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Expanding Palliative Care's Reach in the Community Via the Elder Service Agency Network

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Abstract

Over the past two decades, palliative care has established itself as a promising approach to address the complex needs of individuals with advanced illness. Palliative care is well-established in US hospitals and has recently begun to expand outside of the hospital setting to meet the needs of non-hospitalized individuals. Experts have called for the development of innovative community-based models that facilitate delivery of palliative care to this target population. Elder service agencies are important partners that researchers should collaborate with to develop new and promising models. Millions of older adults receive aging network services in the US, highlighting the potential reach of these models. Recent health care reform efforts provide support for community-based initiatives, where coordination of care and services, delivered via health and social service agencies, is highly prioritized. This article describes the rationale for developing such approaches, including efforts to educate elder service agency clients about palliative care; training agency staff in palliative care principles; building capacity for elder services providers to screen individuals for palliative care needs; embedding palliative care “champions” in agencies to educate staff and clients and coordinate access to services among those with palliative care needs; and leveraging telehealth resources to conduct comprehensive assessments by hospital palliative care teams for elder service clients who have palliative care needs. We maintain that leveraging the resources of elder service agencies could measurably expand the reach of palliative care in the community.

Keywords

Palliative care; elder service agencies; community-based initiatives

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Over the past two decades, palliative care has established itself as a promising approach to address the complex needs of individuals with advanced illness. Palliative care employs a holistic, interdisciplinary perspective and focuses on alleviating burdensome symptoms and attends to individuals' emotional and spiritual needs and concerns. Palliative care also helps affected individuals receive treatment that is consonant with their core values and goals, and provides much needed support to family members and caregivers (1). Palliative care has been associated with numerous positive outcomes, including decreased symptom burden (2), improved quality of life (3), enhanced satisfaction with care among chronically-ill older adults and their caregivers (4), and reduced healthcare costs (3, 5, 6).

Palliative care is well-established in U.S. hospitals and has begun to expand to meet the needs of non-hospitalized individuals. For instance, palliative care services have been successfully integrated into ambulatory clinics, most notably oncology practices (3). Efforts have been successfully undertaken to train a range of providers (e.g., nurses and social workers) how to deliver key components of palliative care in ambulatory settings (7). In addition, palliative care is now provided through some home health care agencies (8–10). Other examples of the expansion of palliative care include initiatives supported through capitated managed care plans. One large health system in Ohio (Summa Health) partnered with the local Area on Agency Aging office to develop and pilot a home-based palliative care program targeting community-dwelling older adults newly enrolled in a Medicaid waiver program (11). The investigators demonstrated the feasibility of delivering interdisciplinary palliative care to homebound older adults using a model that included patients' primary care physicians (12).

The above efforts highlight the potential to deliver palliative care in the community. Initiatives to reach older adults with less access to healthcare services are especially needed. Low-income ethnic and racial minorities may particularly benefit, as these populations have significantly greater rates of chronic illnesses than other groups (13, 14) and are less likely to receive inpatient palliative care (15–18). Experts in the field have called for the development of innovative models to deliver community-based palliative care to address these and other gaps in service delivery (15, 19–21). Working with agencies that serve older adults where palliative care needs are likely high should be particularly encouraged. One promising and highly underutilized approach is to develop models in partnership with elder service agencies.

Elder service agencies constitute a broad array of programs and services designed to help older adults remain safely in their homes and delay or prevent institutionalization (22). Agencies include senior centers that offer meals, exercise programs, as well as educational and wellness programs, and case management programs that connect older adults with in-home supports such as home-delivered meals and other services, including transportation, legal assistant and benefits. In addition, elder service agency staff maintains ongoing contact with older clients to assess for additional needed services. Elder service agencies provide and link to specific resources for older adults as well as their caregivers. Caregiver programs provide: 1) information and service referrals, 2) access to group and individual counseling, education, benefits and entitlements, 3) respite care, and 4) general assistance with housing, finances and home safety.

Elder service agencies are appropriate partners in the area of palliative care service delivery because: over 90% of clients who receive services from these agencies have multiple chronic conditions (23); many also have corresponding activity of daily living deficits (24) and report poorer self-rated health compared to older adults who do not receive these services (24). Although the palliative care needs of this population have not been well described, it is anticipated that these needs are substantial given their levels of multimorbidity, functional deficits, and poor self-rated health. Approximately 10 million adults ages 60 and above receive aging network services (25), highlighting the potential reach of palliative care models if linked with these agencies. Furthermore, most elder service agencies have missions that align well with key tenets of palliative care, i.e., a focus on improving older adults' quality of life and addressing family and caregiver needs (26–28). Elder service agencies typically work with older adults with chronic illnesses over long periods of time, and have established trust with their clients, which could potentially help to address clients' concerns about a type of care that is often viewed as synonymous with hospice care (29).

Education about healthcare is a common part of the work done by elder service agencies, and could be expanded to include educating clients about palliative care. Indeed, in a recent consensus conference focused on knowledge gaps in palliative care, one of the strongest recommendations to emerge from the conference was a need to educate the public about palliative care (30). In addition, many elder service agencies provide care to homebound older adults via nutritional support and case management programs; these individuals cannot access outpatient palliative care programs because of their functional impairments but could be helped by training staff about palliative care principles and practices.

Other reasons to consider developing palliative care service delivery capacity in partnership with elder service agencies include the fact that many of these agencies 1) routinely provide programming (e.g., meditation, tai chi, chair yoga classes) that can positively impact clients' symptom burden(31); 2) address clients' psychosocial and spiritual needs by linking them to existing spiritual and/or religious resources in their respective communities; 3) provide much needed support to caregivers through education and support groups; and 4) offer classes and other resources to help clients with advanced care planning (32).

Palliative care initiatives that could be considered will vary by type of agency and the needs of older adults served by a given agency. Efforts could include educational efforts targeting older adults, training agency staff in palliative care principles, building capacity at the agency level to screen clients for palliative care needs, embedding palliative care "champions" in agencies to educate both staff and clients and help coordinate access to services in those with unmet palliative care needs, and leveraging telehealth resources to conduct comprehensive assessments by hospital or outpatient based palliative care teams for clients identified as having palliative care needs. Recent health care reform efforts (i.e., Affordable Care Act) provide support for these and other types of community-based initiatives, where coordination of care and services (delivered via health and social service agencies) is highly prioritized, e.g., in the form of patient centered medical homes.

There is also preliminary evidence that agency staff and clients will accept community based palliative care initiatives embedded in their respective agencies. In our team's community

needs assessment conducted in the East and Central Harlem neighborhoods of New York City, elder service agency staff voiced strong support for efforts to develop and implement accessible, community-based palliative care initiatives housed in their agencies; 85% said they would be willing to partner with researchers in these efforts (33). The Harlem Palliative Care Network (HPCN) (28) a multidisciplinary collaborative, successfully partnered with over 150 community agencies, and found that many referred clients for palliative care over the course of the program. The Collaborative for Palliative Care, made up of community organizations and volunteers dedicated to improving compassionate palliative and end of life care, has partnered with multiple community agencies in Westchester County, New York, and successfully fostered educational efforts and implemented multidisciplinary conferences since 2006 (21). Older adult clients with chronic illnesses appear to support these efforts as well. Kayser and colleagues (15) identified strong interest in and need for community-based palliative care services in community-stakeholders, i.e., those living with chronic illnesses and family caregivers from five inner-city communities in the Boston area. Our group's needs assessment revealed that almost 65% of clients interviewed were interested in receiving palliative care, and the majority (80%) wanted to receive palliative care at an elder service agency (33).

In conclusion, elder service agencies are in a unique position to identify older adults with unmet palliative care needs, address psychosocial barriers to utilization of palliative care services, make referrals, and coordinate service access in ways that outpatient and hospital providers often cannot. We maintain that leveraging the resources of elder service agencies could measurably expand the reach of palliative care in the community. The palliative care field should consider developing and implementing care models in partnership with elder service agencies as a way of building capacity to address the palliative care needs of aging adults.

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