that may be invisible to a healthcare provider). Trauma, illness and grief create frightening forests of pain, with unfamiliar roads; in such a context, listening to stories suggests myriad pathways out of dark forests (Sunwolf, 2003). Children, in particular, may feel the need for constructing stories that help them to deal with their illnesses. Clark (1998), for instance, examined childhood imaginative narratives in the face of chronic illnesses. Fear of death was a universal concern shared during Clark's interviews with asthmatic children; a lack of breath always carried a concurrent sense of life-threatening consequences. Clark reported that one child had sheets on his bed depicting Teenage Mutant Ninja Turtles, which provided a basis

for the child's imagined what-if stories, in which, should a nighttime emergency with his breathing occur, one of the Turtles would fly off the sheets and go get the doctor, which calmed him during attacks. Hill (1992), for instance, has used reconstructed fairy tales as a treatment intervention with young girls suffering from eating disorders to break the harmful cycle that occurs when life transitions demand changes that a weak sense of self cannot accommodate. Hill has told adapted Cinderella tales to young girls to assist them to "story" their stressful life changes (e.g., with a new stepmother) and to see those changes in a different way. One young girl, a binge eater, having been told a reconstructed version of Cinderella, described visualizing what Cinderella ate at home and at the ball, what Cinderella might be feeling, and how all this related to her.

The recognition of the potential power of narrative for those who are ill has led to a number of autobiographical and biographical narratives written about illness, treatment, and death, or what Hawkins (1993) called *pathographies*. As two illustrations, Gilda Radner (1989) the famous comedian wrote a text that chronicled the final days of her life, and the poet Audre Lorde (1980) documented her 14-year struggle with breast cancer. Other pathographies emanate from healthcare providers' accounts of their encounters with ill clients (e.g., Brody, 2003) that recognize that "daily practice is filled with stories" (Hunter, 1991, p. 5).

A robust example of the power of community storytelling to teach health-care practices and save lives is the work of scholars at the University of Washington's School of Nursing and the Yakama Indian Health Center, who found through listening to stories that illness tales for Yakama Indian women were part of a journey tale (Strickland, Chrisman, Yallup, Powell, & Squeoch, 1996). Cervical cancer was the leading cancer among Alaskan Native American women, who had a high incident of such cancer and the lowest cancer survival rates of any U.S. ethnic group (National Cancer Institute, 1993). As a result of gaining access to the story circles of these women, Strickland et al. discovered that the elders had the greatest influence on younger women starting the journey ("walking in grandmother's footsteps," p. 145); consequently, getting the Pap test was retold (by elders) as an important part of becoming a woman, much different from the Western approach to teaching health that focuses on lectures in classes, printed information, and watching videotapes.

Uri Ruevenik, a professor of psychology at the University of Houston, describes his work with chronic headache sufferers, who find their inner resiliencies drained by intense family commitments (1995). The clients (a majority of whom are women) feel burdened and frustrated at an inability to control their headache pains, while at the same time guilty for not effectively carrying their roles as parent, spouse,

friend, daughter, sister, or worker. One promising intervention is a combination of medical and psychotherapeutic intervention, which includes storytelling. "Beauty and the Beast" is a story that provides sufferers with novel connections to their modern lives (often described as being in a dark tunnel, rusty, with tarnished energy levels, and inability to regain their former human "form"). Fairy tales are rich resources for helping headache sufferers understand the real world enchantments they are tangled in, as "promises" made, kept or broken, and demanded haunt their worlds. Ruevenik (1995) describes the use of both individual and group work with stories to help clients connect with new options and maintain relatively headache-free lifestyles.

Prophylactic stories (tales of avoiding unwanted outcomes) teach by allowing people to imagine, and then refrain from, activities that are dangerous to their health. Such tales involve counterfactual thinking about what might have been (regrets) or what might yet be (future choices). This form of counterfactual self-talk is storied and leads people to anticipate an unwanted outcome. Waitzkin and Britt (1993), for instance, analyzed self-destructive narratives involving smoking, substance abuse, or sexual activity shared between people and their physicians during hospital encounters, discovering that preventive discourse about behaviors could result in dangerous outcomes to self, intimates, and the wider community. Importantly, however, these shared narratives about what might happen lacked essential contextual variables that would be expected to affect behaviors and choices in the real world.

Matthews, Lannin, and Mitchell (1994) found that narratives helped black women to come to terms with advanced breast cancer by giving them access to multiple sources of knowledge and, thereby, expanding the possibilities of a biomedically defined disease. Riessman (1990) conducted a case study of a working-class man with advanced multiple sclerosis, which severely affected the quality of his life and his ability to provide for himself, finding that through multiple strategic narrative choices that involved the retelling of key events in his biography, this man created a positive masculine identity. This man's restorying of his past enabled a positive restorying of his future, despite massive disability and an impending divorce. Furthermore, self-talk in narrative format has been found to help people to self-reflect and achieve catharsis; an exemplar is the work of Rennie (1994), who found that narratives shared by Canadian psychotherapy patients helped to heal the inner disturbance accompanying their illness. Williams (1984) explored how people with rheumatoid arthritis narrated the origins of their disease and the initial disruption it had on their lives, finding that the stories helped people to create a historical, yet sensible, place for their illness in their new lives.

Transcendence of illness also emerges in tales that function to revision the future for those who are ill. Gray (2001) studied the moral quality of illness narratives and found that narratives can create coherence out of the disordering effects (an investigation of autism on family lives, gathered narratives of Australian parents with autistic children). The stories gathered from the families consistently grappled with moral dimensions of a child's illness in three ways: (a) accommodation (conforming to a biomedical account), (b) resistance (political activism or personal assertiveness), and (c) transcendence. The narratives of transcendence told by some parents, for example, helped them to draw on religious faith to make sense of their children's suffering and to reframe the autism of their children as having value and meaning for their families.

The power of narrative to heal is now so widely accepted that it is being used as an intervention strategy by those in the medical community. Greenhalgh and Hurwitz (2001), for instance, trained medical students to adopt the perspective that the process of getting ill, being ill, getting better (or getting worse), and coping (or failing to cope) with illness can best be conceptualized as enacted narratives within the wider narratives of people's lives.

Two new techniques emerging in narrative medical training focus on listening to patients' narratives: (1) the "stop-talking technique" and (2) the "anything-else question." Dr. Rita Charon's narrative medicine program at Columbia University's medical school encourages physicians-in-training to engage in more effective *narrative listening* by employing a stop-talking technique in which doctors tell patients, "I'm going to be your doctor and I need to know a lot about your health and your body and your life," and then the doctor simply *stops talking* (Associated Press, 2005, p. 10). Dr. William Harper of the University of Chicago teaches medical students that patients inevitably "save" important parts of their story for the moment the physician is terminating the meeting and getting ready to open the examining room door (known among physicians as the "doorknob phenomenon"). Consequently, Harper teaches physicians to use a simple question that actively elicits parts of the patient's story they haven't yet shared: "*Anything else?*" This anything-else question, whether used at the beginning or the end of the physician-patient encounter, can be enough to eliminate the doorknob phenomenon (Associated Press, 2005, p. 22). The importance of an *active* story-receiver focus when stories are being gathered by health-care providers is clear.

Future Directions for Storied Medicine

I will tell you something about stories
they are all we have, you see,
all we have to fight off
illness and death.

—Silko (1977, p. 2)

While there are many storied areas in medical contexts that lack significant research, here a call is urged for three of these. First, long ago, Fran Stallings (1988) urged scholarship on the physical effects of storylistening, yet to date little research makes use of physiological measurements of the effects of storytelling or storylistening, even in medical contexts where measuring devices (pupil dilation, breathing, pulse, blood pressure, heart rate) are readily available. Second, there is a lack of research regarding the effects of using narrative as a deliberate medical intervention, in connection with other (more traditional) interventions; consequently, we know little about the types of illnesses, healing, or contexts in which storysharing works best. Finally, the effects on health-care professionals (who listen to the stories of those who are ill) have been neglected; scholarship has largely focused, instead, on the effects of storytelling and listening on care receivers. Each of these gaps points to new directions that might provide further evidence of the medicinal power of narrative, by illuminating important findings about what stories, told under which conditions, in what format, and to what audiences might help the healing process (Sunwolf, Frey, & Lesko, in press).

In this special issue, the authors begin to fill those gaps. Schram builds on the powerful connection that hope has been found to have to the healing process (both physical and spiritual), describing the archive of hope available in the rich tradition of Jewish storytelling where Elijah is transformed in folktales into the Master of Miracles. Drew and Ryden both explore, in diverse ways, the therapeutic value of story in people living with cancer. Drew takes on the ramifications of cancer survival and quality of extended life for young people following cancer in childhood with powerful stories that explore the negotiated narrative identity of young adults, looking at both narrative dissonance as well as narrative repair. Ryden, on the other hand, explores storytelling as a healing tool in which storied writing offers support for people at Gilda's Club in New York. Galavotti, Petraglia, Harford, Kraft, Pappas-DeLuca, and Sebert describe how a narrative intervention strategy grounded in indigenous folklore in sub-Saharan Africa was created to help mitigate the impact of HIV and/or AIDS, showing concrete effects of tales on human behavior and attitudes. A focus on the healing effects of storysharing for caregivers is offered by Deborah Dysart Gale, who

offers a vivid narrative glimpse into the worlds of those offering home nursing care for loved ones and the negotiation of values in illness tales. Hastings, Hoover, and Musambira challenge us to examine the value of storysharing beyond the boundaries of physical death, as stories both heal and create relational memories. In our epilogue, Laura Simms reminds us of the inherent healing powers of a single tale, well-told, and urges us to reflect upon the qualities of a healing story.

The need for renewed focus on story, as medicine, is poignantly described by a psycho-oncologist, Remen (1996), a pioneer in training physicians in relationship-centered care, who described the role that her gender played in assumptions other physicians made about her listening talents. Remen described what happened when a male physician asked her to visit his patient, who was crying:

I was no more comfortable than he in such situations but I realized early that this was part of my ticket to acceptance and so I would go and listen while someone shared with me their concerns and their experience of actually living with the disease we had diagnosed. At first, I was surprised that people with the same disease had such very different stories. Later, I became deeply moved by these stories, by the people and the meaning they found in their problems, by the unsuspected strengths, the depths of love and devotion, the rich and human tapestry initiated by the pathology I was studying and treating. Eventually, these stories would become far more compelling to me than the disease process (p. xxiv.)

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Note: *Figure 1* from Sunwolf, Frey, and Lesko (in press), adapted from an earlier model in Sunwolf, Frey, and Keränen (2005).