Evidence Snapshot:
End-of-life and outpatient palliative care

Questions

1. What are the existing and commonly used end-of-life (EOL) care and advanced care planning (ACP) options and their impacts on care and quality of life?
2. What are patient and family preferences at EOL?
3. How are outpatient palliative care clinics designed, and what are the barriers and successes associated with care delivery related to oncology patients?

Answers

1. Advanced written directives and do-not-resuscitate orders (DNRs) are widely used ACP forms, but there is room for expansion to ones that emphasize shared decision-making.
2. Patient-physician communication (empathy and pace) is integral in determining patient and family satisfaction with care. There are also opportunities to improve racial/ethnic disparities associated with EOL care, palliative care, and ACP usage.
3. An embedded, co-located model allows for more joint-specialty collaboration and continuity of care, however, there are physician-level barriers to ensuring timely referrals. Implementation of a predictive risk score could also help prioritize patients with the highest potential gains for ACP conversations and symptom management services.

Summary of evidence

1. Existing literature on ACP

According to a systematic review (113 articles published 2000-2012), which explored the effects of ACP, the most widely studied planning tools included: written advanced directives (34%) and DNRs (39%) (Winzelberg, Hanson, & Tulsky, 2005). Additionally, the settings most studied included hospitals (49%) or nursing homes (32%), suggesting an **opportunity to further explore the effects of ACP in the outpatient setting,** as well as **more complex advance care planning options** that establish a mechanism for shared decision-making (i.e. POLST forms).

2. Patient and family preferences

We identified four studies focused on patient and family preferences for severe or terminal illness, two of which had a focus on oncology. Unsurprisingly, while a **majority of terminally ill patients express a desire to die at home, inpatient deaths are more common, often coupled with increasingly complex and expensive care** (Dalal & Bruera, 2017; Winzelberg et al., 2005). Dalal and Bruera (2017) also found that bereaved families have negative associations with inpatient EOL care, late hospice enrollment, or no hospice enrollment.

Cultural differences also influence patient and family preferences at the end of life, and there are racial and ethnic disparities in who receives ACP and EOL care. Winzelberg et al (2005) found that Mexican-American and some Asian American groups of patients—compared to African Americans, Europeans, and Caucasian Americans—have historically been less likely to believe they, as patients, should be the ones making EOL decisions. In 2009, **81.9% of hospice enrollees were Caucasian and only 7.2% were African American** (Mazanec, Daly, & Townsend, n.d.).

Regarding what patients want to know when faced with a serious or terminal illness, **points of dissatisfaction associated with patient-physician communication include**: 1) patient was not involved in the conversation, 2) inadequate information was given to the patient and their family, and 3) when physicians display visible discomfort about sharing information (particularly prognoses) (Kirk, Kirk, & Kristjanson, 2004).

Three ways to improve quality of life at EOL include: 1) increased communication regarding prognosis, palliative care, costs of care, and psychological support; 2) personalizing care to address values and preferences (shared decision-making); and 3) fostering more coordinated care between different specialties, like oncology and palliative care (Dalal & Bruera, 2017).

3. Positive effects of ACP, EOL care, and outpatient palliative care

According to a systematic review that explored the effects of ACP and complex-ACP, there are promising findings related to health outcomes, quality, and utilization of inpatient services (Brinkman-Stoppelenburg, Rietjens, Van Der Heide, & Brinkman, 2014). For instance, **ACP has been associated with reductions in life-sustaining treatment and hospitalizations, and with increases in utilization of hospice and palliative care**. Examples of successful complex-ACP programs include: Let Me Talk program, POLST Forms, Let Me Decide program, Respecting Choices program, Making Advance Care Planning a Priority (MAPP) program, and other self-developed interventions such as the use of social workers. A documented benefit of palliative care is **improved quality of life for seriously ill cancer patients, which included physical and psychological metrics**, in addition to reduced direct and indirect hospital costs (Dalal & Bruera, 2017).

4. Barriers to outpatient palliative care - oncology

There are various barriers to accessing and implementing palliative care clinics for patients who may benefit from symptom management (Finlay, Rabow, & Buss, 2018). These barriers exist at three different levels: patient/family level, physician/oncologist level, and structural/environmental level.

Barriers for patients and families

- Stigma and associations with death
- Fear among racial and ethnic minorities that they are not being given the best level of care or appropriately aggressive treatment plans
- Ethnic/racial/religious cultural difference related to EOL care
- Transportation/physical access

Barriers for physicians and oncologists

- More likely to refer for pain and symptom management than for discussions about goals for care
- Perceived association with dying and hospice, paired with concern about patients' reactions to referrals
- Primary vs. specialty palliative care in oncology practice
- Inaccurate prognosis

Structural/environmental barriers

- Lack of availability or lack of timely access for referred patients
- Practice environments in which PC clinics only accept patients not receiving cancer-directed therapies
- Health services reimbursement structures/coverage criteria (e.g., Medicare 6-month)
- Time and resources available to train medical staff on ACP and EOL care

Barriers that may be easier to tackle from an administrative level include rebranding the term palliative care into terms such as "supportive care" or "symptom management." This could address the patient- and oncologist-level stigma associated with palliative care and dying, and also helps communicate that palliative care can be useful to patients in non-terminal stages of illness. Many of the oncologist-level barriers, and even some of the patient-level barriers, could be addressed with provider and patient education/engagement that is appropriately tailored according to the recipient's needs.

5. Designing an outpatient palliative care clinic

According to Finlay (2018), factors to consider in the design process of an outpatient palliative care clinic include the basic operational model (independent or embedded) and the referral process to be used to acquire patients.

Regarding operational models, in the **independent model, oncology care and palliative care operate separately, though some coordination can occur pending the staffing capacity of both departments**. An advantage of this is that both specialties have more control over their individual operations, especially the palliative care clinic, which might want to work with more interdisciplinary teams. For the **embedded model, the two specialties work side by side in a co-located or collaborative model**. This allows for real-time consultations and joint-specialty discussions about patient issues, which may lead to more consistent messaging to the patient from their care teams. However, further research is needed to assess how health outcomes differ according to the model within which patients receive care.

Regarding referrals, use of an embedded model appears to positively contribute to a smoother referral process and **early integration of palliative care into oncology treatment has been shown to lead to improved quality of life and symptom control** (Muir et al., 2010; Parikh, Kirch, Smith, & Temel, 2013). As stated previously, though, **a key barrier in accessing and referring to palliative care is its association with dying and the idea that palliative care is a component of oncology**, leading to late referrals by physicians (Einstein et al., 2017; Finlay et al., 2018). **One solution to reducing late referrals is the use of data-driven levers for referrals**. One study found promising (but non-statistically significant) results showing that use of the data trigger led to greater percentages of patients being referred to palliative care (Einstein et al., 2017).

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