

# Conducting a Family Meeting

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The material in this booklet has been organized to prepare you for participation in the MSKCC Comskil Training module about Conducting a Family Meeting. It is important that you review this material before attending the training. The following sections are contained in this booklet

- I. Learning Objectives
- II. Background to Conducting a Family Meeting
- III. Typical Sequence of Strategies for the Conduct of a Family Meeting in Oncology
- IV. Goal and Core Communication Components of Conducting a Family Meeting
- V. Preparatory Homework
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## I. LEARNING OBJECTIVES

After completing this training module, you will:

- understand the importance of family-centered care and the complexity of facilitating a family meeting.
- understand the challenges of engaging and supporting the family in the care of the patient with cancer.
- understand the goal and core communication components of conducting a family meeting in the cancer and palliative care setting.
- have practiced or observed the skills and process tasks necessary for the successful facilitation of a family meeting in the cancer and palliative care setting.

## II. BACKGROUND TO CONDUCTING A FAMILY MEETING

Family meetings in oncology occur most commonly in the setting of an inpatient admission or with progression of advanced disease, where the support of the family in the planning of disposition and continuing care is vital to optimize the care of the patient. Such meetings are much less common in early stage cancers, unless in the pediatric or genetic counseling setting. Here we describe a model of conducting the basic family meeting, often co-facilitated by an oncologist or physician and a social worker or psychiatrist. Where a greater level of concern exists for the family as a unit, referral to the MSKCC Family Clinic in the Counseling Center can lead to either formal family or couples therapy.

### *Sources of caregiving support – who is family?*

The family is a crucial resource for patients living with cancer and facing life-threatening illness. Family members often serve as primary caretakers; they guide the provision of support for



loved ones during their final days of life, actively participate in decision-making processes and serve as liaisons and proxy informants to health care practitioners. The journey of illness is thus a shared one, resonating powerfully across the family group. Distress reverberates through the family, leading to recognition of the principle that members are second-order patients within a model of family-centered care.<sup>1</sup> As a result, practitioners and researchers alike have taken an interest in understanding how the family accommodates the strain of serious illness, and in identifying ways to ensure their optimal functioning. This attention to the family has been a striking development over the 50 years since Arthur Sutherland at Memorial Hospital first described cancer in a family context, drawing attention to the intimate reciprocity of suffering.<sup>2</sup>

As caregiving has been progressively transferred into the living room, the roles of family carers have become more pronounced. The principal caregiver is the spouse in 70 percent of cases, children (daughters and daughters-in-law predominate) in 20 percent, and approximately 10 percent comprise friends or more distant relatives.<sup>2,3,4</sup> The family comprises a fictive kin – namely, whoever the patients say their family is. Hence, visiting relatives from overseas, best friends, same-sex partners, or neighbors of those without direct kin could all be involved if they contribute to care giving and support of the patient.

#### *The resilient family*

Resilience can be defined as a positive adaptation arising in a setting of significant adversity, so that the family is seen to strengthen its functioning to the benefit of its membership and community. Central family functions include (a) cohesion, membership and family formation (e.g., Is the family able to maintain a sense of belonging, personal and social identity for its members?); (b) economic support (e.g., Is the family able to provide for basic needs of food, shelter and health resources); (c) nurturance, education and socialization (e.g., Is the family able to affirm social values, foster productivity and compatibility with community norms?); and (d) protection of vulnerable members (e.g., Is the family able to protect members who are young, ill or disabled?).<sup>5</sup> Thus, the adaptive family is able to re-organize its roles, rules and interaction patterns to ensure adequate care and protection of an ill member. Family assets empower growth and transformation via a style of functioning in which members communicate effectively, provide mutual comfort and support and resolve any differences of opinion through flexibility and buoyancy.<sup>6</sup> Resilience is a likely outcome for those families who believe that strength is derived from teamwork, adversity is a shared challenge to be overcome together and their optimism and spirituality delivers new meaning that transcends suffering.<sup>7,8</sup>

#### *The family considered to be "at risk"*

Observational studies of families during palliative care and bereavement led Kissane and colleagues to develop a typology that defined families at risk of morbid outcome during bereavement.<sup>9,10</sup> Poor family cohesion, communication and conflict resolution were determinative of this classification which, in turn, was highly predictive of psychiatric disorder occurring during bereavement for the membership of these families. Dysfunctional families fell into two types, the first fractured, argumentative and help-rejecting; the second sullen, depressed but help-accepting. An intermediate type between well functioning and dysfunctional families had mid-range communication, restricted cohesion and also carried high rates of psychosocial morbidity among members.

Where it is recognized that these families are at greater risk for morbid outcome during palliative care, a preventive model of family therapy commenced while the cancer patient was still alive has been shown in a randomized controlled trial to ameliorate the distress of bereavement for the survivors and support their overall adaptation.<sup>11</sup> This may be an important approach as Higginson and colleagues recently conducted a meta-analysis of 26 studies of palliative and hospice care teams and contrasted a slightly positive effect size on patient symptom outcomes [26 studies, weighted mean 0.33, SE 0.12 (95%CI 0.10, 0.56)] with no proven benefit on caregiver and family outcomes [13 studies, weighted mean 0.17, SE 0.16 (95% CI -0.14, 0.48)].<sup>12</sup> Palliative care as a discipline understands the need for family-centered care, but has struggled to find an effective model to accomplish this comprehensively.

How then do clinicians recognize these families in greater need? While resilient families do well and are not in need of additional psychosocial resources, families with some limitation in their functioning as a group – reduced communication, limited teamwork and prominent conflict – are worthwhile referring for prophylactic family therapy in the palliative care setting.<sup>13</sup> Sometimes a basic family meeting clarifies these relational characteristics and helps to have the family agree to accept help through referral for ongoing work together. Additionally, families where members are already distressed, having suffered cumulative stress, loss and tragedy, profit by early family therapy referral.

#### *Range of family needs*

Systematic reviews of interventions to support family caregivers<sup>14,15</sup> have identified the following challenges to optimally informing caregivers about their role: conspiracies of silence about the prognosis, the timing and amount of information to be delivered, overcoming impaired concentration, avoidant responses, not wanting to bother or outright rejection of the health provider's help. Health systems, in their turn, need adequate staffing, skill training, educational materials and a model of delivering carer training to achieve the desired goal.

Clarity about the content of carer educational sessions is derived from nursing research into the key roles and tasks undertaken by carers in the home as they assist a dying relative: symptom assessment and management, medication administration, help with ambulating, transferring the patient in and out of bed, dressing the patient, liaising with doctors, meal preparation, transportation, and coordinating visits from volunteers and friends to achieve respite for the carer.<sup>16-18</sup> Information needs stand out as the key unmet need in assisting carers' preparation for these roles, thus helping to minimize their burnout and exhaustion.<sup>19-21</sup>

Family education about caregiving is a fundamental service requirement that is applicable to families whose relative is at home, but also relevant to the family of an inpatient. A number of these inpatient families might be preparing for an eventual death at home. In addition to information about caregiving roles as described above, discussion of the emotional demands of the role, the importance of self-care and respite as needed, what to expect as dying approaches, how to manage a home death, how to talk to the patient about death and dying, the process of saying goodbye, the positive aspects of caring, sharing the role among family and friends, and when to seek help are all potentially relevant issues.<sup>22</sup>

Families with special needs include those with young children losing a key parent or where a single parent is dying and will leave children orphaned; families with elderly dying parents while also burdened by physically handicapped or mentally ill offspring; and families that are isolated through migration or in some way disenfranchised from relatives and support. Listening to a family's story and assessment of its needs is a crucial clinical task.

### *Facilitation principles in conducting a family meeting*

Facilitators of a family meeting do well to join initially with each person present through a round of introductions which identify names, ages, occupations, place of residence and relationship to the ill person. Agendas and expectations of meeting together are also fruitfully shared so that all concerns are placed initially on the table at the beginning of the conversation. Linear questions tend to be used here as an exchange between facilitator and individuals speaking about their personal point of view. Facilitators wisely avoid taking sides with individuals expressing contentious issues, lest loss of neutrality damages their ability to guide the family-as-a-whole to their preferred solution.<sup>23</sup> For this module, we introduce some advanced communication skills: circular questions, reflexive questions, strategic questions and summary of family-focused concerns. Each of these is defined and explained below.

**Circular question:** Circular questions explore the current patterns of functioning for the family. To ask a circular question, ask each family member to comment in turn on aspects of others to promote curiosity and reflection by the group as a whole. E.g. "How are your parents and sisters coping with Dad's illness? Who is most upset in your view?"<sup>24</sup> The use of circular questions is a communication skill through which the facilitator preserves neutrality and promotes the family's search for a solution from among its members.<sup>24</sup> Using such circularity, each member can be invited to express an opinion about the needs, functioning, health or interaction styles of other members of the family unit. Thus, "Who talks to whom about the patient's illness?" "Who is most stressed?" "How will the family cope?"

**Strategic questions:** Strategic questions are intended to stimulate change for the family. A strategic question is one that incorporates into the wording of the question guidance for the family toward an outcome that is considered preferable. E.g. "What change in Dad's symptoms would need to occur for you to realize that admission to an inpatient hospice bed is necessary?"<sup>24</sup> As facilitators embed a potential solution into the wording of a question, it becomes strategic in style as a communication skill. Thus, "Is it possible that sharing feelings together will help you grow closer?" Strategic questions can also harness a direction of change: "What might help motivate your son to stop smoking?"

**Reflexive questions:** Reflexive questions invite the family to reflect on possibilities, hypotheses and a range of outcomes to stimulate their internal efforts to improve family life. E.g. "What benefits might come from caring for Dad at home?" "In what ways might this be hard for you as a family group?"<sup>25,26</sup> Reflexive questions promote greater family understanding and insight, serving a catalytic function for the family. There is generally a better outcome for the family as a group when more problem solving is done by the family rather than the clinician.

**Summary of family focused concerns:** A useful communication skill to promote movement toward consensus for the family is for the facilitator to offer a summary that reflects the tension between two or more points of view aired by members. The family's views are reflected back to

highlight levels of tension or discordance in different member's opinions, while maintaining professional neutrality, yet inviting further problem solving by the family. E.g. "As a family, you recognize your father's desire to die at home, your mother's commitment to meet his wishes, and yet your concern is there that his confusion is becoming unmanageable and a burden to your mother. There is no easy answer here, as whichever solution you adopt will appear to demand more of each of you for a time." The goal is not to offer a solution, but to make explicit the advantages and disadvantages of the options, while leaving the choice blatantly as the family's. Further problem solving and consensus-building is then evoked from the family. In circumstances involving future treatment recommendations or avoidance of futile care, the clinician may wish to make a firm recommendation. Delaying delivery of this for a time while searching for their point of view may allow the family to reach that position readily and with greater acceptance than were the outcome imposed without the deliberation that can come from partnership statements.

#### *Key process tasks in conducting family meetings*

Set-up of the meeting: Identifying who are the important relatives that need to be present and who are the influential relatives that may bring wisdom and value to the session? Will the patient contribute usefully and be important to include? What are the barriers to meeting? What clinical staff will be needed to address medical, nursing, psychosocial and spiritual issues?

Co-facilitation: Are there key medical agendas that differentiate from psychosocial needs and should these be separated as distinct agendas for different phases of the meeting? Co-facilitators need to talk about their respective roles and the order of approach before the meeting starts. Medical issues place a greater emphasis on education, planning and clarifying, while psychosocial issues place more focus on listening, empathic skills, and fostering a sense of support. The tenor of these phases of the family meeting can be distinctly different and hence the wisdom of structuring the session to complete one domain before moving to an exploration of the other.

Cultural sensitivity while avoiding collusion: Clarify the family's detailed understanding of the illness and its treatment, its progression and seriousness, their values and religious beliefs, and the appropriate goals of care for this stage of illness. Identify points of consensus and dissonance.

Understand the family's strengths and vulnerabilities: Family traditions, norms and values can be harnessed when recognized as strengths and balanced with their worries and concerns. Achieving understanding of the reality of their family life is vital to pragmatic planning for their future.

Deliver resources as appropriate: Educational materials, DVD or web-based resources, visiting nurse referrals, information sources, home health aides, activity of daily living assessments and occupational therapy aides, community volunteers, psychosocial services, chaplaincy services - a host of resources as needed.

### III. TYPICAL SEQUENCE OF STRATEGIES FOR THE CONDUCT OF A FAMILY MEETING IN ONCOLOGY

Where a physician and psychosocial clinician plan to co-facilitate the meeting, there should be agreement before starting as to what steps each will take responsibility for.

1. Planning and prior set-up to arrange the family meeting
2. Welcome and orientation of the family to the goals of the family meeting
3. Check each family member understands the illness & its prognosis
4. Check for consensus about the current goals of care
5. Identify family concerns about their management of key symptoms or care needs
6. Clarify the family's view of what the future holds
7. Clarify how family members are coping and feeling emotionally
8. Identify family strengths and affirm their level of commitment and mutual support for each other
9. Close the family meeting by final review of agreed goals of care and future plans

### IV. GOAL AND CORE COMMUNICATION COMPONENTS OF CONDUCTING A FAMILY MEETING

Goal: To optimize the care of both the patient and their family through the conduct of a routine family meeting that promotes communication and increases understanding about a) the disease; b) its course and prognosis; c) the key goals of care, and d) assessment of the family's needs, strengths, coping, decision-making capacity and wishes for the future. In the palliative care setting, the creation of a comprehensive care plan that the family understands and agrees with will facilitate teamwork and enhanced coping for all concerned.

Strategies	Skills	Process Tasks
Planning and prior set-up to arrange the family meeting	Clarify Invite questions Restate	Consider who should attend & extend invitations; explain rationale & benefits; acknowledge challenges in attending. Will the patient be included? Who will facilitate? What disciplines will help? Co-facilitators? Plan seating, privacy, tissues
Welcome and orient to the goals of the family meeting	Declare agenda items Invite agenda items Negotiate agenda Ask open questions Clarify Restate	Round of introductions and orientation; Include all present at meeting. Normalize anxiety proportional to intensity
Check each family member's understanding of the illness & its prognosis	Declare agenda items Invite agenda items Negotiate agenda Ask open questions Clarify Restate	Clarify name of illness Clarify seriousness of illness Clarify reasons for admission Clarify each person's concerns Normalize both concordance & divergence of views among family members Respect culturally sensitive views Acknowledge protective urges and any expressed desire to help

Strategies	Skills	Process Tasks
Check for consensus about the current goals of care	Ask open & circular questions Clarify Restate Summarize	Compare & contrast oncological, nursing, social, psychological & spiritual goals of care Reality test sensitively where needed Correct misunderstandings
Identify family concerns about their management of key symptoms or care needs	Ask open questions Preview information Check understanding Clarify Summarize	Consider medication or treatment concerns Hygiene issues Concerns about walking, moving, transferring Concern about nursing Concerns about assessing palliative care resources: -Extra help -Financial issues Need for respite Concern about a sense of helplessness Promote problem solving Educate as appropriate
Clarify the family's view of what the future holds	Ask circular questions Clarify Restate Summarize Make partnership statements	Advanced care directives Health proxy Consider cultural or religious concerns Place of death discussion Provision of care from family if at home Accompaniment, support and help if in hospital Educate as appropriate
Clarify how family members are coping and feeling emotionally	Ask circular questions Ask strategic questions Acknowledge Validate Normalize	Review family functioning as a group, asking specifically about their communication, cohesion and conflict resolution. Identify any members considered to be "at risk" or a concern to others? Discuss future care needs of family or individuals when concern exists. Avoid premature reassurance
Identify family strengths and affirm their level of commitment & mutual support for each other	Ask circular questions Ask strategic & reflexive questions Praise family efforts Acknowledge, legitimize	Review family traditions, mottos, spirituality, cultural norms
Close the family meeting by final review of agreed goals of care and future plans	Summarize Invite questions Acknowledge Make partnership statements Express willingness to help Review next steps	Provide educational materials Clarify future needs, funeral plans Refer those "at risk" to family clinic for further care Consider feedback to patient if they were not present



## V. PREPARATORY HOMEWORK

Are there key steps in the described sequence of Conducting a Family meeting that you do not routinely do? If so, it will be worthwhile planning to practice these in the role play work.

Are there any specific skills related to any steps that you routinely omit? Again, practicing these in role play work will be vital.

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