Financial Aspects of Outpatient Palliative Care

Sarina R. Isenberg, Rab Razzak, Mike Rabow, and Thomas J. Smith

Contents

1 Introduction ........................................................................................................... 2
2 Literature Review ................................................................................................... 3
3 Symptom Management in Home-Based Palliative Care ....................................... 3
   3.1 Cost Effectiveness of Home-Based Palliative Care (United States) ................. 4
   3.2 Cost Effectiveness of Home-Based Palliative Care (Canada) ......................... 6
   3.3 Cost Effectiveness of Home-Based Palliative Care (Australia) ...................... 8
4 Highlighting of Organizations that Have Been Successful in Their Implementation of Outpatient Palliative Care ......................................................... 8
   4.1 Johns Hopkins Medicine Palliative Care Program (Baltimore, USA) ............ 8

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Abstract
Community-based palliative care has become the focus of palliative care’s growth and opportunity. Twelve of the largest randomized control trials on palliative care are community-based and result in equal or greater survival, positive satisfaction from patients and caregivers, and equal or less cost. Surprisingly, sometimes the business case is the easiest to make (Cassel et al. 2015). With health care financing that embraces value-based programs such as serious-illness care models, shared savings, bundled payments, global budget revenues, community-based palliative care shows great promise and may be part of the solution to provide better care for patients at a cost we can afford. Some key obstacles include a shortage of practitioners and the necessity to perform as a public health system instead of a revenue-generating center. We provide examples of some successful programs that are reproducible.

1 Introduction
Studies from the United States, United Kingdom, and Canada suggest that most people prefer to both be cared for and die at home (Gomes et al. 2013a; Bell et al. 2009; Higginson and Sen-Gupta 2000). However, only a minority of deaths occur at home (Cohen et al. 2010). In the US in 2007, 24% of deaths occurred at home among those aged 65 years and older (Teno et al. 2013; Statistics 2010). In the UK in 2010, 21% of deaths occurred at home (Gomes et al. 2012). In Canada, from 1994 to 2004, 30% of deaths occurred at home (Wilson et al. 2009). In addition, the rapid rise of concurrent palliative care alongside disease-directed therapies for diseases like cancer and multiple sclerosis – where people may live a long time and not die – has made many programs retool for chronic ongoing care.

Varied initiatives in outpatient palliative care have focused on aligning care with people’s preferences, improving clinical outcomes during and after treatment and increasing the proportion of people dying at home by decreasing hospital admissions near the end of life. In light of these trends and using a system-level international perspective, this chapter aims to explore what goes into the business planning for outpatient palliative care services.

This chapter describes research surrounding both “outpatient” (that is, clinic-based) and “home-based” palliative care. Clinic-based services may be associated with large health care systems. Home-based palliative care involves caring for seriously ill patients where they live, including private homes, nursing homes, and assisted living facilities. Both types of care may utilize telemedicine. Outpatient clinic-based and home-based palliative cares are sometimes referred to as Community-Based Palliative Care (CBPC).

CBPC developed differently in different countries. While it is outside the purview of this chapter to detail the development in each country, we will briefly list a few key points. In the USA, CBPC developed on a site-by-site basis, which largely reflects the health care system in that country. End-of-life care was and continues to be predominantly funded by the Medicare
Hospice Benefit, which promotes community-based hospice models that rely on home care (Bull et al. 2012). In Canada, CBPC had a more organic development, and while palliative care services and availability vary widely across the country, various provincial initiatives (e.g., the Ontario Palliative Care Network) are working to standardize palliative care and improve access. In the UK, palliative care services were developed similar to the USA, in a haphazard manner, site by site, often as a feature of charities. Since the NHS Cancer Plan 2000 (https://www.thh.nhs.uk/documents/_Departments/Cancer/NHSCancerPlan.pdf) along with end of life (EOL) strategy in 2008, there has been a more systematic attempt to figure out the regional needs, led by the National Council for Palliative Care. The Royal College of Physicians has set target numbers of consultant palliative care physicians to per capita population. This will help identify under-resourced and recognize where there is a greater need for physicians.

In this chapter, we first present a literature review of the research in the finances of CBPC. Second, we provide case studies of organizations that have been successful in their implementation of outpatient and/or home-based palliative care. Third, we provide suggestions and a blueprint for steps to take to create a sustainable and replicable outpatient and/or home-based palliative care program.

## 2 Literature Review

When reviewing the literature, it is important to note that it is challenging to compare across programs and jurisdictions. As acknowledged by Gomes et al. in their 2014 systematic review of the effectiveness of home-based palliative care, what constitutes “home palliative care” varies – be it physician- or nurse practitioner-provided; daily, weekly, or monthly visits; the extent of care that can be provided in the home. Also, importantly, the comparator of “usual care” varies across setting. In the above systematic review, usual care included community care, that is, primary or specialist care at home, outpatient clinics or in nursing homes, and in some instances hospice care (Gomes et al. 2013b).

Others have noted that the existing cost effectiveness and costs savings research on CBPC have certain limitations, including ambiguous currency and cost information, and limited statistical information (e.g., t-test results, confidence intervals, ranges, and disaggregated data) (https://www.thh.nhs.uk/documents/_Departments/Cancer/NHSCancerPlan.pdf). In addition to the above-noted challenges, Davis et al.’s systematic review of trials featuring early integration of outpatient and home-based palliative care found that studies typically had high attrition rates, lack of mention regarding whether participants were blinded, infrequent power calculations, and minimal use of intention-to-treat analysis (Davis et al. 2015). Both reviews noted that many studies in this field do not incorporate family nonmedical factors, including productivity impacts (e.g., patients/caregivers taking time off work as a result of illness or caregiving), use of life savings to cover medical expenditures, and food and transportation. Similarly, a systematic review on the financial impact of caring for family members of patients receiving palliative care found that there is limited research on the financial burden of caregivers; however, the few available studies suggest the financial costs are substantial and result in caregiver burden (Gardiner et al. 2014).

## 3 Symptom Management in Home-Based Palliative Care

Gomes et al.’s recent Cochrane Systematic Review on home-based palliative care demonstrated that, compared to usual care, home-based palliative care increased the odds of dying at home (from their meta-analysis: odds ratio (OR) 2.21, 95%CI 1.31 to 3.71; $Z = 2.98$, P value = 0.003), and small but statistically significant benefits of reducing symptom burden for patients (https://www.thh.nhs.uk/documents/_Departments/Cancer/NHSCancerPlan.pdf). Davis et al.’s systematic review of trials featuring early integration of outpatient and home-based palliative found that most studies demonstrated improvement in
depression and quality of life, decreased caregiver burden, and better maintenance of caregiver quality of life; however, they also noted that some trials demonstrate symptoms and quality of life did not improve (Gomes et al. 2013b). Sarmento et al. conducted a meta-ethnography to attempt to identify what components of home-based palliative care leads to these positive outcomes. The two overarching themes that emerged were that the 24/7 availability of home-based palliative care helped patients and families feel they had sufficient access to services, and that effective communication and symptom control made patients and their caregivers feel secure (Sarmento et al. 2017).

To our knowledge, only one trial has shown worse symptoms. Hoek et al. (2017) randomized 74 Dutch patients to weekly palliative care telemedicine sessions or “care as usual” without mandated palliative care consultations. In the intervention group, the Total Distress Score and anxiety scores (but not depression) were significantly worse at week 12. Their explanation was that the telemedicine allowed the patients to give excess attention to symptoms and suffering, and that the usual care had good palliative care as standard. But for the most part, these programs seemed to, according to the qualitative literature, allow patients and family caregivers to focus on living life and preparing for death at home, rather than dedicating time to the medical components of care (Gardiner et al. 2014).

There are specific examples of how concurrent palliative care improves symptoms. The UCSF outpatient team did an observational study of the outpatient cancer program that saw 266 patients at least twice. The only symptom that did not improve was nausea, but pain, depression, anxiety, quality of life, and spiritual wellbeing all improved clinically and statistically ($p < 0.002$ for all) (Bischoff et al. 2013). With US Oncology, Muir and colleagues embedded a palliative care advance practice or doctor or both (but not a social worker or chaplain) in oncology offices (Muir et al. 2010). The symptom burden was reduced by 21%, with ESAS scores falling from 49.3 to 39 (a meaningful difference). Oncology providers ranked satisfaction with the new PC service at 9/10, and consultation requests increased 87%, a doubling per oncology provider. The PC service saved the practice over 4 weeks of time, or 170 min per referral, used time-based billing by the PC group to calculate; this would allow the practice to see 121 new patients. Hospice length of stay, a marker of quality care, increased from 15 days to 24 days with palliative care consultation ($p < 0.001$) (Scheffey et al. 2014). In addition, opioid prescribing practices improved when palliative care saw the patient, with extended release analgesic prescriptions rising from 45% to 73% and pain scores dropping by 2/10 (Muir et al. 2013). The billing revenues from the palliative care providers paid their salaries, but the average half day session for a doctor and advance practice nurse included four new and six to eight follow-up visits in a half-day session, productivity which can be hard to sustain as a fulltime practice (Alesi et al. 2011).

### 3.1 Cost Effectiveness of Home-Based Palliative Care (United States)

While there is good penetration of inpatient palliative care programs in US hospitals, there are fewer outpatient palliative care programs. The total number of outpatient palliative care programs is not known but likely the current capacity in CBPC is inadequate to meet the current need (Bull et al. 2012; Kerr et al. 2015). To date, there have been some studies on the costs/benefits of home-based palliative care, but there is discordance in their findings. Overall, the aforementioned Cochrane Review of home palliative care services for adults with advanced illness and their caregivers deemed the evidence inconclusive regarding the cost effectiveness of this intervention as compared to hospital-based palliative care (6 studies). Similarly, Davis et al.’s systematic review of early integration of outpatient and home-based palliative care found that there is mixed evidence on whether these services reduce hospital length of stay and number of hospitalizations, as well as reduce costs. They suggest that the inconclusive nature of these results may
stem from large variability in studies; standard
deviations are often larger than the means
suggesting lack of precision, skewed economic
data, and heavy influence of outliers. Further,
patient populations are often comprised of those
with diverse primary diagnoses. Rabow et al.’s
systematic review of outpatient palliative care
interventions found that the evidence suggests
these programs reduce health care utilization.
They suggest that while the delivery of outpatient
palliative care is communication-rich, and staffing
intensive, the program’s ability to reduce overall
health care utilization balances out the costs of
delivery, especially in integrated health systems
(e.g., accountable care organizations) (Rabow
et al. 2013).

There are a few notable studies that examined
the cost effectiveness of particular home-based
and outpatient palliative care programs. One of
the most cited cost-effectiveness studies is
Brumley et al.’s work from Kaiser-Permanente
in 2007 that entailed a randomized control trial
in Hawaii and Colorado comparing home-based
palliative care to usual care (Brumley et al. 2007).
This study found that overall costs of care for
those enrolled in the home-based palliative care
program were 33% less than those receiving
standard care (P = 0.03). Further, the average
cost per day incurred by palliative care recipients
(USD$95.30) was significantly lower than that of
usual care group members (USD$212.80)
(P = 0.02). This study and a similar one for
inpatients convinced Kaiser-Permanente to adopt
the palliative care interdisciplinary team in all
their major markets.

Bookbinder et al. found a home-based pallia-
tive care model involving a nurse practitioner
and social worker connected to a palliative care
home team did not generate enough annual reve-
uenue from patient billings to offset the nurse prac-
titioner’s salary costs; however, a model of a nurse
practitioner linked to a hospice program led to an
increase in hospital referrals thereby generating
sufficient revenue to support the nurse practitioner
(Bookbinder et al. 2011). Indeed, an early study of
outpatient palliative care practices suggested that
billing revenue covers less than half of program
budgets (Rabow et al. 2010).

Cassel et al. examined the cost impact of
a concurrent care home-based program designed
for individuals with advanced chronic illness
found that, compared to a propensity-matched
usual care control group, patients in the interven-
tion group had less hospital use (mean hospital
days per month of 0.69 (SD 1.84) vs. 2.62
(SD 3.44), p = 0.001) and lower hospital costs
(mean per month costs of $984(SD $2,776)
vs. $5,195 (SD $7,353), p < 0.02). In addition,
overall, the cost of care in the last 6 months of life
remained relatively the same in the intervention
group ($1,550 4 months before death, $3,711 in
the final month), compared to a significant
increase in the control group ($2,631 4 months
before death, $17,006 in the final month). The
numbers included were for patients with a primary
diagnosis of cancer. This home-based palliative
program included in-home medical consultation,
ongoing evidence-based prognostication of fur-
ther survival, caregiver support, and advance
health care planning (Brian Cassel et al. 2016).

Kerr et al. compared the costs of a community-
based outpatient palliative care program featuring
a hospice-private payer partnership to propensity-
score matched control group, and found that
outpatients costs were significantly lower for
the intervention group at 2 weeks, 1 month,
and 3 months, no difference at 6 months, and
significantly higher at 1 year and 2 years (Kerr
et al. 2014). Lustbader et al., examined the effect
of a home-based palliative care program within
an Accountable Care Organization, compared
to usual care. The study found that the cost
per patient during the final 3 months of
life was $12,000 lower in the intervention com-
pared to control group ($20,420 vs. $32,420;
= 0.0002). This decrease resulted from a 35% reduction in Medicare Part A ($16,892
vs. $26,171; = 0.0037), and a 37% reduction in Medicare Part B ($3,114 vs. $4,913;
= 0.0008). The intervention group also resulted
in a 34% reduction in hospital admissions, a 35% increase in hospice enrollment, and a 240% increase in median hospice length of stay, com-
pared to usual care (Lustbader et al. 2017).

Pouliot found that, in a pre-post study evaluat-
ing the impact of a home-based palliative care
program, patients experienced decreased emergency department visits and inpatient hospital admissions (Pouliot et al. 2017).

In the study of concurrent palliative care embedded in oncologists offices described above, the practice was self-sustaining but may be difficult to sustain (Alesi et al. 2011). In our own practice (RR and TJS), billing revenues will cover at least half the salary (our arrangement with the institution) if the provider sees four patients; a busy practitioner see two new patients and four to six return visit patients in a half-day session and comes close to covering full salary.

It is important to recognize the importance of early versus late referral at their cancer in changing end of life practice patterns. At the UCSF Cancer Center, only 32% of decedents were referred to palliative care, with 68% referred less than 90 days before death (Scibetta et al. 2016). If the patients were referred 3 months before death, the health system saved $5198 due to fewer end of life hospital days with lower inpatient care costs ($19,067 vs. $25,754, \( p < 0.01 \)), while outpatient costs were no different.

Besides the timing of referrals, the number of outpatient visits plays a role in reducing aggressive care at the end of life and resultant expenses. As shown in Fig. 1, as the number of visits increased, less aggressive care near the end of life was provided (less chemotherapy in the last month of life; fewer emergency visits, admissions, and Intensive Care Unit admissions) (Jang et al. 2015).

### 3.2 Cost Effectiveness of Home-Based Palliative Care (Canada)

Most figures from Canadian studies are 5–10 years old; therefore, there is a need for an updated cost-effectiveness analysis comparing home-based palliative care to hospital-based palliative care. Of note, while all hospital-based services are covered under public health insurance in Canada; home care and community care are only partially covered, depending on the province. For example, patients and families in Ontario cover 25–50% of the total costs (Dumont et al. 2009).

While models of palliative care exist across Canada, there are disparities and gaps in access across regions. One study compared costs of 6 months in a palliative care program in an urban versus rural setting and found that the total cost per patient was $26,652 in urban areas (with families covering 20.8% of the costs), while $31,018 in rural areas (with families covering 21.9% of the costs) (Dumont et al. 2015). Notably, these figures reflect inpatient, outpatient, and home-based palliative care, aggregated. Urban families tended to cover more costs related to formal home care, while rural families tended to cover more costs related to prescription medication, out-of-pocket costs, and transportation (Jang et al. 2015). There have also been province-based studies accessing disparities. In Quebec, where home-based palliative care services are provided by the Public Local Community-Based Health
Care Service providers (Locaux de Services Communautaires [CLSC]), one study found large variation in delivery of these services to patients with cancer (Gagnon et al. 2015). Of the 53,316 cancer patients included in the study (representing patients with cancer who died in Quebec between 2003–2006), 52.1% received home visits during the 90 days before death, and of those, 72.5% received three visits or more.

The models of home-based palliative care programs have shifted over time. One study documented changing trends in services models from 2005 to 2015 in Ontario and found that the propensity and intensity to use home-based physician visits and personal support workers increased, while propensity and intensity of nurse visits deceased (Sun et al. 2017).

Regarding the cost effectiveness of these services, several studies have captured the impact of certain models of care on system costs. Klinger et al. tested a model of home-based palliative hospice care in Ontario (Klinger et al. 2013). The study found the average costs were approximately CAD$117.95 per patient day or a total of CAD$17,112.19 per patient over the 15-month study period. These findings are roughly equivalent to the Ontario Auditor General’s reporting that the average per day palliative care costs in the last month of a patient’s life is under CAD$100/day for home-based palliative care. Alternatively, the average costs of other palliative services were CAD$1,100 per day in an acute-care hospital bed, CAD$630 to $770 per day in a bed in a palliative-care unit, and CAD$460 per day in a hospice bed. There is incongruence regarding these costs. A 2010 report estimated that it costs approximately CAD$4,700 per client annually to provide palliative care in the home as compared to CAD$19,000 for acute care annually. A piloted palliative home care service that ran in Ontario from 2000 to 2001 cost CAD$5,586 per patient for a year. From a system perspective, a 2013 study in Ontario projected that expanding in-home palliative care to those currently not receiving such services (approximately 45,000 people per year) can avoid CAD$191 million to CAD$385 million in health care costs. Shifting just 10% of patients at end of life from acute care to home care would save CAD$9 million a year.

A study of palliative care costs in the last 5 years of life among patients in Halifax, Montreal, Winnipeg, Edmonton, and Victoria found that the mean total cost of outpatient palliative care increased by 70% from the first to the last month of life, and the mean total cost of home care was 4.5 times higher during the last month of life compared to 5 months before death. While costs for transportation gradually increased, costs of prescription medications decreased from the fifth to the second last month of life, and costs of medical equipment increased from the fifth to the third month but then decreased from the third to the last month before death (Dumont et al. 2010).

Few Canadian studies have accessed the costs of home-based palliative care from a societal perspective, which considers third-party insurance payments, travelling expenses, caregiving time devoted to patients and missed time from work and leisure. Yu et al. investigated the differences in societal costs of end-of-life care associated with hospital and home deaths, and found that there was no significant differences in total societal costs; however, the higher hospitalization costs for hospital death patients were ultimately equivalent to the unpaid caregiver time and outpatients service costs for home death patients (Yu et al. 2015). Diving deeper into the distribution of societal costs, Dumont et al.’s study of resources utilization during the palliative phase of care in five regions in Canada found that the costs across inpatient hospital care stays, home care, and informal caregiving time were paid for 71.3% by the public health care system, 26.6% by the family, 1.6% by not-for-profit organizations, and 0.5% by other payers. The majority of costs supported by the family were attributable to caregiving time (66.3%), followed by out-of-pocket costs (17.0%), home medical equipment or aids (6.7%), and home care (4.4%) (Dumont et al. 2009).

Further investigating the source of these non-public system expenses, Chai et al. interviewed 169 caregivers of patients receiving home-based palliative care as well as abstracted
data on health care utilization of patients. This study determined that the average monthly cost per patient for these services over the last 12 months of the patient’s life was CAD$14,924 per patient (2011 Canadian dollars), which broke down into 77% unpaid caregiving cost (i.e., caregiver time lost from market labor and leisure) (CAD$11,334), 21% publicly financed health care costs (i.e., costs incurred by the public sector in the organization and delivery of home-based palliative care services) (CAD$3,211), 2% privately financed costs (i.e., out-of-pocket costs for expenditures on consultations with clinicians, travel expenses, private insurance plans supplementing public insurance) (CAD$379). The study also found that the magnitude of costs increased exponentially over the last 12 months of life. A previous study by the same group found that the mean monthly cost per patient for services over the last 12 months of life was CAD$24,549 (2008 Canadian dollars), which broke down into 70% unpaid caregiving cost ($17,184), 26% publicly financed health care costs (CAD$6,396), 4% privately financed costs (CAD$870) (Guerriere et al. 2010).

3.3 Cost Effectiveness of Home-Based Palliative Care (Australia)

A systematic review and meta-analysis of the impact of community specialist palliative care services found the evidence to be inconclusive regarding whether the impact these services have on home deaths, symptoms, and costs. Importantly, none of the studies in this review found a significant effect in favor of an alternative intervention (Luckett et al. 2013). Kralik et al. compared home-based palliative care service utilization among patient with cancer and non-cancer conditions and found that patients with cancer were referred earlier, patients with non-cancer conditions were higher users of home-based palliative care services over a longer period of time (Kralik and Anderson 2008). An Australian home-based palliative care model was found to cost AUD$3,489 per patient, which was largely offset by lower mean inpatient care costs (AUD$2,450), resulting in a net incremental cost of AUD$1001 per patient (McCaffrey et al. 2013).

4 Highlighting of Organizations that Have Been Successful in Their Implementation of Outpatient Palliative Care

4.1 Johns Hopkins Medicine Palliative Care Program (Baltimore, USA)

Palliative care delivery at Johns Hopkins began at the Sidney Kimmel Comprehensive Cancer Centre (SKCCC) with outpatient palliative care, which was run primarily by pharmacy for cancer patients for three half days a week. Once two fulltime palliative care providers joined the hospital, physicians co-led the clinic with pharmacy, and the program also included access to a psychology nurse liaison, social workers (to address psychosocial issues and hospice referrals), and one chaplain. Often there were palliative care fellows staffing the clinic for half the year along with pharmacy residents and pharmacy students. The number of outpatient visits that were billed increased from 200 to over 1000/year from 2011 to 2016.

In 2013, the program developed a half day clinic for non-oncology patients, including those with severe neurological disorders, mitochondrial diseases, chronic obstructive pulmonary disorder (COPD), pulmonary hypertension, and cirrhosis. Due to funding, this clinic for non-oncology patients is only provided by a palliative care physician and an additional palliative care fellow for half the year. The program consults with all patients prior to left ventricular assist device (LVAD) and heart transplant, and periodically sees patients with pulmonary hypertension, heart failure, and liver disease in embedded clinics with the respective teams. Across inpatient and outpatient services, the program uses the modified Memorial Symptom Assessment Scale Condensed (MSAS-C) for symptom assessments, spiritual, psycho-social assessments, as well as...
engages in prognosis evaluation after speaking with specialists. Over half of the patients in the program are primarily referred to receive symptom management; the remaining patients primarily are referred for either goals of care discussions and/or evaluation for hospice.

We have recently estimated the total impact of the palliative care program on the health center, and 2016 activity should save the institution nearly five million dollars (Isenberg et al. 2017) (Fig. 2).

With the increased acceptance of palliative care at Johns Hopkins Medicine among providers, coupled with increased institutional buy-in and more and more accountable care organizations, the program is in the process of developing home-based palliative care with an already established geriatric home-based care program, JHome. This multiprogram collaboration involves stakeholders from home care, geriatrics, pharmacy, business development, and the hospital’s financial analysis unit.

<table>
<thead>
<tr>
<th>Financial impact</th>
<th>Cases/year projected 2016</th>
<th>Financial impact per case</th>
<th>Contribution ($/year)</th>
<th>5 year total contribution</th>
</tr>
</thead>
<tbody>
<tr>
<td>IP PCU margin (1)</td>
<td></td>
<td></td>
<td>$100,000</td>
<td>$500,000</td>
</tr>
<tr>
<td>IP PCU cost $1595 savings/transfer (2)</td>
<td>154</td>
<td>$1,595</td>
<td>$245,630</td>
<td>$1,228,150</td>
</tr>
<tr>
<td>PC IP consult cost savings per case, $2,374 for patients discharged alive (3)</td>
<td>1355</td>
<td>$2,374</td>
<td>$3,216,770</td>
<td>$16,083,850</td>
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<tr>
<td>PC IP consult cost savings per case, $6,871 for decedents, 11% died (4)</td>
<td>167</td>
<td>$6,871</td>
<td>$1,147,457</td>
<td>$5,737,285</td>
</tr>
<tr>
<td>JHFAU vetted savings</td>
<td></td>
<td></td>
<td>$4,709,857</td>
<td>$23,549,285</td>
</tr>
<tr>
<td>Early PC OP consult cost savings per case. $5198/case – if seen 3 months before death compared to near death</td>
<td>297</td>
<td>$5,198</td>
<td>$245,630</td>
<td>$34,355,000</td>
</tr>
<tr>
<td>Hospice referrals cost savings per case, $4348/case; assumes half of the actual savings of $8697 in the last year</td>
<td>800</td>
<td>$4,348</td>
<td>$3,478,400</td>
<td>$17,392,000</td>
</tr>
<tr>
<td>Professional fees, 50% collection rate</td>
<td></td>
<td></td>
<td>$500,000</td>
<td>$2,500,000</td>
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<tr>
<td>Improvement in HCAHPS (2% of Medicare reimbursement in 2017).</td>
<td></td>
<td></td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>Increased ICU bed availability leading to revenue</td>
<td></td>
<td></td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>Reduction in 30 day readmissions</td>
<td></td>
<td></td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>Goodwill; impact on disparities; charitable contributions</td>
<td></td>
<td></td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td><strong>Total impact</strong></td>
<td></td>
<td></td>
<td><strong>$13,643,744</strong></td>
<td><strong>$101,345,570</strong></td>
</tr>
</tbody>
</table>

IP palliative care; IP inpatient; PCU palliative care unit; JHFAU Johns Hopkins Fiscal Analysis Unit; HCAHPS Hospital Consumer Assessment of Healthcare Providers and Systems

Fig. 2  Financial impact of the palliative care program on the health system, projected to 2016
The outpatient program has encountered some challenges, in particular approximately 25% of outpatient visits are no shows. To address this issue, one of the program’s administrative assistants calls patients 2 days before scheduled visits to confirm attendance. This process has decreased no show rates by approximately 25%. The program sees over 1000 patients/year with 468 unique medical record number visits, which are either new visits and/or patients who have not been seen in a year. They have half day clinics for patients with cancer 3 days per week and a half day clinic for patients who have non-cancer diagnoses. Outpatient palliative care program accounts for 14% of the total program work Relative Value Units (wRVUs). The program expects each provider to meet wRVU goals and to cover at least half their salaries and benefits, with the hospital absorbing the rest.

It is critical to bill and collect appropriately for professional fees or the program will not succeed. We show two “Levels of Care” billed by two practitioners who saw patients of similar severity. Provider one – based on chart review and time spent with the patient – is not billing enough to cover his/her salary. Note that provider B documented her time consuming, difficult medical decision-making visit in subsequent visits with the 99233 code (Fig. 3a, b).

The Harry J. Duffey Family endowed the Palliative Care Program at the cancer center, which has now spread across all disciplines. There is an endowed annual lecture on “Hope” and an endowed professorship in Neuromodulation with emphasis on Scrambler Therapy (Majithia et al. 2016). A memorial service is held yearly at the cancer center, and one for all the patients who have died on the Osler Medical Service. Scholarly activities have included the updating of the national clinical practice guidelines in palliative care (Ferrell et al. 2017; Levy et al. 2016); communication in the neonatal intensive care
4.2 The Symptom Management Service at the Helen Diller Family Comprehensive Cancer Center, UCSF (San Francisco, CA)

The Symptom Management Service (SMS) is the clinic-based palliative care program at UCSF’s comprehensive cancer center. The SMS provides comanagement with the oncology teams. The majority of referrals are for pain and depression. Approximately, 60% of patients in the SMS have metastatic disease. The SMS was launched in 2005 in Genito-Urinary Oncology with a single half-day clinic staffed by a palliative care physician and social worker. In 2008, the SMS was available to patients throughout the cancer center. Currently, the SMS has grown to offer 25 half-day clinics weekly across both cancer center campuses. In 2017, the SMS had 605 new patients and 1,436 follow up visits. The program includes physicians (1.9 FTE total across 7 physicians), a nurse practitioner (1.0 FTE), a nurse (1.0 FTE), a program coordinator (1.0 FTE), a practice manager (0.5 FTE), and a chaplain (0.2 FTE). Among SMS staff, physicians are supported from clinical billing revenue. All other staff are supported by the medical center. Social workers are shared with the cancer center programs, as are psychologists and nutritionists. The SMS trains palliative care fellows, oncology fellows, medical residents, medical students, nursing students, and pharmacy residents. SMS clinics are primarily stand-alone but with an expanding number if embedded clinics, including in Breast Oncology and Gastrointestinal Oncology.

The SMS primarily has served patients with solid tumors (the top referring programs are Breast, GI, and GU oncology) but is currently expanding with 2 half-days embedded in the Bone Marrow Transplant Clinic (at yet a third UCSF campus). The SMS program includes annual memorial services at two cancer center campuses, a video legacy project for patients, cancer center awards to leading faculty and staff, and a campus-wide lecture series. The SMS oversees inpatient palliative care services at the affiliated cancer hospital. At UCSF, in addition to outpatient palliative care for cancer patients provided by the SMS, inpatient palliative care is available at the main university hospital; there is a home-based palliative care service for UCSF patients in San Francisco county, and an outpatient palliative care clinic for non-cancer patients will be launching soon.

SMS research has demonstrated improved clinical outcomes in nearly all symptoms assessed and persistence of benefit over more than 80 days (Bischoff et al. 2013). Patients have similar improvement regardless of gender, age, ethnicity, disease stage, disease progression, and concurrent oncologic treatments. In another study, clinician and financial outcomes were explored among UCSF patients who died of cancer. Patients who received palliative care early (in the SMS, prior to 90 days before death) had improved end-of-life outcomes, health care utilization, and total costs compared to patients who received palliative care late (within 90 days of death, primarily from inpatient palliative care consultation).

4.3 Temmy Latner Centre for Palliative Care at Sinai Health System (Toronto, Canada)

The Temmy Latner Centre for Palliative Care (TLCPC) is a department in Sinai Health System (Toronto) that began in 1989, initially providing both hospital and home-based care with a team comprised of one physician, a clinical nurse specialist, social worker, and two chaplains. Co-founded by Dr. Larry Librach and Dr. Frank Ferris, the program is the first and largest organized home palliative care program in Ontario (Temmy Latner Centre for Palliative Care 2015). As of 2015, the program has 21 physicians on staff (17 in the Home-Care program and 6 in...
the In-Hospital Care Program), 2 full-time equivalent (FTE) coordinators, and 3.8 FTE staff (Seow et al. 2013). The program receives referrals from physicians across the Greater Toronto Area. As of 2017, the program includes: a home-based palliative care program serving residents of the Greater Toronto Area, a 32-bed inpatient palliative care unit, and inpatient consultation services within the Sinai Health System. The home-based care program partners with community agencies (i.e., Community Care Access Centres) to provide multidisciplinary palliative care in the home, and there is a physician available to patients 24 h a day, 7 days a week. In addition to the care it provides, the clinicians in the program assist with education providers at Mount Sinai Hospital, as well as providing training in palliative care to all medical students and many postgraduate medical trainees in many specialties at the University of Toronto.

Seow et al. evaluated the effectiveness of the home-based palliative care program comparing 676 patients who received home-based care from TLCPC from April 2009–March 2011, to a comparison group of patients matched on demographics and primary diagnoses. The study found that compared to the control group, TLCPC patients had a 30% (relative risk = 0.70) lower risk of being in the hospital in the last 2 weeks of life, a 35% (RR = 0.66) lower risk of dying in the hospital, a 53% (RR = 0.47) lower risk of visiting an Emergency Department in the last 2 weeks of life, and a three times (RR = 3.02) greater risk of dying someplace outside of the hospital (Seow et al. 2013) A study of patients in this program found that the average monthly cost for these services over the last 12 months of the patient’s life was CAD$14,924 per patient (2011 Canadian dollars), which broke down into 77% unpaid caregiving cost (i.e., caregiver time lost from market labor and leisure) (CAD$11,334), 21% publicly financed health care costs (i.e., costs incurred by the public sector in the organization and delivery of home-based palliative care services) (CAD$3,211), 2% privately financed costs (i.e., out-of-pocket costs for expenditures on consultations with clinicians, travel expenses, private insurance plans supplementing public insurance) (CAD$379) (Chai et al. 2014).

4.4 Outpatient Specialist Palliative Care Clinic, Scarborough, North Yorkshire, England

The specialist palliative care clinic in Scarborough via Scarborough General Hospital (SGH) serves a population of about 220,000 across a mixed urban-rural setting. This program is associated with Hull York Medical School and is in partnership with Saint Catherine’s Hospice. The hospice is an independent charity and gets 70% of its funds from the community donors. The rest is provided by the NHS. Patients have access to lymphedema clinic, complementary therapy, and those in the area have access to bereavement services. They have a community specialist palliative care nurse advisory service including a neurology palliative nurse specialist. In addition, they provide an out of hours phone advice service for patients and relatives and non-palliative care health care professionals which also acts as a liaison point for those at home who may need a medical visit from the GP out of hours service. Patients do not need to be otherwise known to the hospice to be registered for this service. They have an active education center which seeks to upskill non-palliative care clinicians who do the bulk of generalist palliative care, including running 2-day advanced communication skills courses. Palliative care providers are employed by the hospice and NHS Trust and work together as one team across all the settings – hospital, community, and hospice. This ensures continuity of care in all settings. There is excellent integration with oncology, cardiology, movement disorder clinic, neurology, and respiratory medicine. The group uses a needs-based model rather than a prognosis-based model in all aspects of the service. In the UK, the term end-of-life indicates someone with a prognosis of 6–12 months.

5 Blueprint of How to Make Outpatient Palliative Care Sustainable and Replicable

From our clinical experiences, the following are key tips that can help to create and/or enhance outpatient and home-based palliative care...
delivery: 1. Train your team in standardized care that includes goals of care discussions. This means to acknowledge barriers to engaging in these conversations, convince all providers to engage in Advance Care Planning (ACP) such that the difficult discussions are had, and add communication prompts (e.g., communication checklist or even a temporary tattoo (Leong et al. 2016)). The prompts can be built into your electronic medical record system. Use systematic way to assess systems such as a spiritual distress scale, a symptom assessment scale like the Edmonton Symptom Assessment Scale (ESAS). Train all providers in how to complete (and then measure, for program impact) other possible outcomes like the Physician Orders for Life Sustaining Treatment (POLST) completion, hospice referrals, and readmissions.

Second, obtain buy-in from leadership and administrators by asking them what matters most and measuring your impact on it. One qualitative study interviewed clinical and operations leaders at local, regional, and national levels in the US Veterans Health Administration (VHA) to gauge organizational factors that were potentially influencing the adoption of outpatient care in chronic illness. Participants perceived outpatient palliative care as a lower priority for them because there are not sufficient performance measures to gauge improvement nor incentivize update of palliative care. Participants expressed that their buy-in would be increased if were demonstrated to them that the costs of the program offset health service utilization costs, and that issues regarding staffing and space requirements were being sufficiently addressed. Participants were also concerned that palliative care be done as complimentary to other forms of care, to ensure that clinicians did not feel threatened by the palliative care team; building clinician trust and buy-in is perceived as integral, as well as clarifying the roles and responsibilities of outpatient palliative care and primary/specialty care for disease management in advanced chronic illness (Bekelman et al. 2016).

Third, do not be isolated; interface with the larger organization. It is important to align the patient-centered symptom management goals of outpatient and home-based palliative care with the organization’s financial interests, as it may enable more budgetary, political, or operational support (Cassel et al. 2015). Promote the program to providers in the institution to help increase referrals to the program. To do so, it is important to build relationships with providers, as well as educate providers about palliative care processes (e.g., what is involved, how to refer).

Fourth, make the referral and consult process as easy as possible. Make sure the process is as streamlined as possible. Remember to ALWAYS send a letter to the referring doctor to close the loop. It usually takes 3 min in EPIC or Cerner. When interacting to a patient’s other providers in the organization, engage in conversations about prognosis – make sure you obtain permission to discuss prognosis from the involved surgeon or oncologist, as well as the patient.

Fifth, consider with whom to partner. Existing inpatient programs may be convinced to enhance outpatient palliative care programs through the consideration that they help to prevent over-utilization of the costliest health care services, which typically get provided at end-of-life. These programs also help to prevent readmissions and 30-day mortality admissions, which many hospitals in the USA and elsewhere are penalized for in-payment models. The business case is often the easiest to make! Other potential partners include: local meals on wheels program, hospital bed supplier, and personal support worker (i.e., home health aides, community health worker) agencies.

Sixth, make sure your own team is interdisciplinary as that is where much of the evidence of beneficial impact lies, not with individual palliative care providers (Ferrell et al. 2016). At the team level, give team members feedback and performance reviews based on evidence like Fig. 3 above; budget time and finances for travel; monitor team burnout; and facilitate team building exercises (e.g., the group at Hopkins has a bi-monthly palliative care movie night. As you see more complex and difficult patients, develop strategies for dealing with complex patients. Some hints include the following (Text Box 1).
Text Box 1: Dealing with Difficult Families or Patients

- Build rapport – ask about joys (e.g., family)
- Address symptoms first – always the easy place to start
- Set expectations
- Figure out their goal
- Involvement with case management, social workers, and other supportive staff
- Notes – show data as to why you are making a recommendation
- Discuss coping strategies
- If family/caregiver is present, ask how they are coping too
- See regularly – monthly
- Email between visits
- Collaborate with specialists about care

Billing, income, and costs are crucial to long-term institutional support. Go after professional fees as appropriate, and in the USA, use the new Advance Care Planning codes which encourage physicians to document and bill for ACP discussions. Remember, though that while savings are system wide and might accrue to the ICUs, neurology, and home care, the costs are localized and usually come from one cost center. Plug into national/regional groups like Center to Advance Palliative Care (CAPC) for knowledge sharing and collaborations. Use the Center to Advance Palliative Care (CAPC) office and home-based program design toolkits. They provide all the information and tools you need to launch office and home-based palliative care programs.

Bull et al. synthesized and identified five key barriers to outpatient palliative care (Bull et al. 2012). While these five are specific to the USA, many of them translate to other settings.

1. Large scale organizational challenges may hinder services delivery (e.g., differences in provider subspecialization, operational challenges, and lack of sufficient palliative care-trained providers to deliver services).

2. Limited funding to cover the costs of outpatient palliative care. For example, in the USA, Medicare covers palliative care for people with clear terminal diagnoses but not for people with chronic conditions. In Canada, reimbursements for home-based visits do not adequately compensate for the time that providers may spend visiting with patients in their home and travelling to the homes.

3. There is a lack of a gold-standard business model for outpatient palliative care, which means that each organization offering the services must create a business case for senior leadership to justify the incorporation of the program.

4. The fragmentation of care across settings (i.e., from inpatient to outpatient care) can result in difficult coordinating outpatient palliative care post-discharge. Further, as patients with palliative care needs often have multiple providers, it becomes challenges for outpatient palliative care to coordinate services and reduce redundancies with more acute care specialists.

5. There is a shortage of palliative care-trained physicians, nurse practitioners, and other health professionals, which results in few providers able to deliver outpatient or home-based services, let alone inpatient services.

To aid success, consider process changes that can help to reduce financial losses that may impede the success of programs. For example, Bull et al.’s use of Quality Assessment and Performance Improvement Cycles allowed them to identify challenges and inefficiencies in the Four Season’s palliative care outpatient programs, develop strategies to overcome various barriers, institute said strategies and ultimately decrease...
financial losses by 40% (Kamal et al. 2011a, b) (Text Box 2).

Text Box 2: Ways to Improve Efficiency and the Bottom Line

- Do daily or weekly rounds for home-based patients (via teleconference) as needed to trouble-shoot
- Standardize the palliative care visit combining best practice components of care, identified by the National Quality Forum
  - For scheduling, 1 h for new patients, half hour for follow-ups
  - Keep an additional slot open for urgent appointments to avoid emergency rooms visits.
- Standardize data collection using established, validated data collection tools, and regularly aggregate and analyze the data. Bull and colleagues developed the Quality Data Collection Tool (QDACT), in partnership with colleagues at Duke University Medical Center. Use templates, Smart Phrases, and anything else that makes you more efficient.
- Increase referrals to palliative care by reaching out to providers across the health care system and other facilities
- Engage in several initiatives to increase referrals from palliative care to hospice (e.g., using quality metrics to track referrals, educating providers about referral process)
- Mentor providers to hone skills in palliative care delivery
- Introduce incentives to increase provider productivity and satisfaction (e.g., use of a nonfinancial bonus, extra paid time off, for providers who meet performance targets)
- Work to build a culture of accountability with regular performance reviews and sharing of team success
- Increase workforce to reduce provider strain and burnout

Text Box 2: Ways to Improve Efficiency and the Bottom Line (continued)

- Ensure that coding and billing are accurate by checking the billing, and engaging in education sessions
- Ensure that leadership time is best spent, and introduce administrators to perform administrative tasks, so that providers can focus on clinical work
- Clarify job expectations for providers and try to offload some of their non-clinical work to administrative staff

6 Conclusion

Community-based palliative care has become the focus of palliative care’s growth and opportunity. Twelve of the largest randomized control trials on palliative care are community-based and result in equal or greater survival, positive satisfaction from patients and caregivers, and equal or less cost. Surprisingly, sometimes the business case is the easiest to make (Cassel et al. 2015). With health care financing that embraces value-based programs such as shared savings, bundled payments, global budget revenues, community-based palliative care shows great promise and may be part of the solution to provide better care for patients at a cost we can afford.

References


Jang RW, Krzyzanowska MK, Zimmermann C, Taback N, Alibhai SM. Palliative care and the aggressiveness of...


