Dana-Farber Cancer Institute

EXPERT REVIEW

Early Palliative Care as an Adjunct to Disease-Directed Care in Breast Cancer: Evidence and Opportunity

The content for this expert review document is based on a presentation by James A. Tulsky, MD, given on February 26, 2025.

Key Summary Points:

Responding to emotion in serious illness communication:

- **Recognize emotion as a barrier to reasoning**. Heightened emotions such as fear or anxiety make it harder for patients to process information and remember details. Slow down and adjust your approach accordingly.
- **Use empathic communication.** Look for verbal or nonverbal "empathic opportunities" and respond with empathic continuers, (e.g., "I can see this is overwhelming") rather than quickly shifting back to facts or treatment options.
- **Pair empathy with clear information.** Research shows that combining explicit prognostic details with empathic statements reduces patient anxiety and uncertainty while improving trust and satisfaction.
- **Don't avoid empathic communication due to lack of time.** Research shows that empathic responses add only 21 seconds to visits and significantly improve patient experience and trust.
- **Invest in practice and training**. Empathic communication is a learned skill. Training tools, coaching, and feedback can double the use of empathic responses and foster stronger patient-provider relationships.
- **Acknowledge your own emotions.** Being aware of how your feelings, e.g. fear, sadness, guilt, influence conversations can help you stay grounded, communicate clearly, and better support patients.

How to overcome mismatched expectations in serious illness communication:

- **Clarify treatment goals early.** Ensure that patients, caregivers, and providers explicitly discuss whether the primary aim is cure, life extension, or palliation before major decisions are made.
- **Identify decision influencers.** Recognize the role caregivers and family members play in shaping choices and avoid underestimating their influence. Even when rapport with the patient is strong, differing caregiver beliefs or priorities may strongly affect decisions and should be explored.
- **Align perspectives through open communication.** Proactively address differing expectations among patients, caregivers, and providers to build a shared understanding of the care plan.

How to overcome prognostic uncertainty in serious illness communication:

- **Assess understanding first.** Ask what the patient knows or expects to tailor the conversation.
- **Share clear, comprehensive information.** Use plain language and check comprehension regularly.
- **Explore priorities before options.** Uncover patient values and goals to guide decision-making.
- **Align recommendations with goals.** Frame treatment steps around what matters most to the patient.

How to learn and practice communication:

- **Communication is a skill that can be developed.** Approach it like any other clinical skill, with practice, observation, and feedback.
- **Use observation and self-reflection**. Ask a colleague to observe your communication, record sessions, or practice real-time self-monitoring to identify strengths and areas for improvement. Reflect on what went well and what can be improved.
- **Plan for continuous improvement.** Generate new strategies or approaches to try in future conversations, treating each interaction as an opportunity to refine skills.

Background

Palliative Care Overview

Palliative care offers relief from symptoms, pain, and stress that result from cancer or any other serious illness. The main focus of palliative care is to improve quality of life for both the patient and their family. It should be emphasized that palliative care is appropriate at **any age** and at **any stage** of illness. This does not mean that all patients need palliative care, but that the decision should be separated from a person's age or stage of disease. The decision to seek palliative care should instead be based on whether someone has specific needs that can be addressed. Palliative care can be provided together with cancer-directed treatment; there are no prognostic requirements and there is no need to choose between treatment options.

Hospice, on the other hand, is meant for those who are in their last weeks or months of life. There is a prognostic requirement, which is defined as less than 6 months. Hospice care offers additional services, some of which may be provided in the patient's home. To receive hospice care, patients may need to give up coverage for disease-directed treatments.

Evidence for Early Palliative Care in Cancer

When referring to early palliative care, we are generally referring to patients with metastatic disease who may have years to live. The evidence for early palliative care in cancer begins with a cornerstone study published in the New England Journal of Medicine in 2010 on "Early palliative care for patients with metastatic non-small-cell lung cancer" by Temel and colleagues, which reported two major outcomes.[1] The first showed that across a number of quality of life measures, patients in the palliative care arm showed improvement at 12 weeks compared to the patients receiving standard of care. In addition, the study also showed a 3-month survival benefit in the palliative care group.

The authors went on to repeat this study in a metastatic breast cancer population but did not find an improvement in quality of life. However, they reported more end of life discussions (67% vs 41%; p=0.006), more Medical Orders for Life-Sustaining Treatment forms completed (39% vs 14%; p=0.002), and a greater rate of hospice enrollment (39% vs 14%; p=0.002) in the palliative care arm versus the usual care arm.[2] To date, this is the only randomized clinical trial on palliative care in the breast cancer population. A multi-center, retrospective cohort study examining 340 patients with metastatic breast cancer was undertaken in twelve French cancer centers between 2019 and 2020 and found that patients who received palliative care more than a month before their death were more likely to receive less chemotherapy.[3]

A retrospective review looking at goals of care and advanced care planning among adolescents and young adults (AYA) with cancer who were approaching the end of life also found that earlier discussions about supportive palliative care may reduce late-life intensive measures.[4] The authors looked at the last documentation of goals of care and compared them to the treatment received at the end of life. In the patient group who said that their goal was to receive care focused on palliation and/or quality of life, 29% (319) ended up in the intensive care unit and 32% (285) had more than 1 ER visit in the last 30 days of life, suggesting that these are the patients that we may need to focus more on.

In a literature review, Rosenberg and Wolfe describe the benefits, needs, and challenges of palliative care for AYAs with cancer.[5] The authors concluded that, based on the evidence, there is a need for more primary palliative care education for oncology teams, comprehensive symptom assessments, the development of standardized referral criteria, more open and timely prognostic conversations with AYAs, and increased multidisciplinary support. There are major research gaps in this population and new research pursuits are strongly encouraged. Table 1 offers a list of suggested priorities based on Rosenberg and Wolfe's review of the literature.[5]

Table 1: Research Priorities for Adolescents and Young Adults (AYAs) with cancer who were approaching the end of life.

1) Assessing:
   - unmet needs (eg spiritual, existential distress)
   - AYA experiences in the era of targeted therapies,
   - polypharmacy
2) How to support transitions of care
3) Best practices in supporting AYA quality of life during survivorship.
4) Understanding the impact of cancer on children of older young adults
5) Understanding methods of palliative care delivery

Source: Rosenberg AR, Wolfe J. Palliative care for adolescents and young adults with cancer. Clin Oncol Adolesc Young Adults. 2013;2013(3):41-48. doi: 10.2147/COAYA.S29757. Epub 2013 Mar 24. PMID: 29657924; PMCID: PMC5898449.

Why Palliative Care Works

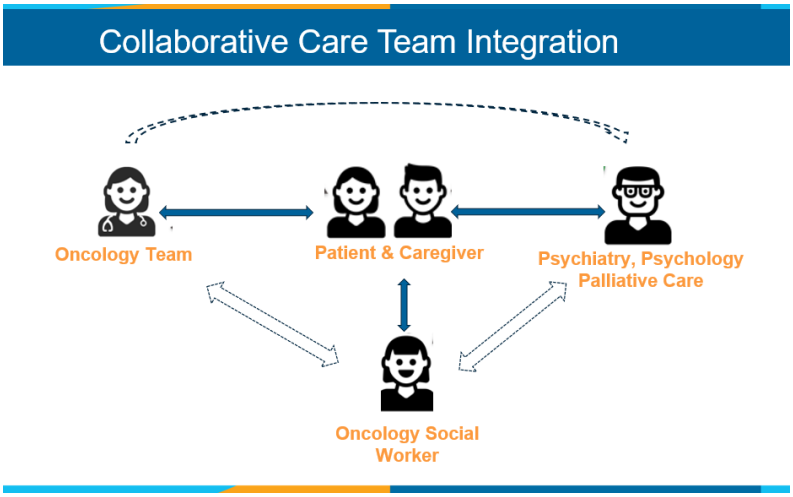
Palliative care providers, as well as oncology providers, actively manage symptoms and perform psychological assessments. The difference is that oncology providers also monitor patient's treatment, drug interactions, trial protocols, and so on. When patients see palliative care providers, symptom management is the key focus of their care. This division of labor allows for a more specialized focus. Palliative care providers may have more time to help patients tolerate strong and often oscillating emotions, and to teach patients coping and shared decision-making skills. Finally, they can titrate discussions to enhance prognostic awareness within tolerable limits; this is a key point since people have varying levels of prognostic awareness, and prognostic awareness can change over time.

Models of Care

A Specialty-Aligned approach[6] has been commonly used in palliative care, which suggests that palliative care interventions are most effective when they are aligned in the context of a particular specialty or a specific population. The idea behind the Specialty-Aligned Palliative Care model is that:

1) The palliative care team is embedded in the specialty (i.e. they participate together in education, training, co-rounding, out-patient visits, and have frequent communication between clinicians).
2) Early engagement is encouraged (e.g., at any age, any stage, upstream of decisions, and prior to end of life).

3) It is an interprofessional palliative support team (e.g., MD, NP, PA, social worker, chaplain).
4) There is longitudinal continuity (i.e. the same clinicians across care settings. Success is often based on how well the team knows each other and how familiar they are with the disease).



The Palliative Care team at Dana-Farber Cancer Institute has developed the Supportive Oncology Collaborative Model which is specialty-aligned (i.e., disease-center aligned) and includes patient screening and tracking (rather than referrals) to ensure greater access for those in need. The model includes resources that can be deployed more efficiently in a stepped-care approach to those who need services. The model is evidence based and has been proven to be effective, with over 100 randomized controlled trials demonstrating its effectiveness in supporting mental health. The model is also measurement-based and will treat to target, by including metrics such as pain, depression, and anxiety scores.

Under the Supportive Oncology Collaborative Model, there is a comprehensive evaluation of all distressed patients by a Social Worker using standardized validated instruments. Initial plans of care are then initiated, which include counseling and behavioral interventions as well as referrals to palliative care and other specialties. Weekly case rounds (similar to tumor bords) are held with Social Work, Psychiatry, Psychology, and Palliative Care where all participants discuss and determine the patient's plan of care. The plan of care may include behavioral therapy, medication recommendations, team interventions, further medical evaluation, etc. Patients are followed over time and if they are not improving (based on objective measures), a re-evaluation is undertaken.

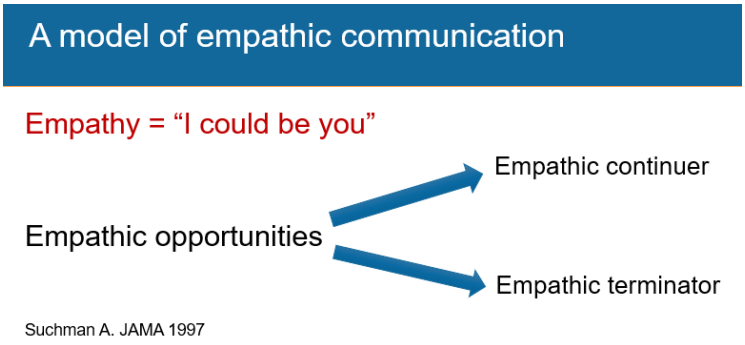
Serious Illness Communication: Data and Pearls of Wisdom

It may sometimes be difficult for providers to have conversations with patients about their goals of care and future plans. Sometimes, providers may have trouble bringing up the topic of palliative or end of life care, either because they are uncomfortable themselves or the patient avoids the topic. In breast cancer specifically, the pace of disease is different from other cancers and can be much slower, making the right time to discuss palliative care and end of life care difficult. The sections below address the key barriers that need to be overcome in these difficult discussions: emotion, mismatched expectations, prognostic uncertainty, and a lack of cognitive framework.

How to respond to emotion in serious illness communication:

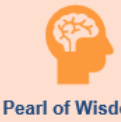
A substantial body of research shows that when people are in a heightened emotional state, the reasoning centers of the brain are less effective, making it more difficult to process information and make decisions. Studies also demonstrate that heightened emotions, such as anxiety, can impair memory and therefore reduce a patient's ability to recall details discussed during a medical conversation. As a result, engaging in complex or high-stakes discussions with patients in such a state can be challenging, and may require additional strategies to ensure understanding and informed decision-making.

To overcome these communication barriers, the **model of empathic communication**[7] has been widely used. The definition of empathy in this context is the sense that "I could be you". When a provider feels empathy, it means they have some sense of what the patient is going through. The expression of empathy happens when they are able to convey that sense to someone. The model of empathic communication suggests that there are empathic opportunities that arise in conversations that providers have with patients. Sometimes they are obvious, like a patient admitting that they are scared, and sometimes they can be subtle. When an empathic opportunity arises, a provider can respond with an **empathic continuer,** for example "I can see this is overwhelming for you" or "this must be really hard". The other option is to respond with an **empathic terminator,** where the provider stops the conversations and moves on to providing the patient with information.



Van Vliet et al.[8] tested the model of empathic communication in a study that used recordings of an oncologist speaking to a patient with breast cancer. They created four different videos of the oncologist providing the patient with different amounts of explicit prognostic information and using various levels of empathetic statements. The researchers showed the video to 51 breast cancer survivors, asking them to rate the doctor and measure their own levels of uncertainty, anxiety, self-efficacy, and satisfaction. The video that had the lowest uncertainty and anxiety and the highest self-efficacy and satisfaction was Video 1, which used explicit information about the prognosis coupled with empathic language. Some would have guessed that Video 3, with limited explicit information but high empathy language, would have scored better, but it left the participants feeling uncertain. The video with the lowest level of explicit information and empathic content performed the worst.

Video 1: Explicit + and Empathy+
Video 2: Explicit+ and Empathy-
Video 3: Explicit- and Empathy+
Video 4: Explicit- and Empathy-



Patient emotion often masks as a cognitive question

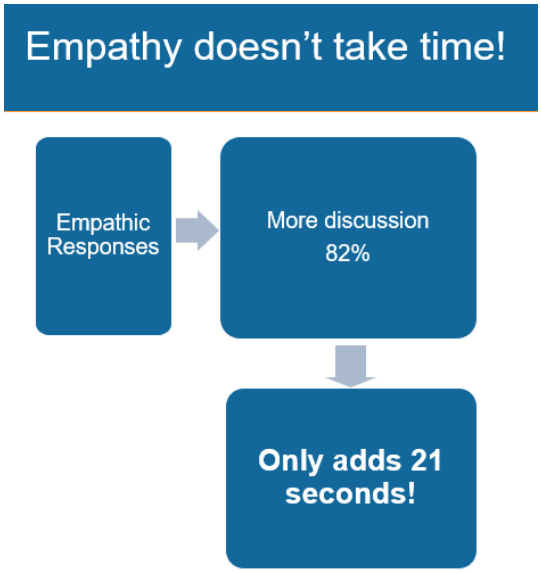
In some patient settings, providers will be asked "isn't there something else you can do?!" Instead of replying with "there are some clinical trials, but I don't think that you'd be eligible," try replying with "I can't even imagine what it's like hearing this news." If a provider hears the question as a factual cognitive question and responds cognitively, they will most often not address the root intention of the question, which is the patient's expression of emotion. Expressions of emotion are best responded to with an emotion managing statement.

Finally, empathy in provider-patient communication should not be viewed as a kindness; it can be kind, but that is not the sole purpose. Instead, it is a way to effectively have tough conversations and manage your patients.

What happens in practice?

One study[9] examining oncologists' reactions to cancer patients' verbal cues found that when an empathic opportunity arose, oncologists responded with empathic language (continuers) only 28% of the time. A similar study,[10] with a larger number of patients (n=51) and oncologists (n=51), found almost identical results, with only 27% of oncologists responding with continuers.

These studies show that providers most likely know they should be doing this, but they are not doing it nearly enough. The most common concern for using empathic language is that the visit will take too long. This concern was measured by Kennifer et al.[11] who looked at the difference in the visit time when providers used empathic responses. They found that empathic responses led to more discussion 82% of the time but only added 21 seconds to the visit.



In the SCOPE study,[12] oncologists were taught empathic communication skills through a 1-hour online learning tool. The study results showed that the intervention doubled the number of empathic statements oncologists used and doubled the number of times oncologists responded to empathic opportunities with empathic language. The study demonstrated that this can be an easy, learned behavior that can change practice. The study also reported that there was a statistically significant increase in patients' trust when their oncologist received the training compared to oncologists who did not.

These studies show that, in practice, this type of communication is effective in advancing conversations and fostering trust between providers and patients. It is important to recognize that providers' own emotions can also shape these interactions. For example, feelings such as fear, guilt, or sadness may influence the way information is shared and decisions are framed. By acknowledging and managing these emotions, providers can communicate more clearly, remain sensitive to patient needs, and create a supportive environment that encourages openness, mutual understanding, and shared decision-making.

How to overcome mismatched expectations in serious illness communication:

Differences in expectations can arise when patients and their families hold ideas or perceptions that do not align with those of the provider. These differences can lead to misunderstandings, reduced trust, and challenges in making collaborative care decisions.

A recent study[13] looked at 70 triads of patents, caregivers, and oncologists taking care of a variety of advanced cancers. The study focused on a recently made treatment decision, usually at the time of the subsequent visit after a therapy change decision was made. The study measured whether or not the patient, the caregiver, and the oncologist agreed on the goal of treatment (i.e., cure, longer life, or palliation) and how influential the caregiver was in decision-making.

The study results showed that out of the 70 triads, only 28 triads (40%) agreed on the goal of treatment, with the most common goal being to live longer. When asked about the influence of the caregiver, the oncologist was more likely to underestimate the importance of their role in decision-making.

Pearl of Wisdom

Clarify goal of treatment before decision-making

Pearl of Wisdom

Know who's influencing the decision

It is important for providers to ensure that the treatment goals are clearly discussed and agreed upon by everyone involved in the patient's care, and to be aware of who may be influencing the decision-making process. For example, a provider may have an excellent rapport with the patient, yet the caregiver, who may hold different beliefs, priorities, or concerns, could significantly influence the final decision. Recognizing these dynamics early allows providers to address differing perspectives, promote open communication, and help align all parties toward a shared understanding of the treatment plan.

How to overcome prognostic uncertainty in serious illness communication:

In serious illness communication, prognostic uncertainty refers to the difficulty of predicting exactly how a disease will progress or how long a patient will live, even with the best available data. This uncertainty is influenced by several challenges.

First, statistical measures such as median or mean survival can be misinterpreted, where patients may see a median survival time as a precise prediction rather than the midpoint of a range. Also, referring to the "tail" of the curve, i.e., patients who live much longer or shorter than average, can lead to either unrealistic hope or undue discouragement if not explained clearly.

Second, numeracy impacts communication. Patients and families may vary in their ability to understand and interpret numbers, probabilities, and risk, especially when under emotional stress. This can result in over- or underestimating their prognosis or treatment benefits.

Finally, changing science adds another layer of complexity, as medical advances and new treatments can rapidly alter survival outcomes, making providers hesitant to offer definitive predictions.

Prognostic awareness often functions like a pendulum for patients, with many constantly vacillating between believing their hopes are more likely to be realized (e.g., "maybe I will live 10 more years") and feeling those hopes are less attainable. The degree of realism patients have about their prognosis can vary widely, and it is not uncommon for a provider to feel aligned with a patient during one conversation, only to find that at the next visit their perspective has shifted significantly.

This fluctuation is a normal part of the process, and providers should be prepared to navigate these changes over time, understanding that flexibility, patience, and repeated conversations are often necessary.

Offer plain language explanations about prognosis

Addressing prognostic uncertainty requires transparency about what is known and unknown, clear explanations of statistical concepts in plain language, and guidance that help patients plan for a range of possible outcomes while maintaining trust and fostering shared decision-making.

How to overcome a lack of a cognitive framework in serious illness communication:

While there is a paucity of cognitive frameworks that can effectively guide conversations around serious illness, the frameworks that do exist have a number of common attributes, including:

1) **Assessing Understanding**: Prior to providing the patient with prognostic information, it is important to assess what the patient already knows. This is a great opportunity to ask the patient questions such as “what are you thinking?” or “what are you expecting?” The answers may help providers tailor the discussion to the patient’s level of understanding, while also providing the opportunity to clarify misconceptions and ensure that the information shared is both relevant and meaningful.
2) **Sharing Information**: The focus here is on providing information that is both comprehensive and easy to understand, ensuring patients receive the full picture without feeling overwhelmed. Use plain language and avoid unnecessary jargon and complicated statistics. Check frequently for comprehension.
3) **Exploring Priorities**: Invite the patient to talk about what matters most to them. Ask open-ended questions such as “what is most important to you right now?” or “what are you hoping for as you think about your care?” This step helps uncover the patient’s values, preferences, and goals, which can then guide treatment planning and decision-making.
4) **Recommending Next Steps**: After understanding the patient’s knowledge and priorities, outline clear and actionable next steps. Summarize the key points discussed and explain the treatment or care options available, highlighting how each aligns with the patient’s goals. Provide guidance on immediate decisions as well as what to expect in the near future. Reinforce that the care plan is flexible and can be adjusted as needs and preferences evolve.

Many providers often reverse steps 3 and 4, presenting treatment options first and discussing patient preferences after. A more comprehensive approach is to begin with a shared understanding of the prognosis and then ask, “given what we know, what is most important to you?” From there, treatment options can be framed in the context of those goals. This method not only centers the patient’s values but also helps narrow the focus by removing options that do not align with their priorities.

How to learn and practice communication:

Communication is a skill that is learned and refined over time. Strong communication abilities are developed through observation, practice, and constructive feedback. Just like how top athletes or musicians work with coaches to continually improve, health care providers benefit from ongoing guidance to identify strengths and areas for growth. Below are some practical tips to help strengthen communication skills:

- Ask someone to observe you (and tell them what to watch for, like the use of empathic language during the visit).
- Record yourself.
- Become a real-time self-observer (some providers can get to a point where they can watch themselves communicate in real-time and make course corrections).

It is also helpful to debrief after a communication by reflecting on what went well in the interaction, what might have been done differently, or where you got stuck in the conversation. This reflection will help you better understand what happened during the conversation and consider what else can be tried next time. Additionally, seeking out formal courses, either online asynchronous or in-person may be beneficial for providers to improve their communication skill set. Many such courses exist, particularly through VitalTalk (a non-profit focused on serious illness communication).

Take Home Points

- Early palliative care improves quality of life, possibly survival, and decreases non-beneficial healthcare utilization at end of life
- Palliative care works through symptom management, enhanced coping, and cultivating prognostic awareness
- Ideal care models are population-based, interdisciplinary, and specialty-aligned
- Emotion clouds decision-making; empathy moves conversations forward
- Communication skills are enhanced through observation, practice, and feedback

Guidance Statements

The guidance statements in this expert review can be subject to future variations and periodic updates based on new research. Therefore, the information provided in this document should not be considered as being complete or inclusive of all available information. This information does not mandate any particular course of medical care and is not intended to be a substitute for the independent professional judgment of a health care provider. The document does not represent the official institutional position of Dana-Farber Cancer Institute.

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