

## Narrative Approaches in End-of-Life Care

Bronna D. Romanoff, PhD, Barbara E. Thompson, LCSW OTR/L

**W**e live our lives through stories. The stories we tell ourselves about ourselves help us anticipate the events of our lives and move orderly and predictably through our days. These stories make sense of our past and give direction to our future through a process of meaning construction. Our life stories are shaped by our experiences, as filtered through our expectations and core beliefs.

For many individuals and families the diagnosis of a chronic life-altering or life-threatening illness requires a revision of the assumptions that have ordered and guided experiences and necessitates the construction of a new life story. The way individuals re-create meaning and construe their illnesses can have significant implications for long-term physical and emotional well-being. The challenge for the patient and family is to construct a meaningful tale—to write a new chapter of the life story that accommodates a changed reality and lived experience. The palliative care practitioner plays an important role in helping patients and families reconstruct their lives and create meaning at the end of life.

### Telling a Healing Story

All patients have stories to tell, and most are eager to tell them. Some illness stories are familiar and expected. Patients facing illness at the end of a long life may engage in a retrospective reappraisal and seek to maintain connections with others; they often express a sense of acceptance and spiritual well-being. They tell poignant and compelling stories, and patients can be helped to author a meaningful final chapter that is consistent with their life goals.

However, illness and death often do not arrive “on schedule.” Unscheduled illnesses (i.e., those that occur outside the social time frame that associates illness with advanced age), stigmatized illnesses such as HIV/AIDS, and acute illnesses that cause rapid deterioration in patients all challenge the implicit social rules and roles, order, and predictability that afford life its meaning and purpose. Patients and families are thrust into chaos, and the illness stories they tell reflect this.<sup>1</sup>

Because telling a story is an inherently social act, and because stories do not reflect an objective reality as much as a narrative truth created by perception and expectancy, stories can be reshaped and retold to be more adaptive and helpful when faced with life-altering or life-threatening illness.<sup>2</sup> Many psychotherapeutic techniques are based on this premise, and the process of meaning reconstruction is also useful in the practice of palliative care. In the presence of a respectful listener, the narrator or patient tells and retells a story, working on the illness story and working through losses until the account feels coherent and complete. The narrator experiences healing when he or she can tell a story of illness and loss that gives meaning and purpose to his or her life.<sup>3</sup> Healing in the narrative sense is not achieved through the “laying on of hands” of a highly trained specialist; rather, healing is in the “laying on of ears.”<sup>4</sup> The ability to be present for a suffering patient and the willingness to simply listen can be restorative for patients. The goal in palliative care is not to analyze or change the story the patient tells. Rather, the goal is to hear and honor the patient’s story, no matter how often the patient needs to tell it. There is nothing

that needs to be fixed. It is the act of telling the story in the presence of an empathic witness<sup>5</sup> that fosters healing. In this sense, all members of the palliative care team play an important role by encouraging patients and families to tell and review the stories of their lives and by witnessing the profound existential concerns that occupy their consciousness.

### Eliciting Narratives

The interviewer’s approach can substantially influence how a story is told and may inhibit or facilitate the narrative process.<sup>6</sup> For instance, if the interviewer narrowly pursues a line of inquiry that reflects his or her priorities, or if the narrator is interrupted, redirected, hurried, or led to reveal facts related to objective truth rather than storied accounts that value the narrator’s perspective, the narrative responses can be suppressed. When the listener is receptive, the narrator controls the tempo, pace, and movement of the story. Content that may initially appear irrelevant can reveal emerging themes or metaphors that describe a person’s way of being in the world. Stories also explain why things happened as they did and can illuminate the deeper meaning of events. Responding to the narrator with genuine curiosity and requests for more detailed elaboration encourages the “rediscovery of voice in the face of a daunting health-care system or a frightening disease.”<sup>7</sup>

In addition to verbal methods, art making can help people make sense of their experiences through sensory-based approaches (e.g., music, movement, visual arts). According to Stephen Levine, “the therapeutic power of art rests not in its elimination of suffering, but in its

*continued on page 2*

### Inside

Researcher’s Corner . . . . .	4	Highlights of the 2007 Annual Assembly . . . . .	8	Staying Soulful . . . . .	12	Call for Nominations for AAHPM Board and Nominating Committee . . . . .	20
Call for Nominations for Annual Awards . . . . .	5	Treasurer’s Report . . . . .	10	Advocacy Update . . . . .	14		
Metastatic Spine Tumors . . . . .	6	Religion and End of Life . . . . .	11	Call for Proposals . . . . .	20		

Published quarterly by the American Academy of Hospice and Palliative Medicine

## 2007 Board of Directors

### President

J. Cameron Muir, MD FAAHPM

### Executive Vice President

Porter Storey, MD FACP FAAHPM

### President Elect

Russell K. Portenoy, MD

### Treasurer

Karen Cross, MD FAAHPM

### Secretary

Janet Abraham, MD FAAHPM

### Past President

Ronald S. Schonwetter, MD FAAHPM

### Directors at Large

Susan D. Block, MD FAAHPM

Gail Austin Cooney, MD FAAHPM

Ronald J. Crossno, MD CMD

FAAHPM

Neil M. Ellison, MD FAAHPM

Kathleen Faulkner, MD

Nancy Hutton, MD

Solomon Liao, MD FAAHPM

Kathleen McGrady, MD FAAHPM

R. Sean Morrison, MD

Jorge I. Ramirez, MD FAAHPM

Neal Slatkin, MD

Jamie Von Roenn, MD

### Editor

Paul Rousseau, MD FAAHPM

PalliativeDoctor@aol.com

### Editorial Board

Tara Friedman, MD

Jane Loitman, MD MS FAAHPM

Daniel Maison, MD FAAHPM

Dennis Pacl, MD FACP FAAP

Porter Storey, MD FACP FAAHPM

Douglas J. Weschules, PharmD BCPS

### Contributing Editor of Humanities

Lucille Marchand, MD BSN

## AAHPM Staff

### Executive Director

Anne M. Cordes

### Administrator

Terrie A. McKissack

### Managing Editor

Jerrold Liveoak

### Sales

Patrick Filippelli

### Graphic Designer

Sonya L. Jones

Send address changes, administrative correspondence, or letters to the editor to AAHPM, 4700 W. Lake Avenue, Glenview, IL 60025-1485, 847/375-4712, fax 877/734-8671, e-mail [info@aaahpm.org](mailto:info@aaahpm.org). AAHPM Bulletin is published by the American Academy of Hospice and Palliative Medicine, 4700 W. Lake Avenue, Glenview, IL 60025-1485, 847/375-4712, fax 877/734-8671, e-mail [info@aaahpm.org](mailto:info@aaahpm.org). Web site [www.aaahpm.org](http://www.aaahpm.org). ©2007 by the American Academy of Hospice and Palliative Medicine. Advertising is accepted. Contact Patrick Filippelli at 847/375-4754.

## Narrative Approaches in End-of-Life Care

*continued from page 1*

capacity to hold us in the midst of that suffering so that we can bear the chaos without denial or flight."<sup>8</sup> The arts ground us in the senses where images are simultaneously seen, heard, and touched by the artist and witness. Art-based approaches provide a more distanced form of introspection and can prompt storytelling that reveals a person's experience through metaphors that symbolize and convey meaning. Responses are kept aesthetic and metaphoric rather than becoming explanatory and reductive. The use of these approaches requires personal comfort and a degree of familiarity with the methods and materials of various artistic disciplines. The approach to art making, however, is "low skill, high sensitivity,"<sup>9</sup> and emphasis is given to the process and the related narratives that emerge.

### Narrative and Ritual

Rituals are deliberate, detailed, and repeated patterns of activity that are infused with meaning. Within families, rituals can provide a means of linking the past, present, and future, thereby contributing to a sense of continuity and connection during periods of chaos, instability, or transition. Everyday activities, such as family mealtime, can help sustain connections among family members. A routine can become a ritual if it transforms a perfunctory act into a symbolically charged experience that may be repeated in memory.<sup>10</sup> Much as "just listening" is powerfully therapeutic, giving physical care with attentiveness and presence can be profoundly meaningful. Without words or spoken acknowledgment, these quotidian activities can transcend the ordinary.<sup>11</sup> Therefore, it is important to identify existing family rituals and help families create new rituals in response to changing circumstances. Because they are aware of a foreshortened future, patients may wish to create a legacy for the future. Quietly sorting through or dispersing treasured mementos, creating videotapes, or writing letters are activities that can transform relationships and help people prepare for death. Engaging family members in these meaning-saturated activities is transformative for them as well. As in all narratives, the symbolic meanings emerge from the intersubjective creative act, and

can neither be externally imposed nor prescribed through stock exercises.

### Telling a Family Story

Families tell stories, too. Families need to make sense of their new reality when facing the illness and death of a loved one. People at the end of their lives often speak of the need to resolve family conflicts and complete "unfinished business." Although hospice and palliative care workers recognize that a family meeting can be a vehicle for communicating sensitive medical information and engaging in joint decision making,<sup>12</sup> a family meeting can also be an opportunity for shared storytelling that can open space for relationship transformation, transition, and connection.

In hospice family meetings as described by Murphy,<sup>13</sup> all family members gather around the person who is dying, and, in the presence of hospice personnel acting as facilitators and witnesses, are each invited to tell their story of the illness, their worries, and their relationship, without interruption. Each family member speaks their own truth. The narrative of the dying person's life is enlarged as each member adds their own view. As alternative perspectives are recognized, space is created for the story to shift. Rifts can be repaired and unfinished business can be completed. Although stories may not have happy endings, healing becomes possible because the presence of team members allows families to speak candidly about painful experiences in a way they have not been able to do before. In the creation and facilitation of opportunities for individuals and families to tell their stories, and in the respectful listening, one honors the story that is told and acknowledges the potential for change.

### Conclusion

A holistic view of palliative care recognizes that patients' physical, psychosocial, and spiritual needs are inextricably intertwined. In seeking to provide holistic care, the practitioner recognizes that the patient, not the practitioner, is the knowledgeable expert about his or her own life. Proceeding from a standpoint of "not knowing" how best to help, the palliative care professional engages the patient in a

dialogue of meaning by encouraging the patient to tell the story of his or her illness. Telling a story to a willing, nonjudgmental companion acknowledges existing meanings and enables the construction of new meanings that may alleviate suffering. The telling of the story, using the patient's preferred language (verbal, artistic, embodied) offers the possibility to transform an identity and relationship. Family meetings allow family stories to be created, which ultimately helps the family to make sense of illness and loss and construct meanings that are healing and full of hope.

Although it might be preferable to have the team social worker or counselor facilitate the family meeting, all team members have an important role to play in eliciting patient and family narratives and creating healing rituals. Even the simplest caring exchange can contain layered meanings. Time, attentiveness, and respect for the narrator and the story are necessary aspects of the therapeutic

process. Thus, it is important that all team members recognize the therapeutic function of narrative and ritual and be prepared to accompany patients as they reauthor the story of their lives.

## References

1. Frank A. *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago, IL: University of Chicago Press; 1995.
2. Neimeyer RA. Narrative disruptions in the construction of the self. In: Neimeyer RA, Raskin JD, eds. *Constructions of Disorder: Meaning Making Frameworks for Psychotherapy*. Washington, DC: American Psychological Association; 2000:207-242.
3. Gauthier DM. The meaning of healing near the end of life. *J Hospice Palliat Nursing*. 2002;4:220-227.
4. Manning D. *Don't Take My Grief Away From Me*. Oklahoma City, OK: Insight Press; 1979.
5. Kleinman, A. *The Illness Narratives: Suffering, Healing and the Human Condition*. New York, NY: Basic; 1998.
6. Kirsh B. A narrative approach to addressing spirituality in occupational therapy: exploring personal meaning and purpose. *Can J Occupational Therapy*. 1996;1:55-61.
7. Mattingly C, Lawlor M. Learning from stories: narrative interviewing in cross cultural research. *Scandinavian J Occupational Therapy*. 2000;7:4-14.
8. Levine S. Poesis and postmodernism: the search for a foundation in expressive arts therapy. In: Levine SK, Levine EG, eds. *Foundations of*

*Expressive Arts Therapy: Theoretical and Clinical Perspectives*. Philadelphia, PA: Jessica Kingsley Publishers, 1999:28-31.

9. Knill PJ. Unlimiting limits: principles of an "oeuvre-oriented" expressive arts therapy. *Poesis: A Journal of the Arts and Communication*. 2001;2:70-75.
10. Fiese BH, Tomcho TJ, Douglas M, Josephs K, Poltrock S, Baker T. A review of 50 years of research on naturally occurring family routines and rituals: cause for celebration? *J Family Psychol*. 2002;16(4):381-390.
11. Jacques ND, Thompson B. Occupational therapy. In: Jacques ND, Thompson B, eds. *The National Hospice Association: Allied Therapist's Resource Handbook*. Arlington, VA: National Hospice Organization; 2001:69-82.
12. Cheron R, Montello M. *Stories Matter: The Role of Narrative in Medical Ethics*. New York, NY: Routledge; 2002.
13. Murphy NM. *The Wisdom of Dying: Practices for Living*. Boston, MA: Element; 1999.

*Bronna D. Romanoff, PhD, is director of graduate programs in psychology at the Sage Colleges in Troy, NY. Barbara E. Thompson, LCSW OTR/L, is an associate professor of occupational therapy at the Sage Colleges in Troy, NY. Both are faculty members at the Institute for Palliative Care at the Sage Colleges.*

*An expanded version of this work can be found in Romanoff B, Thompson B. Meaning construction in palliative care. Am J Hospice Palliat Med. 2006;23:1-8.*



### Palliative Care – Academics Roanoke, VA

Carilion Health System in scenic Roanoke, VA is searching for an experienced Palliative Care physician to build a leading palliative medicine program to complement its Hospitalist Service at Carilion Roanoke Memorial Hospital, an 825-bed teaching/tertiary referral center serving 1.5 million throughout southwest Virginia.

An "All-American City," Roanoke is a metro area of more than 325,000 located at the southern tip of Virginia's Shenandoah Valley, 3-1/2 hours south of DC via Interstate 81. The area offers an abundance of outdoor activities in a mild four-season climate, affordable living, and excellent educational, professional and cultural opportunities.

Carilion Health System is the largest, not for profit health system in southwest Virginia, with 8 hospitals, 80+ clinics, 7 community-based residency and fellowship programs that are affiliated with University of Virginia and Virginia College of Osteopathic Medicine. Carilion has a history of continual technological advancement and innovation. A recently begun transformation to an academic clinic model includes the announcement of a new allopathic medical school jointly undertaken by Carilion Health System and Virginia Tech.

Responsibilities include the implementation of an inpatient palliative care consult service and the development of a formal curriculum for palliative care education for housestaff physicians. Minimum qualifications:

- ABMS/AOA-BC in any specialty
- Fellowship trained in approved AAHPM Palliative Medicine Program
- Certification through ABHPM, or plan in place to receive certification within 2 years
- Excellent communication, interpersonal skills and computer proficiency

Review of credentials will begin immediately and continue until the position is filled. AA/EOE. Submit CV and cover letter including 3 references to:

Rhonda Creger, Physician Recruiter  
Carilion Health System  
POB 40032  
Roanoke, VA 24022-0032  
Email: [rhondac@carilion.com](mailto:rhondac@carilion.com)  
Office: 540-224-5189

## MEDICAL DIRECTOR

Hospice of North Central Ohio is in its 15th year of serving communities throughout the North Central area of Ohio. We are a not-for-profit agency that has a average daily census of approximately 90 hospice patients, a newly constructed 12-bed inpatient facility, and a staff of over 90. It is our desire to find a full-time Medical Director to oversee the medical direction for all clients admitted to Hospice of North Central Ohio.

Medical Director: Full time position responsible for the overall medical component of our patient care program, ensuring adequate physician services, resolving any conflicting patient care decisions, and coordinating individual plans of care.

Qualifications: An Ohio-licensed M.D. or D.O with certification in hospice and palliative medicine, or willing to obtain certification. We would also prefer 2 years' experience in private practice. Expertise in pain and symptom management with knowledge of primary medical and palliative care preferred.

In return we offer a very attractive compensation package with incentives.

Interested candidates may send curriculum vitae to:

### Human Resource Manager

1050 Dauch Drive  
Ashland, OH 44805  
Phone 419-281-7107; Fax 419-281-2166  
Email [jdw@hospiceofnorthcentralohio.org](mailto:jdw@hospiceofnorthcentralohio.org)

