

# Chapter 8

## Medical Family Therapy in Oncology



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Cancer diagnoses encompass a broad and varied group of diseases that share the feature of abnormal and uncontrolled cell growth. In the United States alone, an estimated 1.6 million new cases of cancer were diagnosed last year (American Cancer Society, 2016). Once considered a death sentence, many cancers are now treated as chronic illnesses that require long-term management (McCorkle et al., 2011). This shift from acute to chronic care for patients with cancer represents a culmination of continually evolving medical advances that have succeeded in prolonging survival and expanding the range of available treatment options.

Whereas the prevention, detection, and treatment of these diseases have been a focus of biomedical research for more than a century, interest in the psychosocial “human side” of cancer emerged only in the last half of the twentieth century (Holland, 2000). Historically, it was common for oncologists to withhold disclosure of a cancer diagnosis; they believed that patients would be harmed by such information. This view contributed to the exclusion of behavioral health professionals from cancer wards. As treatment advances promised a greater chance of survival, the stigma and fear surrounding cancer diminished. It became permissible to talk openly about the diagnosis, itself, alongside the psychological and social implications of living with cancer.

The National Cancer Institute and the American Cancer Society were established to promote cancer research and education in the early twentieth century. However, it was only in the mid-1970s that a new field called psycho-oncology was established to study and address the psychosocial challenges faced by patients and their families (Holland, 2000). Over the ensuing 40 years, a large body of research has

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accumulated that documents the extent of psychosocial burdens and distress experienced by cancer patients and their families. Consequently, it is now a routine to integrate support services into the cancer care delivery system (Pirl et al., 2014). There is greater recognition, too, that the impact(s) of a cancer diagnosis reverberates throughout the family system—with evidence about adverse effects across physical, emotional, and social functioning of caregiving family members many years past the onset of caregiving (Kim, Shaffer, Carver, & Cannady, 2015).

Psycho-oncology has been predominantly led and practiced by the more traditional disciplines of psychiatry, psychology, and social work. However, the systemic mind-set of medical family therapy (MedFT) is crucial to this field as patients and families navigate an increasingly complex and fragmented care experience. In this chapter, we orient MedFTs to the oncology setting and its key players and present an overview of the trajectory of cancer care from diagnosis to active treatment, surveillance, and advanced disease. We also describe evidence-based intervention models that have been developed to mitigate distress and optimize patient and family adjustment and coping.

We begin with the following clinical vignette; it illustrates common themes in patients' and families' experiences with the diagnosis and treatment of cancer and the multiple levels at which a MedFT can effectively intervene to help navigate this process.

### **Clinical Vignette**

[Note: This vignette is a compilation of cases that represent treatment in oncology. All patients' names and/or identifying information have been changed to maintain confidentiality.]

*Helen and Ray were married for 21 years, with a 16-year-old son and 19-year-old daughter. Ray was diagnosed with stage IV pancreatic cancer after an extensive workup for worsening back pain. When he was initially diagnosed, he and Helen were shocked to learn that the disease had already spread to his liver and lungs. Ray underwent a course of first-line chemotherapy, which initially appeared to contain tumor growth. Several months later, a follow-up scan showed that Ray's disease had spread. Ray then accepted enrollment in a trial of a new immunotherapy drug, although he and his wife were told that its success rate was not likely to be higher than 20%.*

*A number of weeks after starting the clinical trial, Ray's nausea, weight loss, and bone pain worsened. The couple began to decline social invitations and pressed their college-aged daughter to come home more often. Hearing about his symptom complaints, the oncologist referred the family to a palliative care team. The couple interpreted this suggestion as a signal that the oncologist had lost all hope of recovery, and when the palliative care physician suggested that they consider the pros and cons of continuing treatment, they "fired" her.*

*As Helen grew increasingly anxious, she asked for more frequent appointments with the oncologist and expressed frustration with what she perceived*

as Ray's treatment team's lack of responsiveness. Noticing Helen's mounting anxiety and being aware of the strain that it was placing on his nursing staff (who described Helen as "demanding," "in denial," and blocking her husband from expressing his wishes about possibly discontinuing treatment), the oncologist requested a MedFT consultation to add support for the family and to help facilitate better communication with the team.

In a meeting that the MedFT arranged with both the couple and the primary nurse assigned to them, he (the MedFT) was able to solicit from Ray and Helen their disappointment with the oncologist's decision to "delegate" Ray's symptom management to palliative care, feeling that he was abandoning them prematurely. They added that although the oncologist had not openly discussed Ray's prognosis, there was a palpable change in his demeanor recently. They noticed diminished enthusiasm when he talked with them.

Using a series of strategies designed to put the couple "back in charge" of the cancer experience, the MedFT facilitated a discussion with Ray and Helen about their preferences for communication about difficult illness and treatment topics—both with the oncologist and with each other—highlighting their changing needs as Ray's cancer care became more complex. Critical here was the ability of the MedFT to normalize the couple's reactions, highlighting their attachment to the oncologist and team and their fear that the palliative care referral represented abandonment by the team. The primary nurse was then able to assuage Ray and Helen's concerns by clarifying the role of the palliative care team within a larger, overall treatment approach.

Following this meeting, the MedFT completed the loop by speaking with the couple's oncologist about what he had learned, highlighting the couple's strong attachment to him. A plan was suggested for the primary nurse to arrange weekly check-in phone calls with the family to provide a more routine and structured means of addressing ongoing symptom management concerns. This plan was cemented by the oncologist, who reiterated his firm commitment to remain Ray's primary provider regardless of his involvement of other team members.

The MedFT continued to meet with the family to facilitate conversations about the future and to examine their choices in responding to the terrible uncertainty they faced. The couple's son and daughter were eventually drawn into these sessions. Their children's pointed questions about Ray's treatment options further pressed the couple to talk openly about the "what ifs."

Grief was shared as the MedFT normalized the sadness and worry that preoccupied each of them. Ray's daughter shared that she often cried alone and worried about burdening her mother with her fears. Ray was surprised to learn that his children wished to join him at his oncology visits and to accompany him to treatment. Over time, he was able to express to the family his understanding that his time left in the world was limited and that he wished for a "quiet" and "peaceful" death at home. The family was ultimately able to grant Ray these wishes when he died 2 months later.

## What Is Cancer Care?

Choosing a specialist and treatment site is one of the first decisions made by families following a cancer diagnosis. The process by which families make this decision can itself offer clues as to how they will navigate future decision-making during care (e.g., the degree to which the family draws on their social networks, seeks multiple opinions, or divides roles). Approximately two-thirds of newly diagnosed cancer patients in the United States choose to be treated at an “accredited” cancer center. This designation is made by one of two overseeing agencies, including (a) the American College of Surgeons Commission on Cancer (COC), which has accredited 1500 hospitals in the United States on the basis of predetermined clinical care standards, and (b) the National Cancer Institute (NCI), which has accredited nearly 70 cancer centers on the basis of clinical care and academic standing. At an accredited cancer center, patients and families are typically navigating a large and very complex medical system. They are asked to interact with what feels like a dizzying array of specialists and treatment teams. They also may be asked to participate in ongoing cancer research trials or to submit to experimental protocols if patients do not respond to established treatment regimens.

Given the complexity inherent in modern cancer treatment, MedFTs working in a specialized cancer center must interface with a myriad of specialists and disciplines. Because the majority of cancer care takes place in an accredited cancer center, the concerns, issues, and clinical practices discussed in this chapter will reflect this particular context.

### *Treatment Teams in Cancer Care*

The following highlight key professionals involved in cancer care teams:

**Oncologists.** The oncologist is the lead physician in a patient’s care team; he or she is thereby responsible for diagnosing cancer and planning medical treatment. Because of the oncologist’s central role in helping patients and families make sense of the disease and its management, the quality of communication between patients, families, and oncologists can have a significant impact(s) on various aspects of the care experience and has itself been a focus of much attention (Epstein et al., 2017; Kissane et al., 2012). There are three types of oncologists that may be involved in a patient’s care: (a) medical oncologists who specialize in administering chemotherapy and other medications (e.g., targeted therapies, immunotherapies), (b) surgical oncologists who perform surgical procedures such as taking biopsies or resecting tumors, and (c) radiation oncologists who are trained to administer radiation therapies.

**Oncology nurses.** Oncology nurses perform a wide array of tasks, including the direct delivery of treatment (e.g., chemotherapy infusions) in the clinic setting, educating patients and families about how to manage treatment-related side effects, and

coordinating access to services and resources across the treatment facility. As front-line providers, nurses routinely assess the practical and emotional support needs of patients and families, including general distress and caregiving needs. Nurses therefore serve as a kind of “relational bridge” (McLeod, Tapp, Moules, & Campbell, 2010, p. 6), linking the family with other helping systems. Furthermore, because of their close partnership with families over time, nurses are often privy to the intimate details and dynamics of family life and can thereby be a valuable resource to those providing psychosocial support.

**Palliative care physicians and nurses.** The palliative care team is a consultation service called upon by the primary oncologist to assist with symptom management for patients at any point along the treatment trajectory. Palliative care specialists focus their work on the relief of suffering, defined broadly to include physical concerns (e.g., lymphedema, nausea, shortness of breath, neuropathy) and psychological, social, and spiritual difficulties that threaten to diminish the patient’s quality of life. Because of their holistic approach, palliative care providers are inclined to be patient- and family-centered and therefore collaborate frequently with behavioral health providers. Palliative care specialists are most often enlisted in caring for advanced cancer patients, whose symptom burden is greatest. However, there is a large body of research showing that early integration of palliative care into cancer treatment improves clinical outcomes for both patients and families (Bakitas et al., 2009; Smith et al., 2012).

There are persistent misperceptions about the role of palliative care among patients, families, and oncologists (e.g., the tendency to equate these services with hospice care), which unfortunately can impede referral and uptake of these services (Bauman & Temel, 2014; Schenker, Park, Maciasz, & Arnold, 2014). MedFTs may encounter these barriers when collaborating with a palliative care team (as in our vignette, above) and can play an important role in facilitating communication and understanding across teams and within the family about how to best use this service.

**Behavioral health providers.** Behavioral health providers in cancer treatment may include social workers, psychologists, psychiatrists, MedFTs, and others. All provide mental health services and collaborate with medical providers to provide comprehensive and integrated behavioral healthcare.

**Oncology social workers.** The oncology social worker helps patients and families manage distress and cope with cancer-related challenges. He or she may lead group support programs and/or provide psychoeducation about topics related to cancer management (e.g., communicating with children about a parent’s illness). Social workers may also provide brief targeted counseling to patients or link patients and families to financial support and other resources. They are often colocated in the clinic setting and are thereby able to collaborate closely with oncologists, palliative care specialists, and nurses. However, they primarily see patients and families by referral. Because it would not be unusual for families to interact with all of these professionals, it often falls to MedFTs (see below) to ensure that contacts between

the family and these different professionals are coordinated and consistent. Just as the medical oncologist is usually the person who acts as a “quarterback” for the patient’s treatment plan, it may well be the MedFT who serves a comparable role in integrating the family into the overall treatment plan.

**Psychiatrists.** The psychiatrist is a medical doctor who treats clinically elevated levels of depression, anxiety, and other psychiatric conditions that either emerge or are exacerbated during cancer care. Psychiatrists are able to prescribe medications to alleviate symptoms of these presentations, alongside common patient struggles with insomnia and fatigue.

**Psychologists.** Clinical psychologists are involved in screening, identifying, and treating psychological distress among patients and families facing a cancer diagnosis and treatment. Psychologists are trained to deliver evidence-based psychotherapy interventions to address these concerns. Both psychologists and psychiatrists may provide supportive or cognitive-behavioral therapy to help patients or caregivers cope with cancer-related stresses. However, because they are not often well trained in couple/family therapy, it is more likely that a MedFT would be called upon to intervene with families when needed.

**Medical family therapists.** Oncology teams recognize that a supportive and well-functioning family is a key component of effective cancer care, but many acknowledge that collaborating with families can be challenging (Kissane, 2013; Zaider et al., 2016). When 912 hospital oncology nurses in the United States were asked to rank a list of obstacles to providing high-quality end-of-life care, the highest-ranked obstacle on average was working with anxious family members. Of the top ten primary obstacles perceived by nurses, seven pertained to families (e.g., families not accepting a patient’s poor prognosis, nurses having to deal with angry family members) (Traeger et al., 2013).

In recent years, there have been numerous calls to integrate family-centered support services into cancer care and to more routinely assess the family’s capacity to manage the chronic and often unpredictable demands of aggressive treatment and other illness-related stressors (Kent et al., 2016; Northouse, 2012). The unique value of MedFTs therefore lies in their ability to apply a broader biopsychosocial-spiritual (BPSS) lens to engaging and intervening with distressed families (Engel, 1977, 1980; Wright, Watson, & Bell, 1996) and to model the benefits of family-centered care for others in the oncology team. Often, this involves adding family-level assessment and intervention practices to routine care, such as gathering basic information about membership of the caregiving family, normalizing the family-level challenges that accompany cancer treatment, making contact with multiple family members when possible, and drawing on their perspectives and prior experiences in solving problems that arise during treatment.

This kind of family engagement has been well incorporated into many pediatric oncology and critical care settings (Kazak, Boeving, Alderfer, Hwang, & Reilly, 2005; Schaefer & Block, 2009), wherein providers rely heavily on family members as

surrogate decision-makers. On the other hand, most adult oncology settings have not yet established the resources and protocols needed to routinely address family needs. Instead, most focus on the patient, alone. It is not surprising, then, that despite reporting a high number of unmet support needs, family members of adult cancer patients typically underutilize existing psychosocial care services (Sklenarova et al., 2015).

As in cancer care generally, the field of psycho-oncology has been oriented toward developing individually based interventions that target the patient's well-being and adjustment. Conjoint couple and family therapies in cancer remain sparse, although families who are offered the opportunity to convene for support together consistently report high satisfaction with this modality (Hodgson, McCammon, & Anderson, 2011; Ostroff, Ross, Steinglass, Ronis-Tobin, & Singh, 2004). MedFTs have the skills to provide more intensive family system-oriented interventions to address communication difficulties, conflict management, and other relational challenges that are not typically targeted in most psychotherapies for cancer patients.

**Chaplains.** Chaplains offer spiritual support; they provide patients and families with opportunities for prayer or engagement in religious rituals to address existential distress. They may serve patients and families who are admitted to the hospital and can be called upon to meet with patients at any time during care in the outpatient setting.

**Radiologists.** A radiologist is a medical doctor who uses medical imaging—such as X-ray, CT, MRI, or ultrasound—to examine internal bones or organs to facilitate making an accurate cancer diagnosis or determine the status of an existing cancer. Because such diagnostic procedures are administered by technicians, patients and families do not tend to directly interact with the radiologists who are interpreting the results. This is in contrast to the radiation oncologist (i.e., when radiation therapy is a component of the treatment plan).

**Genetic counselors.** Genetic counselors help patients and their families interpret results of genetic screening tests; they use this information, in combination with information from personal and family histories, to help family members understand their genetic risk factors for certain types of cancer. Because of the many challenges that arise in coping with genetic risks, genetic counselors often work collaboratively with psychosocial providers.

## Fundamentals of Care in Oncology

MedFTs working in oncology and psycho-oncology must be familiar with a myriad of content, including common trajectories of care within this treatment context, indicated methods for family assessment, and helpful ways to support families after care has concluded.

## *Cancer Care Trajectory*

To understand a family's experience with cancer, it is important to consider where they are in the physical and psychosocial timeline of the disease. As with many serious illnesses, cancer follows a developmental course with distinct psychosocial tasks and challenges accompanying each phase (Rolland, 2005). The course of cancer treatment can also be characterized by alternating periods of crisis (e.g., initial diagnosis, unplanned hospital admissions), chronicity (e.g., routine schedule of ongoing treatment or surveillance), and anticipatory grief (e.g., terminal phase of illness). It is thereby important for MedFTs to have a road map of the medical transitions and milestones associated with a particular disease group (e.g., the first 100 days after hematopoietic stem cell transplantation) so that they can anticipate and normalize periods of heightened anxiety and need(s) for mobilization.

In their published guidelines for distress management in oncology, the National Comprehensive Cancer Network (NCCN) identified a set of critical transition points in cancer treatment during which patients and families are especially vulnerable to distress and may benefit from psychosocial consultation (NCCN, 2017; Pirl et al., 2014). These include:

1. Initial period of diagnostic workup and decision-making
2. Preparation for treatment or surgery
3. Planned or unplanned changes in treatment modality
4. Planned or unplanned withdrawal of treatment
5. Discharge from the hospital
6. Transition from active treatment to long-term surveillance
7. Disease recurrence or progression
8. Transition to hospice and end-of-life care

In the clinical vignette above, Ray and Helen's transition from an initial treatment course to news about disease progression was distressing because of the resulting physical changes for Ray (e.g., fatigue, pain). It was disorienting, too, because of the changes made in his treatment regimen and in the number and type of providers involved in Ray's care. As families differ in their adaptability and manners in which they integrate changes in their environment, it can be useful to track whether and to what extent patterns of family life change in response to the demands of a particular illness phase. Such patterns can include how families allocate resources (e.g., time, effort, money), communicate with one another, negotiate and resolve differences, make plans for the future, and/or balance time together versus apart.

For example, at the time of an initial diagnosis (i.e., a crisis period), a family may dedicate more resources to researching treatment choices, seeking multiple opinions, and discussing cancer-related issues than would be necessary during a later phase of illness. In the vignette above, Ray's daughter, who typically spent her weekends away at college, came home more often to be with her parents. Ray, who may have been accustomed to expressing a difference of opinion with his wife, became more

withdrawn and passive. At the same time, Helen became more protective and less inclined to argue with Ray. Often families are not aware of the degrees to which cancer has reorganized aspects of their lives and relationships. MedFTs can normalize these disruptions as an expected part of being in “cancer territory” and can empower families to evaluate and make choices about the accommodations they make.

Clinical course changes also precipitate changes in the nature of the relationship between the family and medical team: couples and family members may assume more passive “backseat” roles during a crisis period (e.g., when a patient is first admitted to an intensive care unit) but then shift into “copilot” roles during a chronic or long-term follow-up phase of care when oncologists rely on them to maintain vigilance and track symptoms (Reiss, Steinglass, & Howe, 1993). In the vignette above, Ray and Helen longed for their oncologist to maintain his position as the “captain of the ship,” despite the need for consultation from other specialists.

### *Assessing Families in an Oncology Setting*

Family members are ubiquitous in oncology clinics, interfacing with almost every provider and/or taking part in (or at least being present for) all consultations. However, and as previously noted, most cancer care settings do not yet have a systematic process for assessing the concerns of caregiving family members or for determining what support needs are warranted beyond those of the patient. Referrals to a behavioral health provider are often made at the request of the family or by another clinician (e.g., nurse, oncologist, chaplain) who perceives elevated distress, poor caregiving capacity, or other psychosocial risk factors among family members. Family assessments can occur during a single encounter in the inpatient or outpatient setting or across several sessions as part of a planned course of family therapy (Hudson, Thomas, Quinn, & Aranda, 2009; Kissane & Hempton, 2017; Rolland, 1994; Zaider & Kissane, 2009). Ideally, families are offered a psychosocial assessment or “checkup” with a MedFT during critical transition points throughout their cancer experience (Rolland, 2005), although this is seldom done in practice.

A single family consultation (also known as a “family meeting” or “family conference”) is used routinely by medical staff in palliative care, critical care, or pediatric oncology settings to enlist the collaboration of family members in decision-making, clarify concerns or questions related to cancer and its management, and achieve consensus about treatment planning moving forward (Hudson, Thomas, Quinn, & Aranda, 2009). Although these meetings are typically led by the oncologist and other medical specialists, the presence of a MedFT ensures that psychosocial issues are addressed in addition to strict medical concerns. In helping to coordinate such a meeting, MedFTs should consult in advance with the medical team, patients, and family members about who should be invited. Families may need explicit permission to invite members who are not directly involved in caregiving tasks but nevertheless are key influences (e.g., close friends).

Particularly during a crisis period, family members may also ask to meet with a MedFT without the patient present. This is done usually with the intent to protect the patient from emotionally painful content or unresolved conflict. While such requests are common, they can raise worries about appropriately managing confidentiality or competing alliances. It is possible to honor this kind of request by allotting time for discussion with individuals and families together, underscoring that the goal of such sessions is to help the family find adaptive solutions to communication difficulties—rather than have the MedFT become a primary conduit of communication among them.

Guidelines for conducting a family meeting in an oncology setting have been put forth in research and clinical literature (e.g., Gueguen, Bylund, Brown, Levin, & Kissane, 2009; Hudson et al., 2009), usually with an emphasis on identifying and addressing caregiving needs. All assessment models emphasize general therapy techniques such as joining with each family member in the room and structuring the meeting from the outset by setting and eliciting a realistic agenda. Other components of a family assessment include (a) eliciting the family's "illness story," especially what they understand to be the current status of the disease and goals of treatment; (b) learning about prior experiences with illness, major transitions (e.g., immigration), or other adversity in the family's history; (c) identifying successful adaptation strategies that the family has used in the past; (d) pinpointing perceived strengths and vulnerabilities in their coping responses; and (e) discussing current and future support needs, both practical and emotional (Kissane & Hempton, 2017; Zaider & Kissane, 2009).

It is also important to listen for any implicit beliefs that a family might hold about what caused the disease (e.g., trauma, poor health habits, family history, religious sources) or beliefs about nonmedical factors that are assumed to be important to the patient's survival or protection from recurrence (e.g., positive thinking, low stress and conflict). An initial consultation might then conclude with a summary of the family's strengths and vulnerabilities, incorporating relevant psychoeducation about common challenges that families are expected to face when their lives are affected by illness. In the vignette above, for example, the MedFT may comment on the strong advocacy that Helen provides while, at the same time, highlighting the enormous responsibility that she feels toward keeping her husband well.

Normalizing and helping the family anticipate the emotional and relational tasks that lie ahead can be sufficient to empower them to forge ahead with good teamwork and communal coping. No matter how well functioning, many families navigate this experience without recognition of the choices they can make or of the internal and relational resources available to them. Thus, in addition to data collection, the joint family assessment will also affirm the unique values and skills that the family brings to this experience. Finally, as is with Ray and Helen, even 1 to 2 sessions focused on immediate concerns can facilitate conversations that are comparatively difficult for the couple or family to have on its own.

## ***Supporting Families During the Posttreatment Phase of Cancer***

Cancer is often thought of in popular culture as a single entity, but different cancers vary greatly in their clinical course(s). Consequently, a MedFT may be called upon to help with a wide array of issues depending on the type of cancer at hand. Although the most prevalent of these issues will be attendant to the diagnostic and treatment phases of cancer, increasing attention is being paid to two other issues: (a) late effects of otherwise successful cancer treatments and (b) posttreatment psychological sequelae. Prominent examples of treatment effects include infertility issues, impotence, permanent side effects from radiation scarring, and the like (Institute of Medicine Committee on the Future Health Care Workforce for Older Adults, 2008). Common psychological sequelae include chronic depression and PTSD-like symptoms (Brown, Madan Swain, & Lambert, 2003; Kazak, Boeving, Alderfer, Hwang, & Reilly, 2005).

Many presume that these issues are experienced primarily by patients, but research has shown that patients' family members also suffer significant posttreatment effects from the cancer experience (e.g., Kim, Kashy, Wellisch, Spillers, Kaw, & Smith, 2008). Further, sequelae like infertility or impotence impact relationships within the family. Particularly stressful are the issues raised when cancer occurs in

### **Clinical Vignette**

[Note: This vignette is a compilation of cases that represent treatment in oncology. All patients' names and/or identifying information have been changed to maintain confidentiality.]

*Walter is a 16-year-old adolescent who is 1-year posttreatment for leukemia that included a course of chemotherapy and a bone marrow transfusion. He is the oldest of three siblings in a family that had no prior experience with a serious medical illness in any of the children or their parents. Despite the oncologist's assurances that Walter is now "cancer-free," his parents continue to view him as at risk for a recurrence of the disease. Walter, for his part, wants to return to a "normal" life, including rejoining his soccer team and taking on a full academic schedule.*

*In a follow-up visit, the oncologist notes that Walter's parents seem unable to be reassured that all is well. They instead ask multiple questions about what to look for as early warning signs of cancer coming back. When she tries to take Walter's side in emphasizing that he is now fully capable of leading the life of a normal teenager, tension quickly arises between the oncologist and Walter's parents (and between Walter and his parents). Sensing that an escalating and counterproductive rift is developing right in front of her, the oncologist suggests that the family have to consult with the team's MedFT.*

*When she met with the family, the MedFT was quickly able to assess the problem (i.e., hypervigilant parents who are experiencing unresolved PTSD symptoms typical of the posttreatment phase of leukemia in an adolescent family member and who are consequently in conflict with the said teenager who sees them as overly controlling). Maintaining the goal of helping to normalize what the family is going through, the MedFT refers Walter and his parents to a multiple-family discussion group (MFDG) program she has been running at the Cancer Center. This type of program typically brings together 4 to 6 families during the posttreatment phase of cancer to talk together about their experiences. Based on a combination of psychoeducational and family system principles, MFDG models are usually conceptualized as deriving their power from an ability to establish a non-pathologizing, collaborative environment within which a community of families who can share both challenges and coping strategies for dealing with cancer (Steinglass, 1998).*

*During the first MFDG session, Walter's father expresses his feeling that the cancer diagnosis and the treatment experience were akin to "being taken hostage by a terrorist" and that he continues to have nightmares in which he is in Walter's hospital room crying uncontrollably. Parents from other families in the group immediately chime in with comparable feelings. A mother from another family talks about her confusion every time her daughter develops a mild cold. "Should I rush her back to the Cancer Center, or just call her pediatrician?" Heads nod around the room as other parents endorse this sense of fear and confusion.*

*At the same time, adolescent patients in the group speak up forcefully for how they no longer want to be labeled as "cancer patients." They have thrown away the hats they used to wear to hide their post-chemotherapy hair loss, and they have gained back all of the weight that they lost. It is time to return to their lives.*

*The MedFT leading the group is then able to use these "data" to normalize both reactions that are being expressed and to point out how the differing emotions expressed by patients versus parents is also part and parcel of typical reactions advanced within families as they progress through the posttreatment phases of cancer treatment.*

children or young adults. In these situations, parents and spouses are often confused and distressed about the long-term implications of their family member having had cancer at a young age and about whether to think of the cancer as having been "cured" or to, instead, think (and worry) about it as "in remission" (Ostroff, Ross, & Steinglass, 2000).

Many cancer centers, aware of these issues, have established educational programs and support groups for family members. However, these programs typically do not bring patients and family members together. MedFTs, equipped with the biopsychosocial-spiritual (BPSS) orientations that define their efforts, can play an important role in shaping these programs to better reflect the needs of families as families.

## Cancer Care Across the MedFT Healthcare Continuum

Although the oncology setting offers diverse opportunities to engage and support families, the level of intervention provided by MedFTs, and the degrees to which their roles are integrated with the patient's medical care, varies considerably. We use Hodgson, Lamson, Mendenhall, and Tyndall's (2014) MedFT Healthcare Continuum here to describe different levels at which the MedFT can be integrated into a cancer care system.

At *Levels 1 and 2*, the MedFT is familiar with a BPSS framework and applies it occasionally to his or her interactions with patients and their families but is nevertheless focused primarily on how the cancer patient is coping with immediate, disease-related concerns. He or she recognizes the important role(s) of caregiving families but will attend to the family only when needed to ensure the safety and well-being of the individual patient. Principal skills at these levels include providing acute, one-to-one support to a patient or distressed caregiver and serving as a liaison to the medical team on behalf of the patient and family when necessary.

MedFTs at this level intervene independently of any medical care provided, oftentimes in a separate location. They are not routinely introduced to patients and their families and have minimal contact with the primary oncologist except to exchange essential background information about a referred case. A MedFT working at this level will accept psychosocial care referrals for complex or "high-risk" cases from a member of the primary disease management team and will apply interventions that are oriented to short-term crisis management, psychoeducation, and practical problem-solving.

In our first clinical vignette, a MedFT working at this level may meet with Helen alone at the oncologists' request, hear and address any pressing questions about Ray's disease course and treatment, clarify the reasons for the oncologist's referral to palliative care, and provide information about a range of support services offered at the hospital. This MedFT would focus his or her interaction on de-escalating Helen's anxiety by providing empathic support, normalizing her worries, and problem-solving ways to meet caregiving needs.

At *Level 3*, MedFTs are embedded in a specific disease management team (e.g., a hematology or urology service). Working on-site, they interact directly with clinic staff and are routinely sought out by them for formal and informal consultation. Within inpatient units, MedFTs at this level will regularly join the oncologist and

**Table 8.1** MedFTs in Oncology: Basic Knowledge and Skills

MedFT Healthcare Continuum Level	Level 1	Level 2	Level 3
Knowledge	<p>Familiar with the biopsychosocial-spiritual (BPSS) framework as a general guide in care.</p> <p>Understands that cancer is associated with multiple biopsychosocial-spiritual challenges.</p> <p>Familiar with common complications resulting from cancer treatment (e.g., hair loss, fatigue).</p> <p>Aware of the importance of family members in caregiving and advocacy roles on behalf of the patient.</p>	<p>Understands how the BPSS framework pertains to the patient’s and family’s response to cancer.</p> <p>Can distinguish between BPSS challenges accompanying different phases of cancer treatment.</p> <p>Understands common treatment regimens and side effects associated with specific types of cancer (e.g., breast cancer, lung cancer, GI cancer).</p> <p>Familiar with family system concepts and can appreciate the aspects of family life that may impact and be impacted by cancer.</p>	<p>Understands psychosocial adjustments and critical transition points associated with specific cancers/diseases.</p> <p>Familiar with (and can anticipate) how certain patient- and family-level characteristics (e.g., history of loss, trauma) will contribute to the family’s adjustment to a cancer diagnosis and treatment.</p> <p>Knows (and can identify) common marital or family relationship dynamics that arise in the context of coping with cancer and understands how these may impact the family’s partnership with the oncology team.</p>
Skills	<p>Offers acute support or crisis management to patients and family members during times of high distress (e.g., after receiving bad news, changing treatment plans, anticipating surgery, or coping with an unplanned hospitalization), usually on a one-to-one basis.</p> <p>Accepts referrals for high-risk or complex patients and/or caregivers from the oncology team; can understand the basic nature of a patient’s disease with access to his or her medical records and will follow cases in a separate site with only occasional contact with the oncology team.</p>	<p>Can anticipate and educate patients and families about common individual-, family-, and social-level challenges associated with cancer.</p> <p>Can engage and join with multiple family members in a conjoint consultation that is focused on the patient’s caregiving needs.</p> <p>Can facilitate general support groups for individual patients and/or caregivers.</p>	<p>Proactively accesses families by attending case conferences and liaising with oncology team to identify those who may be at risk for elevated distress—or adjustment difficulties.</p> <p>Conducts family meetings or family therapy sessions with a dual focus on the patient’s individual cancer care concerns and overall family functioning (e.g., communication, distribution of roles and responsibilities, intimacy or sexual functioning problems, parenting).</p>

nurses on rounds so that they can present themselves to patients and families as part of the care team. In outpatient settings, MedFTs will participate in case conferences and team meetings to acquaint themselves with all active cases, regardless of psychosocial risk status.

MedFTs at *Level 3* may still see families primarily by referral from the medical team, but they are comfortable providing both short-term and long-term couple/family therapy. Because this MedFT is better known to care team's oncologists and nurses, he or she can more effectively advocate for the support needs of the family and will have more influence on the nature and quality of care delivered by other clinic staff. The MedFT may also participate more actively in research collaborations, using his or her systemic and biopsychosocial perspective to guide research questions.

Returning to our clinical vignette with Ray and Helen, a MedFT working at this level may introduce himself/herself to the couple early in their disease course and offer more frequent meetings to discuss the challenges that arise as Ray transitions to new care sequences. Because the MedFT is working with Ray's primary oncologist, he or she will more actively "translate" the perspectives of the family to the oncology team and vice versa. This MedFT will also be comfortable encouraging the couple to bring their young adult children to sessions and addressing the dynamics in the family system more broadly (Table 8.1).

At *Level 4*, MedFTs are consistently integrated into an oncology practice, providing consultation to patients and families routinely, and as an accepted part of standard cancer care. For example, instead of having the oncologist refer families to the MedFT when they are determined to be of high risk or at the point of crisis, the oncologist might introduce the MedFT at an initial visit or at a critical juncture in the patient's treatment course, with the intention of normalizing his or her supportive role on the team.

The MedFT working with Ray and Helen is using interventions most closely matching this higher level of involvement and integration. For example, he is likely to speak with Ray and Helen *alongside* their oncologist or primary nurse and convene multidisciplinary meetings with multiple team members at key transition points in their disease course. The MedFT may even anticipate the family's support needs by learning from the oncologist about new developments (e.g., scan results) in advance of their visit and planning time with the family to process bad news.

At *Level 5*, the MedFT will also provide training and supervision to medical and behavioral health trainees and providers in order to promote the use of family-centered care practices and to address the support needs of the healthcare team. He or she may conduct couple/family therapy sessions conjointly with the nurse, social worker, or oncologist involved in a given case to ensure that the perspectives of all family and team members are well represented and coordinated. This MedFT is also proficient in the conduct of research to better understand systemic factors impacting treatment in cancer care and/or to test interventions that advance integrated health services (Table 8.2).

**Table 8.2** MedFTs in Oncology: Advanced Knowledge and Skills

MedFT Healthcare Continuum Level	Level 4	Level 5
Knowledge	<p>Provider is affiliated with (and located within) a particular oncology clinic and thereby maintains adept understandings about disease management and treatment-related side effects and is familiar with the range of tests used to follow disease statuses. She or he is also familiar with how the oncology clinic operates, including the roles and relationships of all team members and various specialists.</p> <p>Adept knowledge regarding methods for assessing and intervening with couples and families who are dealing with more complex disease-related relational dynamics or psychosocial circumstances (e.g., comorbid psychiatric or medical conditions, language barriers).</p>	<p>Conversant with oncologists, nurses, and other team members and specialists regarding a myriad of disease-related complications and other aspects of care.</p> <p>Well versed in the sundry legal, medical, and ethical considerations involved in treatment decision-making, particularly during the advanced stages of illness.</p> <p>Familiar with widely disseminated empirically supported interventions for couples and families coping with cancer.</p>
Skills	<p>Able to offer training, supervision, and consultation to other oncology providers about the complexities of supporting patients and their families at all stages of cancer care.</p> <p>Plans and facilitates interdisciplinary family meetings to jointly address the patient’s and family’s BPSS concerns, as well as their potential impact(s) on one another.</p> <p>Skilled to conduct multiple family groups and to provide more intensive longer-term psychotherapy with couples and families when indicated.</p>	<p>Alongside direct clinical care is proficient in leading or coleading initiatives that advance integrated behavioral healthcare models within the oncology team and promote the routine engagement of families as part of patients’ cancer treatment planning.</p> <p>Participates in hospital ethics committee, informs quality of care standards in the oncology clinics, and contributes to research regarding the implementation of family-centered care practices.</p>

## Research-Informed Practices

There is growing evidence that demonstrates that couple- and family-based interventions are associated with significant benefits. Brief (6–10 sessions) therapies have been developed and tested in research trials for couples and families across early and advanced stages of disease. Many of these interventions emphasize psychoeducation and skill enhancement (e.g., the therapist coaches couples and

families in constructive communication and coping skills), whereas others are more exploratory and insight oriented. Common to all these interventions is the conjoint participation of both patient and family members and a focus on family-level management of the illness. We will highlight some of the most empirically supported interventions below for illustration.

*Intimacy-Enhancing Couples Therapy* (IECT) targets early phases of the cancer disease course, wherein the patient-partner dyad (not the whole family) is the more likely unit of care (Kissane et al., 2016; Manne, Kissane, Nelson, Mulhall, Winkel, & Zaider, 2011; Zaider & Kissane, 2011). IECT is one of a large number of therapies that have been designed and tested for couples coping with breast, prostate, lung, head, and neck cancers, as well as for couples facing advanced end-stage illness (Badr & Krebs, 2013; Dockham et al., 2016; McLean, Walton, Rodin, Esplen, & Jones, 2013; Scott, Halford, & Ward, 2004; Zaider & Kissane, 2011).

IECT was designed specifically for men with localized prostate cancer and their partners who are adjusting to postsurgical changes in sexual functioning. The treatment protocol consists of 4 to 6 sessions during which the IECT therapist guides couples through behavioral exercises intended to strengthen communication and problem-solving skills that will help them manage cancer-related concerns (e.g., erectile dysfunction, incontinence). Couples reflect on sources of physical and emotional intimacy pre- versus post-cancer, become aware of any identity-related losses that men may experience as a result of physical changes, and identify strategies for preserving intimacy despite the disruptions caused by treatment-related side effects. A pilot trial testing the efficacy of this intervention against a “usual care” control group found significant improvements among couples receiving the therapy in measures of communication, responsiveness, marital satisfaction, and intimacy (Manne et al., 2011).

*Emotionally Focused Therapy* (EFT) is based on principles of attachment theory; it targets couples’ relationship functioning by working to repair and/or build secure interpersonal bonds between partners (Johnson, 2004; Wiebe & Johnson, 2016). EFT guides its participants through three distinct stages, including (a) de-escalation, wherein couples develop insights/understandings regarding negative interaction cycles that drive their distress; (b) restructuring interactions, wherein couples create new emotional experiences and exchanges that lead to more secure connections with each other; and (c) consolidation, wherein couples work together to solve problems as a team now equipped with secure attachment and improved relational functioning. Researchers have shown that EFT is effective in reducing a variety of individual (e.g., depression; Dessaulles, Johnson, & Denton, 2003; Denton, Wittenborn, & Golden, 2012) and relationship (e.g., forgiveness; Makinen & Johnson, 2006) concerns. Within the field of oncology, EFT has demonstrated effectiveness for couples coping with breast cancer (e.g., Naaman, 2008), terminal metastatic cancer (e.g., Mclean, Walton, Rodin, Esplen, & Jones, 2013), and cancer/chronic illnesses of their children (e.g., Cloutier, Manion, Walker, & Johnson, 2002; Walker, Johnson, Manion, & Cloutier, 1996; Walker, Manion, Cloutier, & Johnson, 1992).

*Family-Focused Grief Therapy* (FFGT) targets families coping with advanced, poor-prognosis cancers whose members were at elevated risk for psychological dis-

tress (e.g., depression, anxiety) during both the palliative care phase of treatment and later during bereavement. A family is determined to be “at risk” if at least one of its members reports significant impairment in family relationships on the Family Relationships Index, a well-validated screening tool that asks about the quality of family relationships (Schuler et al., 2014). Scores on this screening questionnaire have shown to be highly predictive of family members’ long-term psychological adjustment, both during advanced illness and in ensuing bereavement (Kissane, Bloch, Onghena, & McKenzie, 1996; Schuler et al., 2017).

By identifying high-risk families and strengthening their capacity for mutual support in the months prior to a patient’s death, FFGT aims to help families navigate the loss of their loved ones more adaptively and potentially prevent the emergence of prolonged grief disorder in the future. The therapy begins with the patient present and continues with surviving family members during bereavement. The continuity of care prescribed by this model is based on the observation that high-risk families are more likely to follow up with bereavement support when the therapist knew, and helped care for, the deceased member. Sessions are 90 minutes long and spaced 2–3 weeks apart so as to allow time to process clinical content and accommodate scheduling demands. During the early assessment stage of therapy, behavioral health providers use circular questions to understand how the family communicates about cancer, how roles and responsibilities are distributed, and how the family negotiates differences. A separate session is dedicated to constructing and exploring families’ genograms. In addition to collecting “data” about family constellations, and about cross-generational experiences with illness and loss, this session is used to encourage reflection on which values and coping styles in a family’s history will be preserved and which will be left behind.

Based on what emerges during these early assessment sessions, the behavioral health provider then works collaboratively to establish relational goals for the family. A central part of this “intervention stage” of therapy involves facilitating difficult conversations about death and dying. Having learned about their prior experiences with loss, a MedFT can help the family talk about what, in their view, constitutes a “good death.” He or she helps family members acknowledge and express their grief, identify existential and spiritual concerns, and anticipate strengths and vulnerabilities that may arise in the aftermath of loss. Feelings of guilt, anger, disgust, and burden in the context of caregiving are named and normalized. Rather than act as a primary source of support and reassurance to family members, the behavioral health provider asks questions that redirect the family to providing empathic support for one another. Examples might include “Is it helpful for your daughter to cry when she thinks about your illness?” or “How will you know when dad is feeling lonely?” Because the therapy is time limited, a MedFT should remain focused on realistic goals and not necessarily attempt to resolve long-standing conflicts.

A multisite, randomized clinical trial demonstrated the efficacy of this therapy in reducing the prevalence of prolonged grief disorder in a group of 170 high-risk families. The prevalence of prolonged grief disorder by 13 months after loss was 15.5% in the group of families that received no intervention and only 3.3% among families who received 10 sessions of FFGT (Kissane & Hempton, 2017).

## Conclusion

Oncology is a broad and varied field of healthcare wherein patients and their families interface with a myriad of specialists across the disease course. MedFTs can play a crucial role in helping families navigate this terrain, as they maintain skills needed to engage and intervene with distressed families, facilitate their partnership and participation with the treating team, and model benefits of family-centered care for other healthcare providers. Although there is widespread recognition that caregiving families are a crucial resource to cancer care, most oncology clinics do not routinely assess for the BPSS challenges experienced by adult patients and their families. The challenges that families face are best understood in connection with particular transition points in the disease trajectory, when distress and burden are felt more acutely (e.g., beginning of active treatment versus transition to survivorship versus end-of-life care). In addition to serving as a bridge between the family and oncology team, MedFTs may provide couple- and family-based interventions to strengthen mutual support among family members, encourage open sharing of grief, facilitate awareness about coping styles, and generate creative solutions to the commonplace adjustment difficulties that accompany cancer treatment. Research in this area has demonstrated that couple-/family-centered intervention models can significantly reduce distress for patients and their caregiving family members. Integrating these approaches into oncology practice settings—so that care for families is a standard part of cancer treatment planning—remains an important goal that MedFTs are particularly suited to address.

### Reflection Questions

1. As a MedFT working with families who are experiencing profound loss, trauma, and existential distress due to cancer, what will you need to pay attention to in yourself? What might block versus facilitate your ability to be emotionally present while bearing witness to others' suffering?
2. How might relationship dynamics *within* a family (e.g., poor communication, rigidity in roles, low tolerance for uncertainty) impact, or be impacted by, the relationship dynamics *between* a family and oncology medical team with whom you are working?
3. While assessing a highly anxious family during cancer treatment, what questions could you ask to help differentiate cancer-related versus non-cancer-related sources of distress?

## Glossary of Important Terms for Care in Oncology

**Biopsy** A surgical procedure to remove a segment of a tumor for the purpose of determining a precise diagnosis.

**Carcinoma** A cancer that begins in the skin or tissues that line the inside or cover the outside of internal organs.

**Curative treatment** Treatment intended (and expected) to destroy the cancer.

**Disease-free survival (DFS)** A measure of time following treatment during which no signs of cancer are discovered.

**Localized** A cancer that is confined to the area where it began; it has not spread to other parts of a patient's body.

**Malignant** A tumor is malignant when there is evidence of disease, as differentiated from a tumor said to be "benign" or noncancerous.

**Metastasis** The spread of cancer to organs beyond where it began (which is referred to as the "primary" or "original" site).

**Palliative treatment** Treatment intended to relieve symptoms and pain associated with the cancer.

**Remission** The disappearance of cancer signs and symptoms (but not necessarily the disease, itself); this can be temporary or permanent in duration.

**Tumor markers** Substances that can be measured in the blood, urine, or body tissues to indicate the presence of cancer.

## Additional Resources

### *Literature*

Breitbart, W. S., Breitbart, W., & Poppito, S. R. (2014). *Individual meaning-centered psychotherapy for patients with advanced cancer: A treatment manual*. Oxford, England: Oxford University Press.

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Watson, M., & Kissane, D. W. (Eds.). (2011). *Handbook of psychotherapy in cancer care*. Hoboken, NJ: Wiley-Blackwell.

### *Measures/Instruments*

Family Relationships Index (FRI). <https://www.ncbi.nlm.nih.gov/pubmed/15546124>

National Comprehensive Cancer Network Distress Thermometer. [https://www.nccn.org/patients/resources/life\\_with\\_cancer/pdf/nccn\\_distress\\_thermometer.pdf](https://www.nccn.org/patients/resources/life_with_cancer/pdf/nccn_distress_thermometer.pdf)

Psychosocial Assessment Tool. <https://www.psychosocialassessmenttool.org>

## Organizations/Associations

American Psycho-Oncology Society. <https://apos-society.org>  
 International Psycho-Oncology Society. <http://ipos-society.org>  
 Society for Behavioral Medicine. <http://www.sbm.org>

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<sup>1</sup>Note: References that are prefaced with an asterisk are recommended readings.

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