Commentary

Liminality in Pediatric Palliative Care

American Journal of Hospice & Palliative Medicine®
2017, Vol. 34(4) 297-300

DOI: 10.1177/1049909116629758
journals.sagepub.com/home/ajh
SAGE

Brian S. Carter, MD[1,2]

Abstract

Palliative care for infants, children, and adolescents encompasses numerous transitions and thresholds of uncertainty that challenge conventional clinical medicine. Palliative care clinicians have opportunities to be more comfortable amid such challenges, or perhaps even overcome them, if they are attuned to the unique times and places in which patients, their families, and caregivers find themselves throughout illness and recovery or transitioning toward the end of life. Patient–clinician encounters often dwell in these *liminal* places. The concept of *liminality* gives validation to the patient or family's being "stuck in places betwixt and between" a past life rich with relationship and purpose and an acute, chronic, or critical illness. Or having resolved the acute crisis of hospitalization that place between the past bounds of illness and the uncertain path forward, perhaps even toward death. Liminality provides a framework for addressing the unbound spaces that patients and families occupy: What is past is behind—the present place is tenuous and temporary, and what is ahead uncertain. This place is where palliative care clinicians can offer clinicians and families guidance.

Keywords

palliative care, pediatrics, end of life, transitions, rites of passage, chronic care

Introduction

The French ethnographer Arnold van Gennep referred to a "liminal phase" in his seminal work *les Rites de Passage* seeing it as integral to "rites of passage . . . [that] are repeated at every change in an individual's life."[1(p74)] In his work, he characterized these passages, or transitions, as consisting of 3 phases: separation, margin, or threshold (*limen,* in Latin) and aggregation. The first phase, *separation*, is characterized by either the physical or the symbolic detachment of an individual from an earlier fixed sociocultural structure. During the second phase, characterized by transition and referred to as the "liminal" state, the individual becomes less well defined, perhaps even in a state of ambiguity as he or she passes through a new sociocultural realm that is different from the past but is not a determined or a final state. Finally, in the third phase, the individual participates in a reaggregation or reincorporation into a final determined and accepted state. In this new state, the individual assumes a place identified by certain roles, rights, and obligations and is expected to behave in accordance with certain customary norms and ethical standards.[1]

This idea was further advanced by anthropologist Victor Turner in the latter half of the 20th century. He contributed to its widespread use in anthropology, psychology, pastoral care, and philosophy.[2] Turner described living in the liminal as a state, " . . . of pure possibility whence novel configurations of ideas and relations may arise . . . Its [potential] is unbounded, infinite, limitless . . . and is accompanied by processes of growth [and] transformation . . . that is [ultimately] a change in being"[2(p97)]

The application of the anthropological notion of liminality has recently been made in adult palliative care.[3] Observant clinicians will agree with those who claim:

> Hospitals are ultimately liminal spaces, where people are removed from their day to day lives, taken into a betwixt and between space of being diagnosed, treated, operated upon, medicated, cleansed, etc. For many people, hospitals are places in which their previous identities as a healthy person, as a mobile person, as an immobile person, are stripped bare. New identities such as a cancer survivor, a more mobile person with a new hip, a rehabilitated person with one less limb are forged . . . In hospitals, medical experts determine the rites of passage undertaken.[4(p73)]

An application of liminality might also be suggested in pediatric palliative care where matters of uncertainty in a child's prognosis and attendant planning and decision making with parents are addressed[5,6]:

> Under conditions of uncertainty, interpretation of and response to uncertainty depend on societal norms, personal characteristics,

[1] Department of Pediatrics, School of Medicine, University of Missouri at Kansas City, MO, USA
[2] Children's Mercy Bioethics Center, Kansas City, MO, USA

Corresponding Author:
Brian S. Carter, MD, Children's Mercy Bioethics Center, 2401 Gillham Road, Kansas City, MO 64108, USA.
Email: bscarter@cmh.edu

Table 1. Types of Liminality in Pediatrics.

Time	Individual	Group
Moment	• Sudden onset of illness; new diagnosis • Change in health status while living with a chronic or life-limiting condition • End of life	• Fetus, newborn • Infant, child • Adolescent, young adult • Others with similar diagnosis
Period	• Gestation • Birth; transitioning to neonatal life • Infancy; dynamic child development • Puberty; teen years	• Unborn but similarly diagnosed • Newborns in ICU • Similarly diagnosed children, managed in similar settings • Children with life-limiting conditions
Epoch (life-span)	• Individuals standing "outside society" by choice or designation • Twins/multiples	• Religious or culturally separate groups • Ethnic/social minorities • Immigrant groups • Similarly diagnosed groups • Genetically diagnosed but awaiting disease onset

Abbreviation: ICU, intensive care unit.

> experience, and values, and by the manner in which the questions are formulated or risks are communicated. Physicians would do well to try to get a better understanding of these influences. They should also seek to get a better understanding of the decision makers before them. Only then will they be able to inform their patients and their patients' families about risk in a way they can understand.[5(p652)]

Liminality in Pediatric Palliative Care

Palliative care for infants, children, and adolescents encompasses numerous transitions and thresholds of uncertainty. These realities often challenge the conventional practice of clinical medicine. Working in palliative care affords clinicians opportunities to overcome, or at least be more comfortable amid, such challenges. It also requires an aptitude of awareness to the unique times and places in which patients, their families, and both professional and lay caregivers find themselves along a journey through illness and recovery or transitioning toward the end of life. Patient–clinician encounters will entail opportunities to acknowledge before, and respond amid, these *liminal* thresholds and transitions.

The concept of *liminality* gives validation to both the peculiar predicament of the child patient and his or her parents. The pediatric palliative care patient, or family, may seem "stuck in places betwixt and between" a past life rich with relationship and purpose and an acute, chronic, or critical illness. Or, having resolved the acute crisis of hospitalization, they may remain between the past bounds of illness and the uncertain path forward—perhaps even toward death. The patient may be grappling with ambiguity upon recently being diagnosed with a life-limiting condition, "Who am I?" "What will become of me?" Or a parent may be reeling from a newly diagnosed critical condition for her unborn baby, "What has become of my pregnancy?" "How can I adapt to new notions of motherhood?" "Can my baby even live long enough to fulfill the dream of being a family?"

Liminality possesses dimensions of time and space (Table 1). It is part of the patient–clinician encounter. Within palliative care, it equips clinicians with a framework with which to address the seemingly unbound spaces that patients and families occupy. What is past is behind—the present place is tenuous and temporary—and what is ahead is uncertain. This place is where the palliative care clinicians may find their skills most valuable—to patients, families, and other clinicians.

Illness as a Liminal State

In the historical sense, a liminal space, or the notion of liminality, arises from the Latin "limen," meaning "threshold"—the bottom part of a doorway that must be crossed when leaving one room and entering another. Taking the model advanced by van Gennep and Turner, and applying it to the state of the ill child—or her parent(s) as they, too, deal with the journey of diagnosis, the unfolding of disease management, and individualized prognosis, one can identify a most challenging place (and perhaps time) for patients, families, and providers is the liminal space between periods of at least some defined degree of past health and an uncertain future. For caregivers focused on acute care interventions, it is uncomfortable to dwell in this place. Intensivists, emergency physicians, and surgeons all aspire to diagnose, intervene, and see results toward healing. Diagnostic journeys may be long and sinuous. Therapeutic interventions may meet with a good response, no response, or an adverse response in any individual patient. And continued healing, convalescence, and follow-up are generally anticipated to proceed with a positive slope—inclined toward restoration of health and well-being.

When acute-care providers encounter patients who seem to become "stuck"—not making progress, failing therapeutic interventions, and perhaps even dying—they will likely benefit from the assistance of supportive palliative care experts. Interdisciplinary palliative care staff members bring new aspects of support, tolerance, or acceptance to things "not going

according as planned'' or ''hoped for.'' It becomes important for all concerned to acknowledge over time that frequently new questions arise when people realize that they are ''in a different place.''[7] Helping patients, families, and professional caregivers becomes more comfortable in these different places, or even that place between illness and healing has long been integral to the healing professions—''To cure sometimes, to relieve often, to comfort always''—15th Century French proverb (perhaps of Hippocratic origin but this is unknown).[8] But when the modern acute-care system with its organ- or disease-specific specialists, their apparatus technology, and propensity to ''do something'' simply because it can be done, hijacks the path of human healing, it often takes the palliative care clinician to redirect care toward the whole patient, his or her family, and their desired path.

For pediatric patients ranging in age from infancy through young adult years, palliative care clinicians must be comfortable in spaces defined as much by child development, cognition, and a maturing capacity for understanding and choosing as by a certain disease (Table 1). Children may be experiencing something that upsets their sense of life's order and begin to wonder what illness, family, or a future means. Parents, with often widely different life experience from clinicians, may bring varying coping skills themselves and yearn for greater understandings—not simply more information—from all health-care professionals. They may need support and even direction in what comes next, whether their child is headed toward cure, long-term debilitation, or a journey toward death. Clinicians may feel that their role is to be supportive to parents while at the same time realizing that they have seen other children succumb to their disease, and they may be challenged in balancing that space between not dashing parental hopes and coming to grips with reality.

In these and other situations, pediatric palliative care clinicians can be helpful in exploring, reflecting, and understanding how there may be some assignment of meaning to the child's condition, the parent's hopes, and the staff's desires. It is the palliative care nurse who will help walk with the child and family—to see them through turbulent and uncertain times; the chaplain that honors, or may guide, their spirit through transitions; the psychologist who attends to adaptive coping; and the physician or advance practice nurse who relieve the symptoms of discomfort that come with, through, and beyond these liminal places. Timothy Quill, the palliative care physician and author, wrote in his early work *A Midwife Through the Dying Process* that one of his patients aptly described this process as being more than providing palliative care to her, more than prescribing pain medications, rather, " ... to have somebody who was willing to stay there with me through all the possibilities ... would be willing to still have ... a doctor-patient relationship with me ..."[9(p15)]

Potential Limits of Liminality

Imposing the template of liminality onto palliative care in pediatrics may not always work. Thompson, in her qualitative study of women with ovarian cancer and the appropriateness of applying the anthropologic term of liminality, noted a number of by-products that caregivers may need to be aware of.[10] She notes that patients in a liminal state characteristically have problems communicating their experience and uses the term ''communication alienation'' to describe their inability to articulate their experience to someone else who would understand, not having the words to describe their experience, and how it may affect relationship with others. Such alienation with other people may even drive parents (and youth) to the Internet for a sense of belonging.[10] For those involved in pediatric palliative care, an approach to minimizing such alienation might include the use of peer support groups for patients or parents; the provision of effective, empathic, open communication; and the diverse work that palliative care clinicians do in attending to physical, spiritual, and behavioral health support.

Thompson also relates that her study participants noted a sense of boundedness, an awareness of their own limited period of time. For children, and their parents, the future is both limited and changed but so, too, may be the experience of time itself. Affected children, and their parents, in the liminal state may have a greater capacity to be aware and appreciative compared to their peers. As such, their choices, activities, decisions, and priorities may well change, as they experience a sense of urgency or a need to create legacy.[11] This boundedness may also empower patients and parents toward their own advocacy.[12] Such actions may actually reflect what Turner referred to as the liberating nature of liminality, noting that in an anthropologic sense liminality is a state " ... of pure possibility whence novel configurations of ideas and relations may arise."[2(p97)] Empathic inquiry of the pediatric patient or his or her family's sense of boundedness may be helpful for the palliative clinician in addressing needs or facilitating life goals. Individual patients or parents may see the liminal state as one during which they can revisit life's gifts, relationships, or small opportunities within a given day or assign it a transforming potential.[13]

For the palliative care clinician to find his or her place in addressing liminality in pediatric palliative care, attention to the dimensions noted herein is required. Similarly, attention to the patient's or family's narrative is also important.[3] Clinicians need to be aware of the particular place in a patient's story in which they encounter him or her. Is it a preliminal place or time—just entering into a clinical encounter, establishing a relationship, and prehospitalization? Or is it in the midst of the liminal phase—awaiting a diagnosis, experiencing a treatment, hearing a prognosis and inquiring what it means, and reliant of health care professionals for support? Can palliative clinicians have a role in a postliminal period? It would seem so in realizing the continuity of palliative and bereavement care. Such patients or families may now be home, having already experienced the life-changing nature of their condition, its treatments, and their potential for cure. Alternatively, the life-changing nature of their condition and treatments may leave them in a new and different place from before—beset with a chronic condition, not cured, or even dying. Their needs will be

different from those characteristic of the liminal phase—but they are no less important in addressing.[3,14,15]

Conclusion

In conclusion, pediatric palliative care clinicians utilizing the anthropologic framework of liminality can approach their patients/families and provide an empathic presence, understanding the liminal nature of the space and time in which they reside. In this place, they facilitate open communication across and between caregiving team members and the patient/family—and possibly assist in gaining some sense of comfort even while involved parties may feel ''stuck.'' They assist with meaningful reflection, matters of identity—both psychosocial and spiritual—and explore with families any sense or meaning of boundedness. This may lead to a patient or a parent gaining some enhanced autonomy, empowerment, advocacy or legacy building, or simply to an accommodation and acceptance of the place and presence of helpful others amid that space between states of health, a path toward cure, a changed life with chronic illness, or the end of life and healthy bereavement.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

References

1. Van Gennep A. *The Rites of Passage*. London, United Kingdom: Routledge & Kegan Paul; 1960.
2. Turner VW. *The Forest of Symbols*. Ithaca, NY: Cornell University Press; 1967.
3. McKenchie R, Jaye C, MacLeod R. The liminality of palliative care. *J Soc Anthropol Cult Stud*. 2010;7(2):9-29.
4. Long D, Hunter CL, van der Geest S. When the field is a ward or a clinic: hospital ethnography. *Anthropol Med*. 2008;15(2): 71-78.
5. Haward MF, Lorenz JM. Communicating risk under conditions of uncertainty: not as simple as it may seem. *Acta Paediatrica*. 2011; 100(5):651-652.
6. Jane Noyes J, Hastings RP, Lewis M, et al. Planning ahead with children with life-limiting conditions and their families: development, implementation and evaluation of 'My Choices'. *BMC Palliative Care*. 2013;12:5. Web site. http://www.biomedcentral.com/1472-684X/12/5. Accessed January 25, 2016.
7. Back AL, Trinidad SB, Hopley EK, Edwards KA. Reframing the goals of care conversation: ''We're in a different place.'' *J Palliat Med*. 2014;17(9):1019-1024.
8. Schenck D, Churchill LR. *Healers: Extraordinary Clinicians at Work*. New York, NY: Oxford University Press; 2012.
9. Quill TE. *A Midwife through the Dying Process*. Baltimore, MD: Johns Hopkins University Press; 1996.
10. Thompson K. Liminality as a descriptor for the cancer experience. *Illness Crisis Loss*. 2007;15(4):333-351.
11. Akard TF, Gilmer MJ, Friedman DL, Given B, Hendricks-Ferguson VL, Hinds PS. From qualitative work to intervention development in pediatric oncology palliative care research. *J Pediatr Oncol Nurs*. 2013;30(3):153-160.
12. Hirsh CD, Friebert S. Primary pediatric palliative care: psychological and social support for children and families. *Pediatr Rev*. 2014;35(9):390-395.
13. Little M, Jordens CFC, Paul K, Montgomery K, Philipson B. Liminality: a major category of the experience of cancer illness. *Social Sci Med*. 1998;47(10):1485-1494.
14. Macdonald ME, Liben S, Carnevale FA, et al. Parental perspectives on hospital staff members' acts of kindness and commemoration after a child's death. *Pediatrics*. 2005; 116(4):884-890.
15. Contro NA, Larson J, Scofield S, Sourkes B, Cohen HJ. Hospital staff and family perspectives regarding quality of pediatric palliative care. *Pediatrics*. 2004;114(5):1248-1252.