

The Spiritual Strength Story in End-of-life Care: Two Case Studies

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Abstract

In this article I analyze two brief case studies to propose that a “spiritual strength story” has five defining characteristics: (1) it is brief; (2) it is ontological; (3) it uses symbols and metaphors; (4) it is a “big story” or meta-narrative with a positive spiritual and/or religious focus that informs other narrative data; and, most conspicuously of all, (5) it repeats. Cultivating awareness of the “spiritual strength” narrative type can help to improve the quality of inter-professional patient-centered care teamwork and understanding, especially in regard to the reflexive, embodied and relational aspects of palliative and end-of-life care.

Keywords

Health care professionals; interpellation; listening; metaphor / symbolism; narrative inquiry; religion / spirituality

Introduction

For Frank (2004), what distinguishes palliative care is not expertise in pain control, as crucial as this skill is, but that it is dialogical insofar as “it seeks to expand not only what patients say about themselves but also the capacity of caregivers to hear what their patients say” (p. 111). Likewise, other researchers have explored the possibilities of narrative inquiry in palliative care contexts (e.g., Thomas et al., 2009) that extend from the context of individual patients and their caregivers to the context of the health care team as a whole (e.g., Blickem & Priyadharshini, 2007). For Meier & Beresford (2008), for example, what distinguishes palliative care is the collaborative practice of the entire interdisciplinary team. Yet how exactly can the dialogical aspects of patients, clinicians and health care teams be expanded in palliative and end-of-life care? One way to help this process flourish, I would suggest, is to adopt the latest developments in narrative inquiry from the perspective of spiritual and religious care.

Whereas previous studies have illuminated how palliative care patients responded to singular open-ended questions such as, “What is most important for you to achieve?” (Quill et al., 2006), and “What bothers you the most?” (Shah et al., 2008), I begin with the spiritual assessment question: “What spiritual strengths does the patient draw upon to address his or her spiritual needs/distresses?” This question is included on the Spiritual Assessment Form I use to summarize my conversations with patients on the palliative care unit at the Toronto Rehabilitation Institute and to communicate my findings to the inter-professional team. As Hodge (2001) summarized, common spiritual strengths include rituals, participation in faith-based communities, and knowing that one is loved unconditionally and that there is a deeper spiritual purpose to life. Accordingly, these kinds of topics can be expanded upon in formal qualitative spiritual assessment interviews by which clinicians can help clients to “discover,

clarify and articulate their stories” by using reflective listening techniques, in including “minimal prompts (‘And then what happened?’ ‘And?’ ‘But?’), accent responses (in which a key word or phrase is repeated in a questioning tone of voice), and embedded questions (‘I’m curious about...’ ‘I’m interested in knowing...’).” But what about expanding the capacity of caregivers themselves in order to hear what their patients say? What might caregivers be missing?

I propose that narrative itself is a kind of spiritual strength that clients may have articulated already in conversations with their caregivers, which their caregivers might have missed, and which by repetition remain ready and waiting for the caregiver, not the patient, to discover more fully. That is, following Phoenix & Sparkes (2009), I suggest that patients oftentimes express spiritual strengths as a kind of a brief meta-narrative that clinicians can learn to listen for in casual conversations, which can then become the narrative source for expanding the dialogical aspects of patient centered care.

As Phoenix & Sparkes (2009) indicated, the ontological narrative they termed “Life is what you make it” framed the life of their subject, “Fred” in their article “Being Fred.” This was the “big story” in Fred’s narrative, they said, that involved the plot structure and content of working hard to make the most of life, even despite encountering what some might perceive as setbacks or negative experiences. Likewise, my clinical work as a hospital chaplain has revealed to me a similar kind of ontological narrative structure with a decidedly spiritual and/or religious focus that I call a “spiritual strength story.” For example, one of my patients who was a Roman Catholic would routinely end our conversations by saying, “Afterall, I’m one of ‘those,’” with his hands folded in a gesture of prayer after making the sign of the cross, with his eyes closed, and his head tilted upward, indicating that he was a deeply religious person and that his religious beliefs should be taken seriously. His religious faith that was summarized in his ontological

narrative, “I’m one of ‘those,’” revealed a source of significant spiritual strength for him, that, like “Fred’s” “big story” termed “life is what you make it” in Phoenix & Sparkes’ (2009) analysis, framed his life story and involved plot and content. It was also an embodied narrative that invited relationship and further exploration with me, a Roman Catholic chaplain.

Therefore, I propose that a “spiritual strength story” has five defining characteristics: (1) it is brief; (2) it is ontological; (3) it uses symbols and metaphors; (4) it is a “big story” or meta-narrative with a positive spiritual and/or religious focus; and, most conspicuously of all, (5) it repeats. Cultivating awareness of the “spiritual strength story” in clinical relationships can help to improve the quality of inter-professional patient-centered care and understanding, especially in the reflexive, embodied and relational practice of palliative and end-of-life care. To illustrate my definition of this narrative type I will present examples of the “spiritual strength story” in two case studies, one drawn from my own practice as a palliative care chaplain, and the other from the work of Dr. Richard Coaten, a dance movement psychotherapist who uses embodied practices in his work with older people with dementia. I will conclude with a discussion of some of the ethical implications of utilizing this kind of narrative data in health care, including non-finalization, respect for alterity, and the need for collaborative inter-professional practice.

Case I: I am the tree of life

The first time I met James Oak (a pseudonym) he introduced himself to me in good humor by saying, “I am the tree of life.” He intended this to be obvious pun on his name. This 91-year-old palliative care patient repeated this pun to me in subsequent conversations, which piqued my curiosity and interest, and I soon suspected that it represented a “spiritual strength story” for him that was worthy of further exploration. Thus I reflected my interpretation back to him later on in our developing clinical relationship in the manner of what Savage (1999) called a “story check”

and as a means to open up a discussion about the potential meaning of this metaphor for him and how it could be used to enhance the quality of his care. However, he denied any deeper meaning or significance to it at all. “Oh, that was just a joke!” he said, dismissively. Nonetheless, as he reviewed his life with me over the course of many conversations, his “tree of life” metaphor did indeed appear to be a significant overarching theme that became more and more apparent to me, if not to him, at least consciously.

Mr. Oak would talk to me about how oak trees are characteristically large, full, and strong trees that provide much needed food, shelter, and protection to many small animals. I perceived this to be a significant metaphor for him in reference to his own life story, particularly with respect to his enduring focus on his love and care for his family, which was a topic that dominated his conversations with me and with other clinicians as well. “My philosophy in life is love,” he said to me, and his eyes would well up with tears whenever he would talk about his devotion to his family. “Without family, you’ve got nothing,” he would say.

The life review Mr. Oak conducted over many conversations with me included various vignettes that corresponded to the theme “I am the tree of life.” Many of these details would also repeat verbatim, one of which revealed a special poignancy. Embedded in his perspective of life lived fully over 91 years with much love and devotion to family was the enduring pain of the loss of his father when he was a young boy. Oak thus extended this “tree of life” metaphor to his life when he was a child, and to his father’s life by saying that his father was abruptly and prematurely “cut down in the crash,” by which he explained that the stress of the stock market crash in 1929 caused the sudden heart attack that killed him.

From a Christian perspective, Oak’s spiritual strength story “I am the tree of life” resonates with the “I am” sayings of Jesus in the Gospel of John—most notably, “I am the bread

of life” (John 6: 35). However, Oak never made this connection directly in our conversations. He was Christian but non-practicing in any denomination. When I asked him if he regarded himself as a “spiritual person” he said, “I try to be.” This positive stance towards spiritual growth especially at the end of a long and full life corresponds also to the “I am tree of life” story that is indeed the summary expression of spiritual strength embodied in life lived deeply and broadly out of love for family.

Case 2: An extraordinary little rhyme

Dr. Richard Coaten is a dance movement psychotherapist with the National Health Service in Yorkshire, England. In his doctoral dissertation (2009) and conference workshops he presents some very compelling narrative data in the form of what he calls an “extraordinary little rhyme.” The context is Coaten’s therapeutic relationship with an 86-year-old client in the later stages of a dementing illness, whom, he said, had very little language left. His interest was piqued by this rhyme or mantra that this client had apparently composed herself and repeated to herself regularly throughout the day and to anyone else who would listen: “I’m Doris Sarah Loxley (a pseudonym) and I’m lost in a fog, so we sent Willy, a St. Bernard’s Dog who found me and brought me safely home, so we gave him a big juicy bone” (p. 28). As Coaten explained, “here is metaphor, symbolism and meaning . . . [and] the rhyme is supportive of, and connected to her sense of identity and observed well-being.” Moreover, his analysis indicates a very strong spiritual component, as follows,

Metaphorically Doris is lost in a fog, the fog of dementing illness . . . There is a dog in her psyche that knows the way home and can bring her home in spite of the fog of a dementing illness. This is not just any dog but a St Bernard’s, traditionally associated with monks who regard it as their spiritual duty to look after the dogs that save lost souls

in the Swiss mountains . . . Doris can give the dog a name and thank it for bringing her home by giving it a big juicy bone as a reward (pp. 28-29).

All told, I think that this “extraordinary little rhyme” is indeed a “spiritual strength story,” according to my five criteria. Moreover, the impact and meaning of the story does not end with Doris. Rather, Coaten explained that he felt compelled to learn this important rhyme himself, and that he found it helpful within his therapeutic time with Doris to say it with her when she struggled to remember it herself. In this way, Coaten was able to “give these words back to her” in order to help her remain in contact with them—words that he would argue were essential to her own sense of self and personhood. Also, in his intersubjective position and witnessing the response to this giving back of her own words, Coaten gained an immediate validation from her by either a warm and affectionate smile or often by her saying, “you are my friend, my dear, dear friend, I love you and I have always loved you.” Therefore, following the interaction that Coaten said had been repeated on many occasions, he was left with a profound sense of the importance to Doris of the rhyme and this communication held between them. As he put it, “In the process my informant has been able to communicate emotionally, verbally, and non-verbally (by holding my hand at the same time) matters of great significance to her.” In this way it is important to recognize how the spiritual strength story that crystallized in the form of the rhyme, particularly as it represented almost all of her remaining language abilities, did not finalize her in her relationship with Coaten. Rather, Coaten used it to open up new insights and possibilities for therapy as embodied relationship.

Discussion

Discerning the deeper meanings of a “spiritual strength story” begins with curiosity. For example, in my relationship with Oak I was struck at first by how his story “I am the tree of life”

repeated. As Savage (1999) indicated, “A theme can be detected by the recurring use of a single significant word or phrase” (pp. 98-99), and “through themes it is possible to discern the deeper truth” (p. 79). Indeed, this appeared to be the case in the context of the life review Oak conducted with me. Likewise, with his curiosity similarly piqued, Coaten asked, “What aspects of Doris’s life and experience were crystallised in the form of that rhyme?” Moreover, listening to Doris raised some significant reflective questions for Coaten himself that he captured in his “scratch notes,” including: “Why did I as a Dance Movement Psychotherapist choose these words to focus on, and not her movements? Why was I drawn to them?” In this way, Frank (2010) argued that stories interpellate—hail or call—listeners to respond to them in a certain way according to a particular identity (p. 49) that can be expanded beyond one’s own “narrative habitus” (pp. 52ff.). Thus, Frank (2010) asked, “Which call of stories do people answer, among all the stories that call, each day?” (p. 54).

It is important to emphasize that responding and listening to stories, as an embodied act to develop empathic relations and think with other people near the end of life, is no straightforward or easy task. Listening can be especially difficult given not only the demands that institutions place on what one does, but also because listening well is an art that can take time to learn and embody socially. Also, there are potential dangers that might go with listening that can also arise which need to be acknowledged so that we can better understand some of the complexities involved in the listening process, and thus enhance our abilities to listen as best as possible. There are at least three important points to consider and bear in mind when listening.

First, Coaten recognized that whereas Doris’s life and experience might have been “crystallized” in the form of her rhyme, in no way did it “finalize” her in his therapeutic relationship with her. This corresponds to Bakhtin’s (1984) dialogical notion of

“unfinalizability” that is key to a narrative understanding and appreciation of illness and health care. For example, following Bakhtin, Frank (2004) emphasized, “No word can ever be final because anyone can choose to act differently. The unfinalizability of the literary character—or the medical patient—is what requires the author or physician to speak with them, not about them. Only a finalized character could be spoken about, and to speak about a character is to finalize him. Hosts never finalize guests, they remain open to whomever the guest may become” (p. 46).

Furthermore, Frank (2010) cautioned that “typologies should never be considered final” (p. 121)—“Typologies risk putting stories in boxes,” he said, “thus allowing and even encouraging the monological stance that boxes are more real than the stories, and the types are all that need to be known about the stories. . . .The types in a typology are of narratives, not people” (pp. 118-119).

Second, listeners risk simply projecting onto the other their own ideological beliefs and attitudes, values and priorities, fears and hopes, and desires and aversions. Equally, they might misrepresent the other’s views, needs and concerns, and arrive at moral judgments that are inappropriate or paternalistic (Mackenzie, 2006). Thus, listeners who take the stories they hear and reflect them back to the storytellers in an attempt to open up metaphors and explore deeper meanings, must also be prepared for resistance and denial. Savage called this making a “story check”—a process by which you make a guess at the meanings of the deeper-structured stories you are hearing. But first, he said, you should ponder your relationship with the speaker. That is, while an attentive listener might wish to point out a repetitive theme that has been noted, “checking out a story is done only after sufficient rapport and trust have been built. If you do a check without appropriate rapport, people may consider it an invasion of privacy and become resentful and emotionally distant from you. When you have built strength in the relationship,

then the check is perceived as caring and helpful” (pp. 98-99). For example, Doris responded most favorably to Coaten by saying, “you are my friend, my dear, dear friend, I love you and I have always loved you,” whereas when I reflected Oak’s pun “I am the tree of life” back to him, he perhaps perceived it to be an intrusion into his privacy and rebuked me, saying, “Oh that was just a joke!” In this regard, pastoral theologian Cooper-White (2004) cautioned, “One should never impose interpretations or state another’s need for him or her” (pp. 128-29). Rather, she argued that a pastoral stance of humility is required (p. 129) whereby “the patient is not an ‘It’ to be acted on, but a ‘Thou’” (Cooper-White, 2007, p. 243). “This is the heart of the theological task,” she said rightly, “to be with the patient not as the expert who will tell him or her who s/he is, but as a respectful guide to his or her own winding journey in the *selva oscura*, the forest full of shadows” (2007, p. 243).

Third, listeners must respect boundaries in therapeutic relationships, especially the “otherness” or alterity of patients. As Frank (2004) warned, “To infringe on the other person’s alterity—their otherness that precedes any attributes—is to commit violence against the other. Symbolic violence comprises the often subtle ways that alterity is challenged and violated” (p. 115). Thus, for Frank (2005), “Seeking to enter the other’s life seems generous, but it risks losing the mutual otherness that sustains the boundary between persons and thus sustains a fundamental condition for dialogue—that it be between people who are mutually other” (p. 295). Therefore, when listening and empathizing the goal is not to internalise the feelings of the other, but is what Halpern (1996) called “resonance” with the other. To listen well to others is to resonate with their stories. In this way the other’s story does not become my own, but as a listener I strive to develop sufficient resonance with that story so that I can feel its nuances and appreciate the story

being told as embodied. As Frank (1995) has argued, “the problem is truly to listen to one’s own story, just as the problem is truly to listen to others’ stories.”

As well as highlighting potential problems and dangers of listening, some limitations and opportunities of the “spiritual strength story” need to be recognized also. For example, in terms of what constitutes “good” listening, the relational dynamics involved in this process, and the complex needs of the health care team (Propp et al., 2010), it would also be valuable to examine the listening practices of other health professionals, (e.g., nurses, occupational therapists, and social workers) and their understanding of how, where, and when they listen (Browning & Waite, 2010). To complement this approach to narrative research in palliative and end of life care, it would be useful in the future to turn our analytic attention to what Gubrium & Holstein (2008) called narrative ethnography. Here, for example, research could focus on the social organization, interactional dynamics, content, and even objects through which stories interpellate listeners and listening is sustained or reconfigured (e.g., Kellehear, Pugh & Atter, 2009). In this way, research could also focus on what Frank (2010) called socio-narratology, which focuses on “studying what the story does, rather than understanding the story as a portal into the mind of the storyteller” (p. 13). Finally, it would also be helpful to explore the “big” story of the “spiritual strength story” in conjunction with “small stories” that are the focus of much current research in narrative (e.g., Phoenix & Sparkes, 2009).

Listening well in health care environments can contribute to collaborative innovations among members of interprofessional health care teams. Chaplains and psychotherapists, for example, who are attuned to spiritual and religious themes expressed in symbolic language, such as in the “spiritual strength story” type, can help teach other clinicians to raise their own awareness to this significant aspect of holistic patient-centered care. This is important because,

as Hodge (2001) argued from a social work perspective, spirituality might be the most untapped strength among hospital patients.

Conclusion

Like other researchers I have argued that narrative inquiry is helpful to improving the quality of palliative care (e.g., Blickem & Priyadharshini, 2007; Thomas et al., 2009). More specifically, following Phoenix & Sparkes (2009), I have tried to show that narrative analysis of “big story” spiritual assessment data can help inter-professional health care teams enhance the quality of patient-centered care by providing an innovative theoretical framework for thinking with patients in their stories. This framework can help clinicians understand better how spiritual strengths can be expressed in a kind of story that potentially holds deeper meanings worthy of consideration, particularly in light of the many formidable distresses patients face. In turn, this data can reflect back useful information gained from patient perspectives to individual clinicians and to the interprofessional care team as a whole in a way that Frank (2004) argued is essential to palliative care by expanding not only what patients have to say about themselves but also the capacity of caregivers to hear what their patients say.

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