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UNDERSERVED POPULATIONS (H FERNANDEZ, SECTION EDITOR)

Home Based Palliative Care: Known Benefits and Future Directions

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Abstract

Purpose of Review To summarize key recent evidence regarding the impact of Home-Based Palliative Care (HBPalC) and to highlight opportunities for future study.

Recent Findings HBPalC is cost effective and benefits patients and caregivers across the health care continuum.

Summary High-quality data support the cost effectiveness of HBPalC. A growing literature base supports the benefits of HBPalC for patients, families, and informal caregivers by alleviating symptoms, reducing unwanted hospitalizations, and offering support at the end of life. Numerous innovative HBPalC models exist, but there is a lack of high-quality evidence comparing specific models across subpopulations. Our wide literature search captured no research regarding HBPalC for underserved populations. Further research will also be necessary to guide quality standards for HBPalC.

Keywords Home based palliative care · HBPalC · Palliative care · Home care

Introduction

As many as 1.9 million people are completely homebound in the United States; another 5.5 million people have difficulty leaving their homes without the assistance of others [1]. Many homebound individuals have multiple chronic conditions, cognitive impairment, neurodegenerative disorders, comorbid psychiatric illness and/or high symptom burden. In many instances, such persons are not just homebound but also chair- or bedbound, and their prognosis is often quite limited [2]. A recent study of data on community-dwelling Medicare beneficiaries revealed a two-year mortality rate of 40.3% for homebound participants and 21.3% for the semi-homebound, as compared to only 5.8% in those who were neither [3]. The costs associated with the care of the homebound can be exorbitant if solely provided in traditional hospital-based settings. Thus, providing home-based medical care can both improve health outcomes and reduce health care costs by employing tailored quality metrics and expanding the breadth of services available outside the hospital [4, 5]. The COVID-19 pandemic highlighted the importance of home care, and in recognition, the Centers for Medicare and Medicaid Services (CMS) approved delivery of hospital level care to the home, an unprecedented move to improve access to care for homebound individuals.

Given the symptom burden, prognosis and complexity of homebound individuals, Home Based Palliative Care (HBPalC) —in addition to hospital at home, home based primary care, and home hospice care—is a potentially critical service. Distinct from hospice services, which provide comfort-focused care specifically during the final 6 months of life, HBPalC is provided across the continuum of serious illness for many homebound individuals. Over the past decade, there has been a heterogeneous collection of systematic and scoping reviews examining the effectiveness and cost-effectiveness of HBPalC [6, 7•]. We conducted this narrative review to understand the most current evidence surrounding the impact of HBPalC, with a particular interest in benefits reported beyond cost savings.

This article is part of the Topical Collection on Underserved Populations

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Methods

For this narrative review, we consulted multiple databases to assess available evidence regarding the variety of benefits associated with Home Based Palliative Care (HBPalC). Our search was limited to articles published January 2017 – March 2021, and included the following terms across PubMed, Embase, Web of Science, and Scopus: Palliative Care, Home Care, Health Expenditures, Costs, and Cost–Benefit. Two study team members reviewed 106 titles and abstracts and reached consensus to include 32 studies for full-text review based on the following criteria: full-text available, adult population, and focus on palliative care delivered in the home. We included an additional 10 articles obtained through manual search of the aforementioned databases using the following terms: Palliative Care, Home Based, and In Home. These 42 studies contained quantitative or qualitative outcomes related to physical, psycho-emotional, or financial benefits and costs of HBPalC to patients, families, or health systems. Three study team members individually reviewed and extracted data from these 42 studies. Lastly, all authors reviewed data extractions and reached consensus on themes through structured discussion.

Demographics

Approximately half of the studies in our review focused specifically on geriatric patients; all included age-related outcomes and/or services tailored to older adults and their families. Across these studies, the mean age ranged from 72–84 years. Some of these studies described program design targeting geriatric patients [8, 9•, 10] whereas others focused on conditions surrounding death of the elderly [11, 12, 13•]. Many of the remaining studies included geriatric patients without explicit discussion of age-related interventions or outcomes.

We did not observe significant patterns regarding other demographics such as race/ethnicity, sex, educational attainment, marital status, and socioeconomic status.

Benefits of HBPalC

Cost Effectiveness

The majority of data regarding the benefits of HBPalC for patients, their families, and health systems supports its impact on cost-savings and improved resource utilization [14]. Compared to usual care, the addition of HBPalC lowers costs and resource utilization across high-risk elderly [8], cancer and non-cancer [15], heart failure [16], and COPD populations [11]. Evidence that HBPalC adds value to usual care spans the globe, including Australia [17], Belgium [11, 12] Canada [18•, 19], England and Ireland [20], Italy [17] and the United States [9•, 14].

Across these diverse settings, fewer Emergency Department visits, Intensive Care Unit admissions, and shorter hospital lengths of stay drive the high value of HBPalC [21, 22]. The highest yield is associated with HBPalC during the final months of life, including care during active dying [15, 23]. In a retrospective analysis of a Medicare Shared Savings Program, Lustbader and colleagues found enrollment in a HBPalC program led to a significant reduction in costs per patient during the last three months of life. The primary driver was decreased Medicare Part A expenditure associated with increased likelihood of death in the home and use of hospice services [9•].

Symptom Management

We found fewer studies addressing patient outcomes of HBPalC. The most widely reported outcome is adequate management of physical and psychosocial symptoms such as pain, constipation, dyspnea, fatigue, anorexia, anxiety, and depression [24, 25]. Patients with life-limiting illness often develop severe physical, psychological, and spiritual symptoms [26], and many discharged from the hospital will experience worsening of symptoms at home [27]. Ng and Wong conducted a randomized controlled trial of 84 end-stage heart failure patients discharged from hospital to home, comparing usual care to HBPalC over 12 weeks. Symptoms were significantly improved across multiple modes of assessment: physical, psychological, and existential symptoms as measured by the McGill Quality of Life Questionnaire; dyspnea, emotional function, and mastery as measured by the Chronic Heart Failure Questionnaire; and depression and shortness of breath as measured by the Edmonton Symptom Assessment Scale [28].

Ankuda and colleagues conducted a mixed-methods study of HBPalC enrollees during–and three months after–enrollment in an HBPalC program with services divided into medical, emotional/spiritual, social, and practical support [29•]. Nearly all participants reported that medical support mattered most, particularly in the context of distressing symptoms for which determining the appropriate level of care had been previously challenging. However, the authors suggest that patient needs drive what matters most: Those patients with the least functional ability valued practical assistance, those with the most serious illness valued emotional and spiritual support, and those lacking adequate finances valued social services [29•].

Care at the End of Life

Generally, patients and their families prefer to die at home and not in the hospital [30]. Ankuda and Meier reviewed the relevant literature and concluded that HBPalC provided by Hospice and Palliative Medicine-trained physicians were associated with 59% lower odds of dying in the hospital compared to patients without home based care [17]. While any homebased medical care decreased the likelihood of dying in the hospital, those patients who received care by physicians not trained in palliative care were 12% more likely to die in the hospital.

Isenberg and colleagues compared those who did and did not receive HBPalC services in the last 90 days of life and found that even modest use of HBPalC reduces in-hospital death and improves the dying experience [10]. Similarly, McEwen and colleagues performed a mortality follow-back study and determined that formal end of life home care positively correlated with dying at home versus the hospital, especially for those with well-managed symptoms [31].

Increased hospice enrollment may also serve as an important metric for characterizing the value of HBPalC. In a retrospective analysis of over 650 Medicare ACO patients, Lustbader and colleagues reported a significant increase in hospice enrollment (35%) and increased median hospice length of stay (240%) for those who received HBPalC, compared to usual care [9•].

A critical patient-centered measure of the value of HBPalC at the end of life is its ability to increase congruence between preferred and actual place of death, wherever that place may be. Cai and colleagues conducted a longitudinal prospective cohort study of almost 300 caregivers interviewed frequently throughout their enrollment in HBPalC through death [30]. HBPalC was associated with 72% congruence amongst enrollees, inclusive of those desiring to die in the hospital. The authors conclude this result represents an improvement from prior studies of those not enrolled in HBPalC programs [30].

Informal and Family Caregivers

There is a small but growing literature base supporting various benefits of HBPalC for informal or family caregivers. In their scoping review of HBPalC interventions, Hofmeister and colleagues identified a dominant theme of caregiver support in over 20% of relevant studies [7•]. Naoki and colleagues recognize that the emotional and physical burdens placed on caregivers can impede family satisfaction with end-of-life care, citing the potential for HBPalC to improve end-of-life experiences for patients and their caregivers [32]. A review by Miranda and colleagues demonstrates that trained, specialist palliative care in the home may be associated with high caregiver satisfaction, though the authors caution on the weak quality of the evidence [33]. Bjornelv and colleagues found that comprehensive multidisciplinary HBPalC positively impacts informal caregivers of those dying at home. Patients spent more days with their spouse at home and fewer days in institutions, increasing time spent together and decreasing financial burden [34].

Evolution and Innovation

Recently, an aging population, changes to health care payment structure, and an increased awareness of patients' preferences to receive palliative care at home have led to evolution and innovation in HBPalC. Transitioning smoothly between health care settings is challenging for patients and clinicians, requiring proactive communication about advance care planning and goals of care, collaboration between distinct health care entities, and robust logistical planning to ensure safe, comfortable transitions between acute care, long-term, and home settings [35•].

As Szegin and colleagues describe in their recent review, transitional care (TC) models utilize interdisciplinary teams who offer services such as pre- and post-discharge assessments, remote counseling, and follow-up visits across settings across patients' trajectories, with the goal of reducing frequent hospitalization, decreasing costs, and improving patient quality of life and satisfaction [35•]. Transitional palliative care (TPC) employs these models to help patients as they transition their focus from curative to palliative treatment. Evidence suggests TPC can effectively tailor care to patient-specific needs and values while improving quality of life and satisfaction, addressing symptoms before sudden worsening, improving communication across levels of care, and providing otherwise unknown information about palliative care to patients and their families [35•]. Though studies were few, the review by Szegin and colleagues suggests that applying TC and TPC frameworks to HBPalC can reduce readmissions, improve quality of life for patients, and support caregivers and providers in making patient-centered decisions [35•]. Wong and colleagues also found increased cost-effectiveness associated with TC compared with usual palliative care services for patients with end stage heart failure [36].

Novel tools for patients and families to use in the home in the absence of professional caregivers have emerged. Webber and colleagues conducted an ecological and retrospective cohort study of HBPalC patients [19]. They provided either a Yellow Folder containing tools to facilitate advance care planning, do-not-resuscitate orders, and home-death planning, or a Symptom Response Kit, including medications and medical supplies tailored to the patients' illnesses, or both. Each intervention was independently associated with increased likelihood of dying at home versus hospital; the likelihood of dying at home was highest with the combined interventions. The Symptom Response

Kit was particularly effective, potentially due to increased caregiver confidence. Over the five-year study period, there was no overall reduction in hospitalizations and emergency department visits; however, sensitivity analyses demonstrated significant reduction in hospitalization during patients' final two weeks to six months prior to death [19].

Structure and training of the HBPalC workforce has evolved as well. Sun and colleagues conducted a prospective study of the propensity for HBPalC services, as well as the intensity of services provided, over ten years [18•]. The authors discovered that the increased propensity for HBPalC use sparked home and community organizations to innovate cost savings strategies. Over the ten years, the use of personal support worker (PSW) services increased, representing a shift away from more expensive nursing services; the intensity of PSW use was highest as patients approached death. Gasper and colleagues showed it might be feasible to expand the reach of an HBPalC team through educating usual home care staff on the principles and strategies of palliative care. A Hospice and Palliative Medicine certified physician led the training, which led to reduced hospital readmissions compared to usual home care [16].

Rapid response palliative care teams represent another area of promising innovation. Le and colleagues describe the first such team in Australia, the Responsive Acute Palliative Intervention and Decision Assistance (RAPID Assist) service, which utilizes a multi-disciplinary team to provide same-day assessments and treatments for palliative care patients in the home, as well as in hospital if complex transitions are taking place [37]. The authors analyzed over 340 of the RAPID Assist team's cases over the course of 12 months and found that 89% of patients who died during the study period died at home, twice the national average. The authors suggest that the rapid response palliative care model can improve complex symptom management, goals of care exploration, and advance care planning amongst the HBPalC population [37].

Future Directions

Amidst the innovation, we believe the current literature reflects the need for a greater degree of standardization across models and increased rigor in research in order to achieve greater demand for—and utilization of—HBPalC services amongst patients and health care professionals.

First, centralized guidelines for HBPalC provider training and program structure, currently lacking, would enable patients, caregivers, and health systems to objectively assess program efficacy and make informed decisions tailored to specific patient needs. In response to Wang and colleagues' retrospective analysis of those receiving HBPalC, hospice, or neither, Calton and Ritchie describe limitations in measuring the quality of care across HBPalC programs [13•, 38] They found limited consensus on provider qualifications, no definition for what constitutes a quality HBPalC visit, and no standard practice for support between home visits. The authors propose the need for national standards for training and competency for HBPalC providers, and for quality measures to ensure accountability across HBPalC programs [38].

Rahman and Rahman similarly caution that, without industrywide standards for processes and outcome measures (i.e. staff to patient ratios; which professions constitute an effective interprofessional HBPalC team), health systems may overly focus on the better-documented cost impact, leading to selection of practices and patient populations that are disproportionately associated with highest profits. The authors suggest more transparency in financial disclosures and quality indicators [39]. Incidentally, even within the area of cost effectiveness, which is arguably supported by the strongest quality of data, a systematic review conducted by Gardiner and colleagues found that creating a comprehensive framework for costs of palliative care from hospital to home remains challenging, given variation in cost and payment approaches across groups [40].

In tandem with stronger guidelines, improvements in the quality of evidence supporting HBPalC would help program leaders to justify and communicate its value to stakeholders. A systematic review of HBPalC services for patients with dementia by Miranda and colleagues found no studies with a high quality of evidence [33]. The studies rarely measured dying at home, and those that did included no comparator. While there was some evidence that these interventions mitigate behavioral issues and pain, it was unclear to what extent, and the authors noted the limited evidence regarding caregiver support, shared decision making, advanced care planning, disease prognostication, and cost-effectiveness [33].

Limited quality of evidence also exists for TPC. Saunders and collegues conducted a systematic review of the relevant literature and could not draw strong conclusions regarding the impact of palliative care transitions from inpatient to HBPalC services. This was due to the wide variety of study designs, heterogeneous findings, and generally low-quality methodology [41].

Relatedly, practice standards rooted in high-quality evidence may allow stakeholders to more precisely identify unmet needs HBPalC can address. For example, Gasper and colleagues describe that within the heart failure population, for whom disease trajectory is complex, unpredictable, and burdensome, the lack of clear differentiation between palliative care and hospice, the lack of administrative support across the acute to home care environments, and difficulty navigating reimbursement lead to missed opportunities to link patients and HBPalC services [16]. Maetens and colleagues similarly found that, despite largely comparable policies and practices across three European countries with

similar clinical contexts, differences between the services offered and the criteria for patient coverage still contribute to underutilization of HBPalC services [12].

Discussion

Being homebound often means facing insurmountable physical, social, and financial barriers to obtaining high quality care. Outpatient palliative care would be largely out of reach for the homebound, so long as its services are limited to inpatient and clinic settings. Growing interest in leveraging innovative models to deliver HBPalC merits a summative exposition of the pearls and pitfalls of the emerging field. Hence, we conducted this narrative review to highlight recent evidence of the impact and future needs of HBPalC. We found three key themes that illuminate the state of recent literature regarding HBPalC.

Cost-effectiveness: A preponderance of high-quality evidence supports the cost-effectiveness of HBPalC compared to usual care. Researchers interested in the financial case for HBPalC should consider comparing cost-savings across specific models of HBPalC, yielding novel and potentially practice-changing data.

Comprehensive services: For patients with serious, potentially life-limiting illness facing gaps between health care levels and settings, HBPalC services may meet otherwise unmet needs–symptom management, family and caregiver support, care at the end of life, and care across transitions between acute care, long-term care, and in-home care.

Variety of models: Wide variation exists in payment and reimbursement structure, personnel, role delineation, and services provided. Little high-quality research regarding the relative effectiveness of specific HBPalC models exists. At present, we cannot suggest a particular model of HBPalC delivery that is clearly superior, within or across subpopulations.

Conclusion

HBPalC is clearly beneficial from a cost-savings perspective, and mounting evidence suggests benefits from a patient-centered perspective. Across geography and illness type, homebound patients, their caregivers, and their health systems benefit from palliative care services. Models for HBPalC delivery are heterogeneous, but refined quality standards and further study may lead to a more coherent narrative about its benefits.

None of the studies we reviewed primarily focused on the role of HBPalC in improving access to—or quality of—palliative care for underrepresented populations. We strongly recommend further exploration of the role of HBPalC for diverse populations and its impact on health equity.

No studies in our review focused on the dynamic between HBPalC and existing home based primary care programs. Additionally, while the majority of our studies included older adults, no studies described partnerships between geriatric medicine and palliative care specialists. Future research may clarity whether multidisciplinary collaboration across palliative care, primary care, and geriatric medicine offers unique benefits for homebound patients.

For many across the continuum of health, the lockdowns of COVID-19 represented a dramatic shift inwards; venturing away from home, previously innocuous, suddenly bore threat. Even as the pandemic shows signs of subsiding in the United States, homebound patients with life-limiting illness will continue to need home based services to manage symptoms, care for their caregivers, and decrease burdensome costs. Based on this review, we suggest HBPalC models have the promise to meet their ongoing needs in important ways.

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Declarations

Conflicts of Interest The authors have no conflicts of interest to report.

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