Key Takeaways from a Home-Based Primary and Palliative Care Literature Review

The Center to Advance Palliative Care (CAPC) reviewed peer-reviewed journal articles indexed in PubMed to understand the evidence base for home-based primary care (HbPrimC) and home-based palliative care (HbPalC) for families facing serious illness. More than 100 articles were identified. Of these, 56 described processes or outcomes of home-based primary care, home-based palliative care, or both, and were included in this review. Below we summarize our findings; please refer to the cited articles for details on methodology, sample size, and context.

Key Takeaways

1. The target populations for HbPrimC and HbPalC largely overlap.
2. HbPrimC programs may already address some palliative care needs (such as pain and symptom management), but gaps remain—particularly in spiritual and emotional care.
3. HbPrimC and HbPalC models independently reduce hospitalizations and costs and improve patient satisfaction, but very limited research has studied delivery of both home-based primary and palliative care as an integrated program.
4. Homebound patients living with serious illness, along with their caregivers, prioritize services that require an interprofessional team approach.
5. Barriers to HbPrimC and HbPalC overlap, but with distinct nuances: palliative care faces persistent misperceptions about its role during treatment, while HbPrimC depends on referrals from PCPs who may view it as duplicative or competitive.
6. Only a small handful of models have been studied that integrate primary and palliative care, with several leveraging certified home health services as the core platform.

1. The target populations for HbPrimC and HbPalC largely overlap.

→ Both services use algorithms to identify eligible patients that rely on diagnosis-based indicators of serious illness and measures of functional impairment, often combined with recent prior hospital or emergency department (ED) utilization. Some HbPrimC programs also target those facing social isolation.[1,2,3]

→ HbPrimC and HbPalC target patients at highest risk for potentially avoidable admissions, particularly older adults with high Charlson Comorbidity Index (CCI) scores and diagnoses such as dementia, CHF, COPD, and diabetes. [4,5,6,7]

- One difference is that the highest proportion of HbPalC literature is on programs treating patients with cancer[8] but cancer does not appear in the literature for HbPrimC.

→ The dementia population represents a clear opportunity for implementing home-based care, given consistent care needs, high caregiver burden, and clear evidence of improved outcomes.[9,10,11,4,6]

→ The population in need of home-based medical care for disease management and palliative needs is growing; however, only a small fraction of this population is receiving services.[2,12]

2. HbPrimC programs may already address some palliative care needs (such as pain and symptom management), but gaps remain—particularly in spiritual and emotional care.

→ In a study of HbPrimC, pain was screened 70% of the time, and constipation and dyspnea 57%. Among those who screen positive, treatment is provided for pain (92%), anxiety (84%), constipation (83%), and psychosocial distress (82%). Only 22% of patients are screened for spiritual needs, and just 4% receive spiritual care.[6]

→ In a similar study, pain was assessed 70% of the time, goals-of-care conversations occurred with 65% of patients, and depression was assessed in 54%. Spiritual needs and behavioral issues were assessed in 22% and 21% of cases, respectively.[10]

→ In HbPrimC, pharmacologic pain treatments were provided frequently (57–91%), along with non-pharmacologic interventions (67%).[13]

→ Persons living with dementia receiving HbPrimC were 23% more likely to also receive HbPalC or hospice (reported as a combined outcome in the study).[14]

3. HbPrimC and HbPalC models independently reduce hospitalizations and costs and improve patient satisfaction, but very limited research has studied delivery of both home-based primary and palliative care as an integrated program.

This literature search found very limited published outcomes from programs that deploy both HbPrimC and HbPalC clinicians serving the same patient panel; however, palliative care skills training for home-based clinicians may hold promise (see #6, below).

Outcome Measure	HbPrimC	HbPalC	Takeaway
Reduces Hospitalization/ Rehospitalization ates	Yes (15,16,17,18)	Yes (7,20,21,22,23,24)	HbPrimC: longer length of stay associated with greater reductions HbPalC: Often demonstrated near end-of-life
Reduces Total Cost of Care	Yes (3,16,25,26)	Yes (7,20,22,23,24,27, 28)	
Improves Symptom Distress	No evidence in this literature review	Yes (24,29,30)	HbPalC often targets symptom distress specifically
Increases Hospice Enrollment	Yes (14,45,46)	Yes (20,22,42, 44)	Both HbPalC and HbPrimC models suggest improved goal-concordant hospice transitions

Increases Patient Satisfaction	Yes (15, 49)	Yes (49)	Both HbPrimC and HbPrimC models show an increase in patient satisfaction

Note that for many studies, the categorization of home-based primary or palliative is unclear, as there are a number of studies that provide home-based primary care to a population with serious illness and provide some basic palliative care services, and others that provide home-based "serious illness" or "advanced illness" care.

4. Homebound patients living with serious illness, along with their caregivers, prioritize services that require an interprofessional team approach.

→ The top needs identified by patients, in rank order, include medical support, emotional support, spiritual care, and practical social service assistance.[31]

→ For both older adults and pediatric patients, attention to the needs of family caregivers ranks high.[32,33]

→ For Medicaid beneficiaries, practical social support plays a particularly important role and is associated with greater savings and overall benefits.[34]

5. Barriers to HbPrimC and HbPalC overlap, but with distinct nuances: palliative care faces persistent misperceptions about its role during treatment, while HbPrimC depends on referrals from PCPs who may view it as duplicative or competitive.

→ Accountable Care Organization (ACO) adoption of home-based care for people with serious illness has been slow, largely due to competing organizational priorities and delayed return on investment.[35]

→ Adequate payment has been cited as a barrier for both types of home-based services.[3,48]

→ Common operational barriers include clinician turnover and poor fit with existing EHR and scheduling systems.[1]

→ Barriers to patient acceptance of HbPalC include discomfort with home visits, concerns about timing, and patients' own perceptions of their health status. Misconceptions about palliative care is the most frequently cited obstacle.[36,37]

→ A related study[38] suggested positioning palliative care as a distinct line of business within hospices, with warm handoffs between teams to be a valuable way to overcome this barrier.

→ Primary care physicians' attitudes and level of understanding remain a barrier to the adoption of HbPrimC.[39]

6. Only a small handful of models have been studied that integrate primary and palliative care, with several leveraging certified home health services as the core platform.

- → Primary (non-specialty) palliative care training improved HbPrimC residents' psychosocial, spiritual, cultural, and communication skills, but had less impact on pain and symptom management competencies.[40]
- → Primary palliative care skills are essential; along with standardized tools, streamlined training, and clear workflows, which can significantly improve identification of palliative needs and increase appropriate referrals to specialist palliative care.[11,43]
- → "Wraparound" palliative care consults (8–10 visits) added to home health episodes or HbPrimC services lead to strong patient outcomes. [24, 41]
- → Who's providing medical care matters. More hospital and ED visits were seen in nurse practitioner-only HbPrimC, but fewer of those admissions can be considered avoidable.[42]

Summation

The distinction between HbPrimC and HbPalC is blurred, and programs of both types often offer a blended model of care [47]. Most home-based programs are finding the high-need, high-risk population and meeting broad needs with an interprofessional team or interdisciplinary coordination. While the evidence base is small, it appears that HbPrimC – including primary care managed by palliative professionals – over the long-term is effective at improving quality of life and reducing avoidable utilization and costs. As disease progresses and prognosis becomes limited, patients benefit from specialty HbPalC services, and if unavailable, clinical staff who are trained in primary palliative care skills that can address the full range of patient and caregiver needs.

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