Leveraging External Resources To Grow and Sustain Your Palliative Care Program: A Call to Action

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Abstract

Hospital-based palliative care is becoming increasingly prevalent. There is growing evidence that it is having a positive impact on patients and their loved ones. In 2008, national data indicated that 58.5% of hospitals with 50 or more beds had a palliative care program. Data from a 2008 survey of California acute care hospitals showed that although 33% of sites had inpatient consultation services, one in five had been operational for only one year. As nascent palliative care programs grow, new issues arise and needs and plans change. Just as palliative care programs benefit from marketing and education plans, they also benefit from a plan to leverage external resources. Largely a missed opportunity, external resources such as organizations, networks, and experts can help palliative care service (PCS) leaders and team members gain information on everything from best practices to funding opportunities, while serving as sources for personal and professional support. The growing number of active PCSs and the increasing availability of support and expertise ensure that new programs no longer have to face challenges alone. Further, the steady increase in the number of new programs has created opportunities for those who are more experienced to serve as mentors for peers who are navigating the challenges of growing and sustaining a clinical service. The authors encourage both mentors and mentees to seek support from or provide support to others in the field. Leveraging the collective expertise and experiences in our field can ensure that palliative care continues to thrive and grow.

Introduction

HOSPITAL-BASED PALLIATIVE CARE is becoming increasingly prevalent. There is growing evidence that it is having a positive impact on patients and their loved ones.¹⁻⁴ In 2008, national data indicated that 58.5% of hospitals with 50 or more beds had a palliative care program.¹ Data from a 2008 survey of California acute care hospitals showed that although 33% of sites had inpatient consultation services, one in five had been operational for only one year.⁵ Thus, as a field, palliative care has both a large cohort of new programs that are launched each year, along with a growing number of established services.

As palliative care programs grow and mature they face challenges that can threaten sustainability. To face these challenges, palliative care service (PCS) leaders need to be versed in a wide range of skills. Leaders of palliative care programs need to be able to deliver clinical excellence and

demonstrate to multiple stakeholders the many ways their services add to the value and quality of care by enhancing clinical and nonclinical outcomes. They need to exercise principles of leadership and understand team dynamics, engage with senior leaders of their hospital or health system, cultivate philanthropic support for their services, and craft sustainable job descriptions for service staff. They also need to balance the creation of a supportive environment, which encourages team members to practice self care, with the seemingly incompatible need to provide comprehensive care to large numbers of patients and families with complex needs. Programs and program leaders need information on clinical, consultation, education, administrative, leadership, and interpersonal best practices, on practices to avoid, and on how to run various aspects of the program. Palliative care team members and team leaders need help anticipating challenges and next steps, gathering community social support and encouragement, and obtaining resources such as funding and personnel.

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Fortunately, there are ample external resources to help PCSs address these challenges. Launching a new program requires developing a business plan, a staffing plan, a marketing plan, and a training plan. An approach to leveraging the services and expertise of external resources such as organizations, networks, and experts is an equally important aspect of ensuring successful growth and sustainability. This paper describes the types of support that PCS leaders and team members can access by engaging with various types of external resources. We also describe how leveraging external resources allows the palliative care field to pool knowledge, gain new information, increase awareness, change attitudes, and further the collective goal of giving patients and families the best care possible.

Types of External Resources

External resources fall into three categories: (1) organizations, (2) networks, and (3) experts. Each of these resources can help palliative care programs identify clinical, administrative, and interpersonal best practices and avoid ineffective practices and common mistakes. These resources provide a comparative check on a program's development and growth pattern, and reassurance regarding common experiences at each stage of the development process. External resources can give program members personal and professional support and enhance relationships. They can also be a gateway to additional expertise and capital, such as funding and collaboration opportunities.

Organizations

Organizations can provide invaluable support to palliative care programs that are in development, committed to sustainability, or looking to expand (see Table 1). Regional and especially national palliative care organizations, such as the American Academy of Hospice and Palliative Medicine (AAHPM), the Hospice and Palliative Nurses Association (HPNA), the National Hospice and Palliative Care Organization (NHPCO), and the Center to Advance Palliative Care (CAPC) offer a wide range of opportunities to palliative care providers including educational resources, seminars, national meetings, and online and in-person trainings. Other national organizations such as the Society of General Internal Medicine (SGIM), the Society of Hospital Medicine (SHM), the American Society of Clinical Oncology (ASCO), the American Association for Cancer Education (AACE), and the American Association of Critical-Care Nurses (AACN) include sections, committees, or interest groups that relate directly or indirectly to palliative care.

Organizations with groups of peers, educators, researchers, and administrators can be the locus of "communities of support." Communities can offer emotional support, mentorship, and collegiality, and serve in the exchange of ideas and strategies. Given that many palliative care clinicians practice in relative isolation and counter to the prevailing clinical focus of their institutions, finding like-minded colleagues outside one's own institution can be fruitful. The community might gather in-person periodically, for example at an annual conference (such as the AAHPM/HPNA annual meeting or a CAPC National Seminar), or might connect in an ongoing manner, such as via a web-based discussion group (e.g., the CAPC Connect Forum; www.capc.org/capc-connect). Within

a community, individuals may find mentoring (e.g., career or academic support from the AAHPM College of Palliative Care), research networks (e.g., the National Palliative Care Research Center or Palliative Care Research Cooperative [PCRC]) or connect with friends and colleagues via social networking. Colleagues outside one's local institution will bring a sense of perspective and the opportunity to benchmark clinical, educational, and administrative issues. Within larger organizations, a formal interest group may be a particularly useful way to connect to others (e.g., the palliative care interest group at SGIM).

Depending on the goals and needs of a palliative care program, virtual communities can be formed in-person or over the Internet. Increasingly, community is created through online blogs, such as Pallimed (www.pallimed.org) and GeriPal (www.geripal.org), which feature commentaries and discussions about palliative care issues.

Palliative care organization websites and palliative care journals online are other sources of up-to-date information. Organization websites list upcoming educational offerings such as End-of-Life Nursing Education Consortium (ELNEC) and Education on Palliative and End-of-Life Care (EPEC) continuing education opportunities. The AAHPM lists certification and licensing information, as well as fellowships and preceptorships for experienced clinicians (www.AAHPM.org). This latter opportunity is important for team members and leaders who would benefit from visiting a well-established palliative care program and gaining experience in another setting. The International Palliative Care Resource Center (www.IPCRC.net), is a gateway to multiple different clinical, education, and leadership palliative care resources, including downloadable curricula (EPEC-Oncology and ELNEC).

Many organizations offer summaries of the clinical evidence base for palliative care, expert recommendations, and guidelines. Some organizations have mechanisms for alerting clinicians to new data, such as the PC-FACS produced by the AAHPM. Others, such as CAPC, offer e-mail alerts describing recently published research, and some offer direction about how to use the new findings strategically in program building or fund-raising.

Organizations can provide a number of different resources and products that can save PCS teams countless hours. These include templates for job descriptions, policies, and procedures; clinical rounding tools; order sets; brochures; information about coding and billing; and clinical survey instruments that can be purchased or downloaded for free and modified for use.

Finally, organization job boards are a good place to advertise for open positions or to seek job opportunities (e.g., AAHPM Job Mart at www.aahpm.org/jobmart/default/careercentral.html and HPNA Job Postings at www.hpna.org/JobPostings.aspx). Such resources also provide access to job descriptions and salary ranges for those starting the hiring process.

Networks

Networks, formal and informal, offer opportunities to collaborate or interact around common program characteristics such as region, health system, mission, or hospital type. The advantages of such interactions include maximizing the impact of the individual programs, solving common problems,

TABLE 1. A SAMPLING OF PROFESSIONAL ORGANIZATIONS

American Academy of Hospice and Palliative Medicine (AAHPM) www.aahpm.org	The AAHPM is an organization of physicians and other medical professionals dedicated to excellence in palliative medicine, the prevention and relief of suffering among patients and families by providing education and clinical practice standards, fostering research, facilitating personal and professional development of its members, and advocating public policy changes.
American Geriatrics Society (AGS) www.americangeriatrics.org	The AGS is a nationwide, not-for-profit association of geriatrics health care professionals, research scientists, and other concerned individuals dedicated to improving the health, independence, and quality of life of all older people.
American Hospital Association (AHA) www.aha.org	The AHA aims to advance the health of individuals and communities. The AHA leads, represents, and serves hospitals, health systems, and other related organizations that are accountable to the community and committed to health improvement.
American Society of Clinical Oncology (ASCO) www.asco.org	The ASCO is the world's leading professional organization representing physicians who treat people with cancer. ASCO's members set the standard for patient care worldwide and lead the fight for more effective cancer treatments, increased funding for clinical and translational research, and, ultimately, cures for the many different cancers that strike millions of people around the world every year.
Association of Professional Chaplains www.professionalchaplains.org	The Association of Professional Chaplains is an interfaith professional pastoral care association of providers of pastoral care endorsed by faith groups to serve persons in physical, spiritual, or mental need in diverse settings throughout the world.
Center to Advance Palliative Care (CAPC) www.capc.org	The CAPC provides healthcare professionals with the tools, training, and technical assistance necessary to start and sustain successful palliative care programs in hospitals and other health care settings. The CAPC is a national organization dedicated to increasing the availability of quality palliative care services for people facing serious illness. As the nation's leading resource for palliative care program development, the CAPC offers comprehensive training for palliative care programs at every stage—from strategic planning and funding to operations and sustainability. The CAPC provides seminars, audio conferences, tools, reference materials, a robust website, and the Palliative Care Leadership Centers™ (PCLC).
HealthCare Chaplaincy healthcarechaplaincy.org	HealthCare Chaplaincy is a national leader in the research, education, and practice of multifaith, patient-centered care. It helps people find meaning and comfort—regardless of religion or beliefs—in stressful health care situations. For nearly 50 years it has collaborated with major academic medical centers and other professional organizations to integrate spiritual care within health care. It is a thought leader for accessible, affordable, and quality palliative care.
Hospice and Palliative Nurses Association (HPNA) www.hpna.org	The purpose of the HPNA is to exchange information, experiences, and ideas; to promote understanding of the specialties of hospice and palliative nursing; and to study and promote hospice and palliative nursing research.
Institute for Health Care Improvement (IHI) www.ihl.org	The IHI is an independent not-for-profit organization helping to lead the improvement of health care throughout the world. Founded in 1991 and based in Cambridge, Massachusetts, the IHI works to accelerate improvement by building the will for change, cultivating promising concepts for improving patient care, and helping health care systems put those ideas into action.
National Hospice and Palliative Care Organization (NHPCO) www.nhpc.org/templates/1/homepage.cfm	The NHPCO is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. The organization is committed to improving end-of-life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for dying Americans and their loved ones.
Social Work in Hospice and Palliative Care Network www.swHPN.org	SWHPN is an emerging network of social work organizations and leaders who seek to further the field of end-of-life and hospice/palliative care. The organization is advancing the role of the social worker in caring for the seriously ill, providing relief from pain, improving quality of life, supporting family and friends, assisting with difficult decision making, and helping people deal with trauma, grief, and loss.

and addressing common challenges, especially those unique to a state, region, or system. Networks are also an important tool for supporting quality improvement and research. Pooling efforts with other PCSs can increase the validity and sharing of general findings and can provide benchmarks

or comparison data for quality improvement or research activities.

Examples of networks and systems include local or regional hospital groups and hospices; health care systems such as the Veterans Administration, Catholic Healthcare West, the

Supportive Care Coalition, and Kaiser; regional collaboratives such as the Spreading Palliative Care in Public Hospitals initiative, supported by the California HealthCare Foundation; and research networks such as the Population-based Palliative Care Research Network (PoPCRN) and the PCRC.

Collaboration provides the opportunity for the development of benchmarking data and access to knowledge beyond what is feasible at a single site. On a national level, the University HealthSystem Consortium (UHC) and the Institute for Healthcare Improvement (IHI) have sponsored programs aimed at improving access to or evaluating outcomes of palliative care. Smaller networks and partnerships can be equally useful. Partnerships centered on mutual training needs or alignment of services, such as the one between the University of California, San Francisco Palliative Care Service and the Zen Hospice Project in San Francisco, the research partnership between the University of Colorado and The Denver Hospice, and the partnership between the Institute for Palliative Medicine at San Diego Hospice, all of the internal and family medicine training programs in San Diego County, and Scripps Health and the University of California, San Diego Palliative Care Service, can be productive and provide mutual support. Networks can also be centered around the initiative and needs of individuals. Local palliative care clinicians can organize clubs and grand rounds that are open to the community, creating a network and sense of common purpose.

Experts

Many programs benefit from accessing the experience, stature, and attention of experts. Experts can collaborate or provide focused, individualized feedback, help with specific technical issues, provide input regarding a particular service, or assist with crafting and communicating the palliative care message to different audiences. An expert can function as mentor, providing longitudinal support, or as consultant, with a brief and focused engagement. Effective mentors inspire a shared vision, challenge the current process, and enable others to act. Mentors can act as role models, provide an external perspective, facilitate access to resources, and guide strategic and business planning, team building, and skill building. Outside experts, by virtue of stature or simply a fresh perspective, can deliver a message about palliative care to hospital leadership, directors, and clinicians that may be better received than the same message stated by local leaders. Any experienced palliative care leader can serve as a mentor to others. Mentors often find they learn as much as they teach and can achieve a strong sense of accomplishment and satisfaction from helping others succeed.

Discussion

The growth of palliative care programs presents many challenges. Fortunately, there are many ways to access help and meet those challenges. Assistance can come from many sources: professional organizations, networks, and experts. By taking advantage of these resources, new and established programs can get the support they need to more easily negotiate the challenges they inevitably face. Perhaps more importantly, by leveraging external resources, palliative care

programs can pool knowledge and advance the collective goal of providing patients and families with the best care possible. It is important to remember that assistance can promote success, that programs and leaders can become a resource to others, and that palliative care programs are never in this work alone.

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