Inclusion and Access: How Can We Serve Everybody?

Inclusion and access” are often discussed in terms of diversity, primarily racial/ethnic diversity. Historically, America’s hospices have had greater success reaching white, middle-class patients. The need to reach out and respond to the changing ethnic face of our communities is recognized as one of hospice’s biggest current challenges and priorities — even though the path to connecting with other populations may take us outside of our comfort zone.

It is possible to view inclusiveness more broadly, however, to simply mean serving the whole community. That would mean being recognized and called upon as the end-of-life resource for the needs of everyone who lives in the community — in all of their varied groups, categories and pie charts.

Besides ethnicity, other important distinctions include religion, age, the growing needs of veterans of military service, socio-economics (e.g., “bad” neighborhoods, the uninsured), place of residence (e.g., urban versus rural, all levels of long-term care), disease and treatment (including the need to offer palliative chemotherapy when appropriate), and the various disabled communities, such as the developmentally disabled. In some communities, an aging prison population may be the biggest frontier of unmet need. Inclusion doesn’t just refer to patients, but also to the hospice’s staff, volunteers, board members, partnering community agencies, and the other consumers of its services, including griever, schools and workplaces.

A striking example of serving the community can be found in NHPCO’s 2005 manual, Providing Hospice and Palliative Care in Rural and Frontier Areas. Hospice of the Wood River Valley in Ketchum, ID, estimates that between direct hospice services, community education, community grief programs, grief response in the schools, support for families in the hospital emergency room, and collaboration with first responders, it had at least some involvement with 92 percent of all who died in the county in 2003.

Misleading Assumptions

For groups that have not been well-served by hospice, it is easy to make assumptions about their lack of need for hospice care — assumptions that may not be borne out by the facts, says Betsy Murphy, business relations representative for Capital Hospice in Falls Church, VA. “We’ve been in this business for 25 years, and it is amazing how many ‘aha moments’ we continue to have” about previously underserved groups.

For example, pediatric hospice patients typically cost more than any available reimbursement source pays, but taking care of these kids can have significant implications in terms of community donations. When hospices discovered that many patients with Alzheimer’s and other dementias were also terminally ill and in need of hospice care, opening their doors to these patients resulted in increased overall lengths of stay. Other hospices have had success building bridges to the African-American community, despite the widespread assumption that African-Americans would be suspicious of this kind of outreach.

“The first thing you need to do is look at the demographics of your own community and how it has changed,” Murphy says. “Are you as administrators aware of what’s really happening in your community?” Rural Loudoun County, VA, which is Murphy’s territory as a hospice marketer, was 98 percent white as recently as 10 years ago. “Now it’s 10 percent Latino. Do you know what proportion of Medicare patients are Latino?” Nationally
it’s seven percent — nearly three million Hispanic Medicare beneficiaries.

A neighboring hospice recently targeted the local Korean community and all of the physicians who serve it, Murphy says. “Has anybody actually quantified what are the outcomes of that kind of outreach in bringing in more patient referrals — and not just from the targeted community?” she wonders.

“If you think you’re already serving the whole community, check that assumption against the facts,” she advises. Your county’s planning department may already have a planning document projecting population trends and healthcare needs for the next five years. “Then, is there a grant out there to support your agency in responding to the unmet needs you identify?”

Hospices may be driven by mission and a desire to better meet the community’s needs, or by the bottom line and financial calculations. Even by the latter standard, however, inclusiveness can be good business. Hospices may be short-sighted in their calculations if they fail to take advantage of opportunities to grow their census, increase their length of stay, and reach new populations with diversified services and product lines. In other words, Murphy says, the hospice needs a belief system that the expense of reaching out to a more diverse patient population will be offset by long-term gains, both for the agency’s mission and for the bottom line.

Where We’ve Been, Where We’re Going

Pat Gibbons, director of the Beacon Place residence for Hospice and Palliative Care of Greensboro, NC, wants to remind hospices of what they have already achieved, and use that accomplishment as a springboard for future advances. The fact that hospices cared for 1.2 million terminally ill Americans last year points to their collective ability to create access.

Take as another example, Gibbons says, the proportion of hospice patients who do not have cancer as their primary diagnosis. Ten years ago, NHPCO published guidelines for determining prognosis in non-cancer diagnoses, which were then adapted by Medicare fiscal intermediaries — although not without some angst and growing pains for the field. But today, more than half of patients served by hospices have non-cancer diagnoses.

“Take that achievement and let the enthusiasm invigorate your whole organization,” says Gibbons, adding that hospices should not forget about HIV patients. Although many of them are living longer — and better — thanks to advances in medical treatment, a significant proportion will eventually need hospice care.

Other hallmarks of a commitment to improving quality in the realm of inclusion and access include:

- Performing periodic community needs assessments;
- Exploring barriers to quality end-of-life care in your community;
- Continuing to work on increasing the cultural competence of the agency and its staff;
- Pursuing collaborative marketing and community relations initiatives; and
- Paying attention to conversion rates (the proportion of referrals that result in hospice admissions) and response time to referrals.

Visit nhpc.org/quality for detailed information, tools and resources for this and the other nine components of Quality Partners. Also look for NHPCO’s revised and expanded Diversity Toolkit due out this spring.

—Larry Beresford

The 10 Components of Quality in Hospice Care

1. Patient and Family Centered Care
2. Ethical Behavior and Consumer Rights
3. Clinical Excellence and Safety
4. Inclusion and Access
   Promoting inclusiveness in our community by ensuring that all people — regardless of race, ethnicity, color, religion, gender, disability, sexual orientation, age, disease, or other characteristics — have access to our programs and services.
5. Organizational Excellence
6. Workforce Excellence
7. Standards
8. Compliance with Laws and Regulation
9. Stewardship and Accountability
10. Performance Measurement