

Editorial

Intergenerational Teen Hospice Programs: Mutual Developmental Benefits for Teen Volunteers and Persons at the End of Life

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The age-old questions posed by Paul Gauguin in his 1897 masterpiece depicting the life cycle, "D'où venons-nous? Que sommes-nous? Où allons-nous?" [Where do we come from? What are we? Where are we going?], are particularly compelling for two groups of people: adolescents and those facing the end of their lives. Adolescents are moving out of childhood and into the wider world of adulthood with the key task of developing an identity. While family continues to be important, peers and the values of the larger society become equally salient as adolescents work to find their place in that society. For a person nearing the end of life, at a time when the larger society has no commonly held answers to these questions, the questions themselves can regain personal urgency. Given these existential and developmental challenges, bringing individuals from these two groups together for companionship can offer an opportunity for growth and discovery on many levels.

In this issue of *Innovations*, we are featuring The Hospice of the Florida Suncoast's Hospice Teen Volunteer Program, which recruits teens to support the activities of the hospice in a variety of ways, including matching teens with patients near the end of life for companionship, practical help and conducting life reviews. Sandra Mahood and other staff at The Hospice of the Florida Suncoast have collaborated with teachers and administrators at high schools in Pinellas County to create opportunities for service-learning through the hospice's programs. Sandra Mahood describes the genesis of that program, which now has 250 adolescent volunteers who serve in nursing homes and the hospice residences or mentor children who have experienced a loss. They also do office work and participate in fund-raising events. Ms. Mahood reflects on the particular conditions that have led to this program's growth, as well as what sustains it, and the elements that others need to consider when planning intergenerational hospice volunteer efforts. We also introduce a new department *Promising Practice*, in which we highlight a similar, yet much smaller, effort at the St. Thomas Hospice in Burr Ridge, Illinois. Such efforts are born out of the pragmatic recognition of the resilience and durability of the grandparent-grandchild alliance as well as a sense that these two groups have untapped talents that could be mined for their mutual benefit.

Developmental psychology offers a theoretical framework that can inform efforts to train adolescents to work with people at the end of their lives. If we assume, as recent developmental theory does^{1,2,3} that *interdependence* among people is the goal of healthy development — rather than a

caricature of independence that devalues relationships and any sign of vulnerability — it makes room for recognizing how much people who are dying may have to offer others. This framework expands the one-dimensional image of dying patients as those who are solely the recipients of care.

Developmental Theory and Its Relevance

For adolescents, the process of developing an identity involves wrestling with these basic questions: "Who am I? What do I value? With whom will I affiliate? What work will I choose? How will I make my life meaningful? What is worth investing in? Where will my efforts be welcome?" During this time, adolescents are trying on different identities, adopting, adapting or rejecting the larger society's mores and values as they decide how and where to locate themselves in this larger world. These developmental tasks were first detailed fifty years ago by Erik Erikson, who built on Freud's psychosocial theories of development to introduce the notion of human development as moving through a series of crises—moments where danger and opportunity coexist.⁴ Erikson posited eight progressive crisis points, each with different constructive and necessary tensions to be negotiated in relation to family and society in order to move on to the next stage. It was Erikson's focus on identity development as the key task of adolescence that gave birth to the term "identity crisis."⁵

Not surprisingly, Gauguin's questions regain immediacy when one contemplates the end of life. Ira Byock has described the importance of life closure and offering people nearing life's end the opportunity to take stock, say goodbye and find activities and rituals that allow for an affirmation that one's life has had meaning.⁶ Erikson described this final stage as a tension between Ego Integrity vs. Despair. For this final stage, Erikson named *renunciation* and *wisdom* as the strengths or virtues that emerge from a successful negotiation of this stage.⁷ Harry Moody criticizes contemporary ways of framing aging, including developmental life span theory for a "failure to articulate a philosophical notion of meaning across the life span." He offers a densely argued philosophical rumination on the meaning of life and old age, and suggests that one needs to recognize and connect three levels of meaning—individual, collective, and cosmic. Moody advocates for "a reappraisal of the role of activity and contemplation in the modern world," and suggests that attending to what "the aged can give us: a reminder, perhaps of the finality of life ... could be a precious gift for those who can receive it."⁸

Regardless of one's stance on stage theory, it is tragic to be made marginal, not to be listened to, or to have one's wisdom remain unspoken because there has been no context or conversation to elicit it. In a culture where many elders no longer live near their families and are not in daily contact with the younger generations, this need to maintain a meaningful link to earlier generations becomes even more pressing. Retirement can be lethal in a work-obsessed society where how busy one is correlates to one's status.

The Need for Meaning and Relationship

Both elders and teens need to feel meaningful. Both need to make contributions to the community that the community then honors as valuable. Researchers studying girls' development have noted the link between the presence of voice and psychological resilience.⁹ This study and related research have confirmed the centrality of relationship and connection to others for women's development and psychological health.^{10,11} In philosopher Sally Gadow's introduction to Natalie Rosel's essay detailing the life-world of a neighborhood of aging individuals, Gadow notes, "Frailty in aging becomes the occasion for 'something common and fundamental—human connectedness and its consequences.' The forms of connectedness are the shapes that meaning takes when the essence of an individual's aging is relationship."¹² Thus another common bond for members of these two groups may be the importance of relationship as a medium for meaning and development. When

physical power and control over one's body wane, relationships with others gain even greater value.

Sharing a sense of marginality to the mainstream of life, teens and elders share existential concerns but come to these questions of identity and meaning from opposite ends of the life cycle. In this way, the needs of people facing the end of their lives, regardless of age, are a clear match with adolescents' need to be useful, be taken seriously, and experiment with new roles and responsibilities. A semi-structured opportunity to meet and get to know each other in the context of a shared activity can bridge the differences in dress, vocabulary, lifestyle, values and ways of making sense of the world—such that each can find solace in other's needs and strengths.

In mid-life, many find answers to life's big questions in "work and love," Freud's famous words about what really counts in life. Most of us find a sense of meaning in the eyes of our loved ones, some in the work we engage in and its impact on the wider community. If opportunities for work and love are limited or made difficult through environmental, political or economic disturbances, then the fabric of community is stressed and can even unravel. For those who are gravely ill, work no longer serves as an organizing *raison d'être*; meaning must be found elsewhere, heightening spiritual and relational concerns. And if the larger society does not make space for teens, offer them constructive opportunities to contribute, i.e., meaningful jobs and education, then it is not unusual for teens to reject that society at great cost to the larger community. For all of these reasons, the larger community has a responsibility to join adolescents, listen to them and make space for them to contribute.

Listening to Teenagers

In the *Personal Reflections* department of this issue, three young people reflect on the impact of their volunteering experiences at The Hospice of the Florida Suncoast. All three agree that they are the ones who have benefited most from the time they have spent working with hospice patients. Emily Tibbetts describes how she began volunteering to fulfill a service-learning requirement in her high school program, but that her contact with patients then led her to appreciate her own life in new ways. When her own grandfather died, she was able to bring some of this newfound understanding to bear on his final days. Justin Lo tells of gaining perspective on himself, and seeing his own problems shrink in the context of conducting a life review with a man who was dying. Listening to this man's telling of his life, one marked by poverty and prejudice, Justin was struck by the man's radiance and appreciation for life. This opportunity to connect in an authentic way, to listen and be moved by the story of another, develops empathy and the capacity to reflect on one's own experience. These are not firmly established capacities that we either have or don't have, but rather ways of approaching life that can be cultivated and developed through experience. Brenda Corace became a hospice volunteer in the wake of losing her two grandfathers and observing the constructive role of hospice in their deaths. Her experience included making a difference in the life of a chronically-ill child, which led her to see herself in new ways as well as evolving a sense of what career she might like to pursue. All three of these teens describe how doing things that matter in the lives of others—at a time when they are actively engaged in figuring out just who they are and what matters—can allow a person to begin to find provisional answers to the question: "Who am I?"

International Perspectives

In our *International Perspectives* department, we hear from Claude Fusco Karmann, who coordinates the volunteer training program in Milan for the Italian League Against Cancer, a non-profit private organization. In Italy, exact replication of the teen hospice volunteer program would be impossible because of a law, which requires volunteers to be at least 18 years old. However, Ms. Fusco Karmann describes the context of volunteerism, volunteer recruitment and training in her setting

and reflects on the role of young people in working with patients with life-threatening illness.

Promising Practice

We initiate a new department in this issue, *Promising Practice*, in which we describe a smaller and newer program at St. Thomas Hospice in Burr Ridge, Illinois. Marijo Letizia, PhD of Loyola University Chicago School of Nursing, and teen coordinators Kay Hammer and Barbara Zerby consulted with Sandra Mahood as they designed this program. These two teen programs illustrate some of the challenges to developing intergenerational programs that work. St. Thomas Hospice has a small program where the volunteer coordinators know each teen personally and a cohesive group identity seems to have emerged among those teens who have chosen to participate. The group activities are informal enough to be fun and spontaneous, and are interlarded with individual meetings with hospice patients and families who have been carefully chosen by hospice staff in advance. The larger, more established and so more institutionalized program in Florida is more structured. Patient-teen direct contact occurs primarily in more supervised settings—either nursing homes or the hospice residences.

Ensuring Success

Matching Structure to Function

What is essential to developing workable intergenerational hospice programs? Readers should note that these different structures indicate the need to tailor a program to the size and goals of the particular hospice. At St. Thomas, teens visit patients and families in their homes, alone. This level of trust is probably possible because it is a small program characterized by close contact with someone who knows the teen and to whom the teen feels a commitment and sense of accountability. In a larger program, where no one person can know all the teen volunteers, teens may need to work in a more structured setting, in which adult staff members are on hand to help the teens navigate unexpected situations and find useful things to do. Regardless, teens will need to have adults they can call on as resources when necessary.

Listening

When we approach people we are aiming to *help* with respect, curiosity and a willingness to learn from them, often they will teach us. It is important to structure the program as a two-way street—each group has needs, if those needs are explicitly recognized and understood by program developers, the program itself will be more successful. It is also important to keep the person primary, whether it is the adolescent or the person facing the end of his or her life. Though hospice staff members are naturally advocates of life review, not all persons who are dying will want to engage in life review or feel the need to perform activities that others would recognize as closure. Similarly, not all teens will want or be ready to have personal relationships with dying patients. Any system of categorization, including developmental theory, tends to objectify the persons studied. To counteract this tendency, it is essential to honor the involved human beings – patients, teens, hospice personnel—as experts on their own experience. Building a ramp to make her home accessible may be what is most important to a particular patient at that moment in time. As the famous physician Francis Peabody wrote over 70 years ago, "The secret of the care of the patient is in caring for the patient."¹³ Listen, and the hospice patient will tell you what he or she needs and wants. The coordinators in the programs described here call on their imaginations to find a way to harness the strengths and energy of teens to help meet those needs when it makes sense to do so.

Supporting Adolescents

Many myths about adolescents persist. Ensuring buy-in of the middle generation, the parents of the teens as well as the staff of the hospice or palliative care group, is also critical to the success of an intergenerational program. Moving from the dependence of childhood into an appreciation for the relationship between independence and responsibility is a process that evolves most easily when it is structured so that teens can succeed. Traditionally, teachers and psychologists have been interested in measuring actual developmental level or what a child could do alone. Soviet psychologist Lev Vygotsky focused on the social nature of learning and described the *zone of proximal development* as the area a child can function at successfully with some help. Performing tasks in the zone of proximal development with support and guidance, the young person can function at a more complex level and solve problems he or she cannot tackle in isolation.¹⁴ One of Vygotsky's key contributions is legitimizing this scaffolding of growth through dialogue and social relationships, as an essential intermediary step to mastery of a skill or new way of understanding.

Teens need training and the opportunity to take on responsibility with just this kind of support. Many have not held paid jobs before, other than an odd babysitting or lawn-mowing job. Some may have worked at a fast food restaurant but the skill set required for interacting with dying patients is entirely different. For all of these reasons, a paid coordinator who has an understanding and appreciation for adolescents is essential to the success of an intergenerational program of this scope.

Part of adolescence is a hunger to make a difference, in the life of someone else, to matter, to do something meaningful, to be affiliated with something larger than oneself and one's family. When adults join adolescents in activities that the adolescents can see are meaningful—meet them where they live so to speak—this engagement can be transformative. But this yearning means that it is incumbent on those adults who seek out and recruit teens to take those teenagers seriously and offer them meaningful ways to contribute. What is "meaningful" can vary from making soup or Valentine's Day cards for patients to conducting life reviews or developing a personal relationship with a person who is dying. For this reason, coordinators need to offer a range of activities that can meet both the abilities of the teens involved and the needs of the hospice patients, with appropriate amounts of adult mentoring and guidance. Whatever the task, evidence that these efforts have made a difference is an important source of data for participants and program leaders.

Accountability and Feedback: Ideas for Program Evaluation

Basic issues of accountability and trust are at the heart of any kind of home care for frail people whether provided by a professional or volunteer, and must not be ignored. Asking the patients themselves for feedback is not a simple question. No patient wants to be labeled "difficult," and patients and families may be hesitant to report dissatisfaction except in egregious cases because of fears of alienating the hospice team or access to services. Continually thinking about evaluation—what it is one hopes to measure or learn about, as well as the most accurate and expeditious way to do so, is important. And asking people directly about their experience is probably still a good way to do so, as long as the inquirer is alert to subtle cues—such as silence—that there may be a problem.

The next challenge for these programs is to develop more careful documentation of the differences that leaders believe the programs are making. It will be valuable to be able to show more consistently what kinds of impact working with people at the ends of their lives has on these teens. Ethnographic methods already exist to document changes in how participants understand an experience, but they are labor intensive.¹⁵ Some strategies could include entry interviews with teens, inquiring about what they hope to get out of the experience and their reasons for volunteering. Programs could teach volunteers some expanded journal writing skills, in addition to the listening

skills workshops they already often provide. Writing fosters self-reflection as well as documenting participants' thoughts and feelings about interactions with patients. Coordinators can conduct exit interviews, which if recorded and analyzed might offer further evidence of the impact of this experience on the adolescent participants. Similarly, it is possible to document the effects of oral life histories on the lives of hospice patients. Working with patients who have little time left is challenging as the benefits and burdens of any research effort must be clear. However, much of this evidence is already available. It does take time to track and record what people are already saying about the experience of producing a life review. Program designers would learn more from systematically inquiring about the process, being careful to look for disconfirming evidence as well. When do teen-patient matches work less well? What can be learned by examining failed attempts at conducting life reviews or the teen-hospice patient matches that didn't take?

In Conclusion

The examples we've chosen to highlight in this issue vary in their size and scope. Both share a commitment to taking teens seriously and have implicitly built in some of what developmental psychologists assert promotes constructive identity formation—belonging to something bigger than oneself, the opportunity to do something meaningful for others who really need it, and so gain an outside perspective on one's own life. Many challenges remain, but much can be learned from the simple act of listening to those who are engaged in this work. We hope that the perspectives we present in this issue will enrich your understanding of the theory and practice of conducting intergenerational hospice programs. Read on, and please post your comments to the online discussion so that we can learn from your experience as well.

References

1. Belenky MF, Clinchy BM, Goldberger NR, Tarule JM. *Women's Ways of Knowing: The Development of Self, Voice, and Mind*. New York: Basic Books, 1986.
2. Kegan R. *The Evolving Self: Problem and Process in Human Development*. Cambridge, MA: Harvard University Press, 1982.
3. Brown LM, Gilligan C. *Meeting at the Crossroads: Women's Psychology and Girls' Development*. Cambridge, MA: Harvard University Press, 1992.
4. Erikson E. *Childhood and Society*. New York, NY: Norton, 1950, 1985.
5. Erikson E. *Identity: Youth and Crisis*. New York: Norton, 1968.
6. Byock I. Beyond symptom management: Growth and development at the end of life. *The European Journal of Palliative Care*. 1996;3(3):125-130.
7. Erikson E., 1950.
8. Moody HR. The Meaning of Life and Old Age. In *What Does It Mean to Grow Old: Reflections from the Humanities*, edited by Thomas R. Cole & Sally Gadow, 11-40. Durham: Duke University Press, 1986, 17, 40.
9. Brown & Gilligan, 1992.
10. Jack D. *Silencing the Self: Depression and Women*. Cambridge, MA: Harvard University Press, 1991.
11. Jordan J, Kaplan A, Baker Miller J, Stiver I, Surrey J. *Women's Growth in Connection*. New York:

Guilford Press, 1991.

12. Gadow S. Editor's introduction, p. 199 in "Growing Old Together: Communalities in a Sarasota Neighborhood," by Natalie Rosel. In *What Does It Mean to Grow Old: Reflections from the Humanities*, edited by Thomas R. Cole & Sally Gadow, 199-233. Durham: Duke University Press, 1986.

13. Peabody FW. The care of the patient. *Journal of the American Medical Association*. [1927;88:877-82] 1984;252:813-18.

14. Vygotsky LS. *Mind in Society: The Development of Higher Psychological Processes*. Edited by Michael Cole, Vera John-Steiner, Sylvia Scribner, Ellen Souberman. Cambridge, MA: Harvard University Press, 1978.

15. Miles MB, Huberman AM. *Qualitative Data Analysis*, 2nd ed. Thousand Oaks: Sage, 1994.