




# Family Meetings in Palliative Care: Benefits and Barriers

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## Opinion statement

Specialists in palliative care view the family meeting as a means to engage patients and their families in a serious illness discussion that may clarify the values of patients and caregivers, provide information, determine care preferences, and identify sources of illness-related distress and burden. The family meeting is considered the best practice for achieving patient- and family-centered care in palliative care. Although studies of the family meeting are limited, those extant suggest that these interventions may reduce caregiver distress, mitigate the perception of unmet needs, prepare family members for caregiving, and improve bereavement outcomes. The experience of palliative care specialists further suggests that the family meeting may reinforce the therapeutic alliance with families, promote consensus, and reduce the need for ad hoc meetings. Physician satisfaction may be enhanced when the treatment plan includes the opportunity to show empathy and see the family's perspective—core elements of the clinical approach to the family meeting. In the oncology setting, the potential to achieve these positive outcomes supports the integration of the family meeting into practice. Clinical skills for the planning and running of family meetings should be promoted with consideration of a standardized protocol for routine family meetings at critical points during the illness and its treatment using an interdisciplinary team. Further research is needed to refine understanding of the indications for the family meeting and determine the optimal timing, structure, and staffing models. Outcome studies employing validated measures are needed to better characterize the impact of family meetings on patient and family distress and on treatment

outcomes. Although better evidence is needed to guide the future integration of the family meeting into oncology practice, current best practices can be recommended based on available data and the extensive observations of palliative care specialists.

## Introduction

Clinicians often meet with patients and families to provide information, answer questions, clarify goals, elicit treatment preferences or obtain consent, and offer instructions for caregiver interventions. These meetings, which are often ad hoc and at the convenience of the physician, may not address highly sensitive issues, such as those arising when breaking bad news or changing treatment approaches in the context of futile therapy [1••]. Meetings of this type often require follow-up visits or calls to address questions or concerns raised by family members who were not present for the original discussion. This common approach to the family meeting—limited preparation, no preplanned agenda, attendance that may or may not include surrogates or important caregivers—often suffices for information exchange and support when clinical management is routine and outcomes are expected [1••]. It is a part of clinical practice, and clinicians may experience little challenge from the communication required.

When the clinical scenario is complex or fraught, however, or when risks are high or prognosis is limited, the family meeting becomes challenging and potentially stressful for the oncologist or other health professionals [1••]. Strong communication skills are needed when the discussion touches on end-of-life concerns, and the clinician should be able to focus discussion on specific outcomes or decisions, while mediating disagreements and promoting consensus. The ability to manage acute distress is necessary, if it emerges in an emotionally charged situation. These types of family meetings often occur in the context of serious chronic illnesses such as cancer, particularly at critical times—diagnosis, recurrence, or a life-threatening complication—or when progressive disease heralds the death of the patient [2].

In the latter context, family meetings are a means to engage in a serious illness conversation with patients and caregivers. Like other serious illness conversations, these meetings call for a planned approach that considers who the attendees should be, what topics should be covered, and what outcomes should be targeted. This type of family meeting is now considered a best practice

by specialists in palliative care and an essential forum for goals of care discussions and advance care planning [2]. Early studies of the family meeting in the critical care setting [3, 4] provided a foundation for the types of approaches preferred by palliative care providers today. Although subsequent research has been limited, the available empirical findings support the conclusion that well-conducted family meetings yield positive outcomes in the setting of advanced illness.

As palliative care becomes increasingly integrated into oncology practice, the role of the family meeting during cancer care may mirror the approach endorsed by specialists in palliative care. Oncologists should be aware of the potential benefit inherent in family meetings that yield serious illness discussions, that are organized ahead of time, and that include the patient, appropriate surrogates, and caregivers and usually more than one treating professional. These meetings have an agenda and a set of expected outcomes. They may impact the plan of care, offer the opportunity to provide information, and provide support during difficult times for both patient and family.

The planned family meeting may address an array of problems and concerns experienced by caregivers. As patients experience the direct impact of cancer and participate in repeated treatment protocols, the responsibilities of family caregivers will increase while resources to support them often remained limited [5]. Family caregivers may help the patient with activities of daily living or with shopping, cooking, and cleaning. They may accompany the patient to medical appointments and be responsible for acquiring health-related information and communicating this information to other family members. Instrumental tasks and the need to support the patient emotionally usually increase in the setting of advanced illness and may result in high caregiver distress and burden when associated with unmet informational and emotional needs [6••]. Specific information gaps reported by caregivers include inaccurate understanding of the patient's medical condition and prognosis, inconsistent information from the medical team, confusing

information and terminology, and unclear treatment goals [7]. The care plan may be perceived as insufficiently respectful of the family's cultural traditions and values.

Family meetings may promote emotional adjustment for caregivers in cancer, while lowering burden, depression, and psychological distress [8••]. Family members benefit from the focused time with the oncologist. They usually value having a clear picture about the patient's prognosis, disease course, and anticipated side effects. When planned and well-conducted, the family meeting also can strengthen the therapeutic alliance with the oncology team; provide a forum for clear communication regarding the patient's diagnosis, goals of

care, and treatment plan; and establish a process by which the oncology team can provide caregivers with direct psychosocial support [6, 8]. Information obtained during a family meeting may afford the caregiver more time for preparation and emotional adjustment [9]. Information can give caregivers a greater sense of control and mastery, promote treatment decisions that align with the patient's and family's values and priorities [9], and potentially prevent unnecessary calls to the oncology team and trips to the hospital [10]. Oncologists who can employ a structured approach to the planning and running of family meetings may be less likely to experience the distress that can accompany challenging discussions with patients and families [11].

## Research on the family meeting

Empirical work to evaluate the process and outcomes associated with the planned family meeting has included qualitative studies and quantitative studies using observational or quasi-experimental designs. Although the available data are limited, they support the potential for positive outcomes noted by palliative care specialists who embrace the planned family meeting as standard practice.

The types of caregiver needs that may be addressed through planned family meetings have been highlighted through qualitative and observational studies in varied populations. Most of the early studies were completed in ICU settings in Australia [9, 12]. A recent review of 50 quantitative, qualitative, and mixed-methods studies evaluating end-of-life care in the intensive care unit, for example, found that interventions undertaken by staff to improve end-of-life outcomes may be ineffective if they are not guided by family members' reported needs and perceptions [13]. An exemplar qualitative study employed dyadic semi-structured interviews to investigate how patients with advanced illness and their primary caregivers experienced decision making when shifting to comfort-focused care. It concluded that consistent information about the patient's health status, trust in healthcare providers, attention to advance care planning, and acknowledgement of the terminal nature of the illness all helped to facilitate a salutary shift to acceptance of comfort-focused care [6••].

The literature generally supports the conclusion that planned family meetings can improve communication about goals of care, patient diagnosis, and extent of illness, future complications, and prognosis [14]. This communication may be experienced by caregivers as demonstrating empathy from the medical team. Studies of family meetings suggest they can reduce caregiver distress [15, 16], lessen perceived unmet care needs [16], better prepare caregivers for tasks [16], and promote better bereavement outcomes [17]. One study found that caregivers reported a sense of comfort following discussions that were transparent and fully explored treatment options [9].

A prospective observational study was undertaken to determine if family meetings conducted by palliative care specialists met the information needs of individuals identified by cancer patients as their spokespersons. Seventy-eight caregivers participated, most of whom were the adult children of the patients. Meetings usually took place at the patient's bedside and had a median duration of 45 minutes. Nearly all the family caregivers found the meeting valuable, in that their information needs were met and their distress decreased or remained stable. Thematic analysis of the data supported the value of family meetings in advanced cancer [18].

The utility of telephonic and telehealth interventions has also been examined. A randomized controlled trial evaluating a nurse-led early palliative care telehealth program for patients with advanced cancer in rural New England (Project ENABLE III) included a structured intervention targeting the needs of caregivers. The intervention focused on telephonic support, trained caregivers in stress management and coping, caregiving skills and organization, and preparing for the future. Caregivers receiving the intervention had lower depression and stress burden scores than those who did not [19, 20]. A study of video consultation for these caregivers is underway [21], and promising results using comparable technology have been reported in the UK [22].

A recent study that included patients hospitalized during the COVID-19 pandemic tested a telemedicine intervention for electronic family (e-family) meetings [23]. Caregivers' ratings of the e-family meetings were high for the ability to ask questions, satisfaction with the ability to express thoughts and feelings, helpfulness in clarifying understanding of the patient's care, and trust of the clinical team. This type of technology-enabled, structured family meeting may address the findings of a more recent study of surrogates of critically ill patients hospitalized during the pandemic. The convenience sample of surrogates identified four major challenges: communication with the medical team, communication among family members, understanding and tracking medical information, and distress related to visitor restrictions. Family satisfaction was related to being able to reach the medical staff, while Facetime contact greatly alleviated caregiver distress [24].

It is possible that planned family meetings in the context of advanced illness may reduce unnecessary hospitalization at the end of life. A quasi-experimental comparison study in Northern Taiwan evaluated whether palliative family meetings held within 7 days of admission to the medical intensive care unit reduced healthcare costs for patients who died [25]. The family meetings were associated with the decision to withdraw futile treatment and complete a "do-not-resuscitate" order. These changes were associated with a 40% reduction in healthcare costs. Future studies of family meetings involving cancer patients with a poor prognosis should evaluate these economic endpoints.

## Clinical implications

The key elements of effective family meetings have been proposed based on extensive clinical experience and limited empirical data [26••]. These elements include specific processes, timing considerations, and staff involvement.

## Important processes

**Preparation.** Information is needed when planning a family meeting for discussion on serious illness. If the patient has decisional capacity, he or she should indicate the family members who should be present. If the patient is unable to participate, the family members can choose to meet at the bedside or in an alternative space. The current medical condition of the patient should be confirmed prior to the meeting, and if input from other clinicians is needed to clarify treatment options, this information should be obtained before the meeting. Some clinicians employ a pre-meeting questionnaire completed by the patient or family to help make the meeting more family-centered and highlight the topics or concerns that are most important [3]. The professional team that will be present for the meeting should agree on the agenda for the meeting. If the objectives for the meeting include specific outcomes, such as an advance directive or a treatment decision, the team should be aware of this prior to the meeting.

**Setting the agenda at the start of the meeting.** The meeting leader should explain the purpose of the family meeting and ensure that all participants understand and agree. This helps to organize and prepare the patient and family for the topics to be discussed.

**Family meetings often begin with questions that solicit understanding of the patient's condition.** A helpful communication approach employs "Ask-tell-ask". The clinician asks the patient/family their understanding of the medical condition. Following the response, the clinician empathetically clarifies and expands on the information provided. This may require direct statements about disease progression or complications. The information presented may be followed by a question that allows the patient or family to reflect on their understanding or their reaction to the information. The clinician may respond to emotion by validating, naming, and aligning with the patient/family using statements such as "I wish we had a therapy to make you better" [26••].

**Reviewing patients' goals of care and treatment options.** Many planned family meetings focus on goal-setting. Goal-setting discussions may address a decision to accept another therapy for the disease or shift to palliative care without disease-modifying treatments. The outcome of these discussions follows the sharing of medical information about the potential benefits and burdens of treatments, the recommendations of the physician, and clarification of the patient's views about therapeutic trade-offs. Questions are addressed to support decision making.

If there are no viable disease-modifying therapies, the goal-setting focuses on what may now be most important to the patient and family and what are perceived to be unmet needs requiring help. In the latter scenario, the discussion may turn to hospice as a source of supportive treatments in the home. Part of the discussion may focus on specific wishes expressed by the patient and desires that can be addressed in terms of feasibility and support for what is possible.

**Concluding the meeting and planning follow-up discussion.** The family meeting often concludes with a summary by the meeting leader that reflects on the update of the medical condition, the patients' reactions and questions that have been answered, and the clarifications that have emerged about the goals of care and treatment options. The plan of care going forward should be briefly described. If a follow-up meeting is needed, the plan to schedule it should be suggested.

## Timing

A planned family meeting may be scheduled routinely, at defined points after cancer treatment begins, or scheduled in response to specific triggers. Routine family meetings may be part of early routine palliative care in patients with cancer, the implementation of which may be facilitated by patient and family education [26••]. Early family meetings may help patients and families engage with advance care planning, make careful goal-centered treatment decisions, and take care of important medico-legal decisions, such as creating a will.

Examples of triggers include recurrence or a life-threatening complication, or when a change in the patient's medical status suggests that a decline is likely. Other triggers may be the need for a challenging treatment decision or the development of disagreement among family members and clinicians regarding the patient's prognosis, the goals of care, or treatments [26••]. Another approach to a triggered family meeting is based on the assessed risk of decline or in anticipation of family challenges related to a transition in care.

## Staffing

The family meeting may be led by the oncologist, the palliative care physician, or other members of the palliative care team such as the nurse and the social worker. An interdisciplinary staff attendance is advisable given the complexity of the issues discussed. Nurses are sometimes called upon to lead the meeting and are well-qualified to do so [27]. A recent study used a modified Delphi method to specify the nurse's contribution to family conferences in Japan, and identified their contribution in three main domains: preparation for the meeting, discussion and facilitating meaning during the meeting, and follow-up after the meeting. The study also yielded the Nursing Practice Scale for End-of-Life Family Conferences, which can be replicated by others [28]. Nurses develop rapport with the patient and family over multiple interactions, they are helpful to patients and families in digesting complex medical information, and they bring extensive knowledge of community resources and ongoing care needs to the clinical encounter. In addition, nurses have benefitted from successful skills-based training programs in palliative care and communication [29–31].

Social workers also contribute meaningful skills to the family meeting in palliative care. Social workers are well-trained in family communication, psychosocial support, patient- and family-centered care, and managing family and team conflict, which can greatly assist the oncologist. In addition, social workers are skilled in accessing community resources and entitlements which promote coping for patients and caregivers, alleviate burden, and encourage follow through for treatment recommendations [32, 33].

Leading a family meeting requires considerable flexibility to ensure that patients, caregivers, and staff have the opportunity to express their point of view. During the meeting, other staff contribute as necessary to facilitate discussion, answer questions, clarify care plans, and provide support [33, 34].

## Barriers and challenges

Family meetings are labor intensive and require clinical skill, administrative support, and willingness on the part of patients and families. In reviewing clinical experiences across many countries, it is evident there are common



barriers and challenges to integrating the family meeting into oncology practice [35, 36].

Oncologists cite lack of training as a barrier to communication with patients and caregivers. Lack of confidence in communicating bad news, sharing prognostic information, and initiating advance care planning has been identified [37, 38]. Oncologists also report finding these conversations stressful and may express concern about destroying hope for patients and families [39, 40].

Lack of time is another frequent barrier as there is generally no set time for the family meeting within the context of a busy oncology practice. Scheduling conflicts and challenges in arranging interdisciplinary participation are frequent challenges. Identifying who should schedule the family meeting and which disciplines should participate may be unclear. Although several studies show promise in using specially trained nurses to conduct family meetings and advance care planning conversations, some nurses also identify concerns about the lack of training in completing goals of care meetings [28].

Lack of reimbursement for the family meeting is an additional barrier to their widespread use. Researchers have not yet determined the cost, cost savings, and revenue generating potential of the family meeting, which makes administrative buy-in difficult. Oncologists report the low rate of reimbursement for supportive care to patients and the non-existent reimbursement for clinical time with caregivers [36]. This makes it challenging to make a business case for administrative help. Insufficient infrastructure and administrative support may undermine widespread implementation of family meetings in oncology [36].

The low level of evidence related to the effectiveness of family meetings is a final impediment to their widespread adoption. Studies are needed to clarify the optimal timing, clinical approach, key outcomes, and costs. Integration of the family meeting into oncology practice will be facilitated by studies that specifically evaluate caregiver-reported outcomes (such as satisfaction, distress, and bereavement adjustment), use validated tools to measure caregiver outcomes, use a more structured, standardized approach, and design implementation trials to test clinical practice interventions [7, 40, 41].

## Relevance to oncology practice

The use of planned family meetings as a means to engage in serious illness discussions is a best practice for specialists in palliative care [42]. Although the existing studies of the approach provide limited information, the data available support clinical observations for positive outcomes, particularly for family caregivers. As early palliative care plays a greater role in the routine management of cancer patients, the planned family meeting is among the specific interventions that deserve consideration as an adopted best practice in oncology [12, 37, 43, 44]. The family meeting is a communication strategy that can efficiently exchange information, promote shared decision making, and mitigate caregiver burden. In our experience, the family meeting is most effective with the presence of an interdisciplinary team that includes the oncologist, the palliative care specialist, the nurse, and the social worker. Moreover, training programs show promise in providing oncologists with communication and palliative care skills which enhance patient and family care [11, 45]. These outcomes are particularly salient for cancer patients, who experience the

potential for progressive disease, adverse impact on function imposed by the cancer itself or its treatments, and the continuing need for complex care planning, decision making, and implementation, for their caregivers, and for the oncologists, who bear responsibility for their ongoing management.

## Declarations

### Conflict of Interest

The authors declare no competing interests.

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