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Challenges in providing family-centered support to families in palliative care

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Abstract

Background—Supporting the family-as-a-whole presents challenges in palliative care, although family meetings are increasingly used in routine practice. The Family Focused Grief Therapy (FFGT) Model guides clinicians in using a range of intervention strategies.

Aim—To examine the therapists' techniques used in assessing 'at risk' families in palliative care to better illuminate what helps and what remains challenging.

Method—Recorded sessions 1 and 2 were coded using the FFGT fidelity coding measure, with its glossary of definitions. Inter-rater reliability between three coders was satisfactory at 88%. Frequencies of strategy utilization were computed, with extraction of examples of both successful and problematic approaches.

Setting/participants—From within a larger study of family therapy during palliative care at a comprehensive cancer center, the first two sessions (n = 144) delivered to 74 families (299 individuals) by 32 therapists were coded and analyzed.

Results—Therapists readily explored the story of illness and families' ways of coping (97%) and assessed communication and cohesiveness in the majority. Exploration of relational patterns occurred in 89% of sessions, use of a genogram in 80%, understanding members' roles in 65%

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and family values and beliefs In 62%. Less use was made of summaries (39%), family mottos (34%), exploration of family conflict (35%) and the formalization of a comprehensive family treatment plan (20%).

Conclusions—Challenges exist in therapy with difficult families. Therapy in the home brings special issues. Therapists can apply most of the interventions prescribed by the FFGT model.

Keywords

Challenges and guidelines; family focused grief therapy; family therapy; fidelity; palliative care; therapy in the home

Introduction

There is widespread recognition that caregiving families play crucial supportive roles for advanced cancer patients. In turn, illness becomes an ‘uninvited guest’ in family life,[1] prompting shifts in the family's identity and coordination of roles and daily routines.[2] Many families show remarkable resilience and adaptation in the face of such stress, but a significant minority become highly distressed. Although caring for a dying relative carries the potential for a deepened sense of meaning, greater connection and accompanying positive affect,[3] research suggests that approximately 18–35% of family members experience some form of psychiatric morbidity,[4] with up to one half of patients and one third of their relatives exceeding clinical thresholds on screening distress questionnaires.[5]

Palliative care has long carried a vision to care for the family-as-a-whole. A consensus statement by the National Institutes of Health about end-of-life care emphasized the importance of addressing caregivers’ needs as families prepare for the death of a loved one.[6] Similarly, the World Health Organization's definition of palliative care includes helping families cope with the patient's illness and their own bereavement.[7]

Family meetings are routinely used in palliative care as a tool for communicating with families about the goals of patient care, symptom management and caregiving tasks.[8,9,10] Hudson and colleagues[13] presented one set of guidelines for family meetings, but their approach does not include assessment of family functioning or the emotional adjustment of those not engaged directly in caregiving tasks (e.g., offspring). Families who feature poor communication, minimal teamwork and/or high levels of conflict are especially at risk for psychological morbidity and intense grief after the patient's death.[11,12] Therapists have more difficulty engaging with, and caring for these families, yet they are clearly in greatest need of support.

Family Focused Grief Therapy (FFGT) is a preventive intervention model that is delivered to these psychosocially ‘at risk’ families during palliative care and bereavement. It is a time-limited therapy, whose aim is to improve overall family functioning by strengthening cohesiveness, conflict resolution and open expression of illness-related concerns. A prior randomized controlled trial testing FFGT against a standard care control arm established its ability to reduce distress and depression for surviving family members both at six and

thirteen months following the patient's death.[13] Additionally, the model was shown to be easily mastered by health care professionals from a range of psychosocial disciplines.[16]

Although the call for family support during palliative care is well recognized today,[14,15] limited evidence exists to inform clinicians about how best to intervene to meet the family's psychosocial needs. Prior research has described the efficacy and feasibility of supportive interventions in improving outcomes for caregiving families,[16] yet we have little information about what the 'active ingredients' are within these interventions, and what therapist skills contribute to their potency. Attention to the session-by-session process of the FFGT model enables this level of analysis.

In this paper, we present data on the key therapeutic tasks in family assessment sessions. We used a model-specific coding system to determine which skills are commonly used by therapists when delivering FFGT to 'at risk' families. We also present qualitative excerpts from sessions to illustrate successful and challenging interactions with families. Thus our goal is to specify key therapeutic elements that need to be in place for families to benefit from such support, and to consider ways for clinicians to achieve more in their work.

Methods

Sample

Family sessions sampled herein took place as part of an NCI-funded randomized controlled trial examining the efficacy and dose-responsiveness of FFGT in improving family functioning and reducing distress in bereavement. For this paper, we sampled 144 audio-recorded sessions, led by 32 therapists, representing 84% of the 172 assessment sessions held during the period of this analysis. Of the remaining 28 sessions, one family refused to be recorded, while 27 sessions (16%) went unrecorded due to malfunctioning equipment or errors operating the recorders.

Families were recruited according to the following eligibility criteria: (1) the patient had advanced/stage IV cancer and was receiving palliative care; (2) the prognosis was one year or less, as corroborated by their physician; (3) at least two family members involved in the patient's care would agree to participate; (4) the family was determined to be 'at risk' based on screening of individuals with the Family Relationships Index (FRI). Eligible families were those in which at least one family member (not necessarily the patient) screened low (total FRI $\leq$ 9) on overall family functioning or provided a cohesiveness subscale score of less than 4 out of 4.

Table 1 presents demographic data on the sample of families represented in this analysis. The cohort consisted of 74 families (299 individuals). Patients had a mean age of 56.2 years (SD = 12.65), 58% were female and suffered from the following cancers: gastrointestinal (68.8%), melanoma (7.8%), breast (4.5%), lung (4.5%), and other (14.1 %; e.g., brain tumors, sarcomas, prostate and gynecological cancers). FRI scores indicated that family functioning was perceived as reduced (mean total FRI = 8.12, with highest possible score of 12), with low scores reflecting poor communication (mean= 2.27/4, SD = 1.15) and conflict resolution (mean = 2.40/4, SD = 1.23). The mean level of depression, as indicated by the

Beck Depression Inventory, was 13.21 (SD = 9.25), which falls within the ‘mild depression’ range on this measure. Higher depression scores were observed among patients (mean= 16.07, SD = 9.60).

Procedure

Families were recruited from Memorial Sloan-Kettering Cancer Center (MSKCC) (86%) and two hospice agencies in New York: Calvary Hospital (9%) and the Visiting Nurse Service (5%). Research assistants identified medically eligible patients and administered FRI screening during outpatient visits or by telephone. Eligible families were asked to complete an informed consent procedure which included permission to record therapy sessions. Families were randomized to receive either six (45.2%) or 10 (54.8%) sessions of FFGT. Those randomized to receive standard care (control arm) were not represented in this sample, as this analysis focused only on therapy. The study was approved by the Institutional Review Boards at all participating sites.

Therapists were masters or PhD-level clinicians from the fields of psychiatry, psychology and social work, with postgraduate training as family therapists. Therapists completed a five-hour FFGT training workshop, which used didactic and experiential role-play methods. Adherence to the model was maintained through weekly supervision, as well as ongoing fidelity appraisal, summarized in a feedback report alerting therapists to areas of low and high fidelity.

Intervention

FFGT is a manualized, empirically supported intervention.[16] Its objective is to strengthen family functioning, and thus promote coping and adaptive grieving. Sessions are 90 minutes long and predominantly held in the home. FFGT is divided into three phases: assessment; focused intervention; and consolidation/termination. The current analysis focuses on the assessment phase (sessions 1 and 2), as content in this phase of therapy is equivalent across the six- and 10-session arms.

Measures

FFGT session coding instrument—The FFGT manual was thematically analyzed to extrapolate goals and core themes for each phase of therapy and these were subsequently built into scales that represented both content (i.e., ‘therapist reviewed family patterns of expressing conflict’) and process of therapy (i.e., ‘therapist provided summaries of issues discussed’).[17] While some items rate the presence or absence of events and therapist's behaviors, others record the number of questions asked about a theme – primarily patterns of family communication, conflict, cohesiveness and grief. A coding manual defined each item, including explicit guidelines for rating each item. A coding sheet was employed for each session reviewed. Three raters (F Del Gaudio, T Zaider and M Brier) were trained to reliability in the application of this instrument. The average inter-rater agreement was 88%. In addition, therapists’ process notes were analyzed in an effort to recognize the key challenges they identified. Missing information was coded as absent. Reasons for missing ratings included missing segments of the audio recording, or technical difficulties in hearing portions of a tape.

Ratings on this measure captured the following five therapist behaviors:

(1) *Engagement*: The therapist describes the merit of family meetings and gathers information pertaining to the story of the illness, such as when and how the patient was diagnosed, and how the family-as-a-whole has been coping. While assessing individuals' expectations, the therapist is committed to building rapport with each family member, thus forming a connection that will advance the therapy.

(2) *Genogram assessment*: Through a graphic representation of a family tree, the therapist maps out a three-generational picture of the family, highlighting relational patterns and roadblocks. The goal is to identify prior coping responses to serious illnesses and deaths, patterns of grief following losses, and exceptional events in the family's narrative.

(3) *Relational assessment:* The therapist promotes awareness of communication patterns, cohesiveness and management of conflict. Review of communication facilitates discussion about death and dying, and reveals what barriers exist to open expression of concerns. Cohesiveness is defined as the ability of the family to function as a team, including the emotional involvement between members. Conflict resolution is understood through an investigation of how the family negotiates and resolves disagreements. Specific types of questions are used to deepen understanding ofthese domains.[18]

(4) *Assessment of family identity:* The therapist elicits key aspects of family identity, including core values and beliefs (e.g., spiritual or religious beliefs). In addition, the therapist asks the family to generate a 'family motto' that reflects how the family views itself.

(5) *Establishing focus of therapy*: The therapist guides the family toward reaching consensus about their main concerns and goals for treatment, and offers a summary of family functioning, balancing strengths with concerns. Once this agreement is reached, the treatment program is planned.

FFGT therapist process notes—Following each session, therapists completed structured process notes for weekly peer-group supervision, in which they outlined their formulation of the family's main concerns, key interventions, perceived outcome and challenges encountered in the session. These written accounts by therapists formed a complementary record alongside audiotapes of rated sessions.

Results

Table 2 presents the frequency of therapist interventions across coded sessions. We elaborate below on each domain, with session excerpts illustrating examples of successful vs challenging delivery of these interventions. Identifying names or other details are altered to preserve confidentiality.

Successful vs challenging engagement of the family

Engaging the family in treatment, a fundamental part of any family meeting, is an ongoing process which requires the therapist to demonstrate understanding and support for each individual, while avoiding alliances with any particular person or point of view. In FFGT, successful engagement required the therapist to: (1) orient the family to the session; (2) explore family members' expectations for support and chief concerns; (3) clarify the purpose of meeting together; (4) gather the story of the illness and ways of coping; and (5) engage less vocal members. As shown in Table 2, the majority of sessions featured these interventions, with the highest prevalence rate (97%) attained for eliciting the story of the illness and assessing ways of coping.

Families sometimes bring a focused agenda to sessions, as illustrated in the following excerpt in which a father's illness raised concerns about a handicapped son, Jacob [Case 063]:

> There is the Jacob issue... there is the driving issue! (Laurie [wife])
>
> ... my biggest issue is how things will be in the future without me, particularly as the future involves our son, Jacob, and there will be implications when I'm sick or dead since I'm doing a lot of the work with Jacob. (Peter [patient])

In some cases, a family's agenda diverges from that of the clinician, or a family member questions the benefit of meeting, thereby blocking engagement. One family member stated [Case 015]:

> Truthfully, I hope it's good for them; it doesn't do a lot for me, but I'm with them.

When family members express reluctance or uncertainty about meeting, the clinician frames clear goals for supporting the family together, and maintains an unambiguous focus on the illness, its impact and family relationships. One therapist summarized an agenda as follows:

> Sometimes families have roadblocks in communication and when they face something like this, problems might get magnified. We can talk about your communication and conflict resolution as things get difficult during times of stress. [Case 043]

Successful vs challenging relational assessment

The therapist asks questions that call attention to the *process* by which the family operates, thus promoting awareness of broad patterns of relating (cohesiveness, communication and conflict management) that may be disrupted by illness. In this sample, 76% of clinicians engaged in a comprehensive discussion of family communication and 76% for cohesiveness.

Interestingly, only 35% of sessions included a detailed discussion of family conflict. Several families were reluctant to discuss conflict, preferring to focus instead on the positive. One daughter avoided discussion of her father's drug abuse, because it had caused prior conflict. She did not want 'to go there' when time was precious, as she thought they were 'in a good place now' [Case 061]. Therapists managed reluctance by normalizing conflict as a natural facet of family life, and focusing their exploration on how the family has negotiated

differences in the past. Therapists balanced curiosity about aspects of longstanding conflict with respect for the family's wish to remain silent.

During a relational assessment, family secrets were sometimes revealed. In one case [Case 100], adult children disclosed alcohol abuse in their parents. At the following session, the parents' absence was quickly understood:

> Therapist: What happened with mom and dad?
>
> Amanda [daughter]: They shut down at the end of the session. They did not appreciate the 'drinking problem' discussion.
>
> Pam [sibling]: Do I wish that this didn't happen? No, I would have done the same... I don't think that we can address that dad is going to die without addressing the past.

While the revelation led the parents to avoid further sessions, it proved to be a valuable experience for the sibling group, as described by the patient's son:

> After you left, Stephanie [therapist], we went to get coffee and I never felt closer to my siblings. We were digesting what went on there.

Successful vs problematic assessment of family history

Therapists investigated historical influences on the family's patterns of relating and coping by engaging the family in a 'family tree' exercise. Family history-taking is designed to be interventive in its own right, raising the family's awareness of cross-generational strengths and vulnerabilities that inform current responses to stress. Patterns of grieving prior losses, marital styles and relational cut-offs prove informative.

Clarifying the purpose of a genogram helps meaningful engagement, but this occurred in only 43% of sessions. When the family did not understand the rationale for this exercise, members were reluctant to participate [Case 055]:

> Olivia: I don't know what all of this is telling you, because it is not telling me a damn thing.
>
> Therapist: We're looking at how your extended family has related to each other, to understand your level of connection and how people get along, [or] didn't get along, and how they supported each other in different crises.
>
> Olivia: That doesn't make much sense to me.

Emphasizing sources of resilience in the family's past is one way to salvage cooperation and protect against any sense of persecution. Nevertheless, discussing historical material sometimes raises painful feelings and memories. In another family [Case 083] where parents kept many secrets, the clinician's investigation of past relationships elicited disapproval:

> Mary: He is a sick man. I don't know why we have to bring in all of this.
>
> Therapist: Sometimes the way we understand families and all they are going through... is to understand what has happened in the past.

Therapists who navigated this challenge successfully were able to acknowledge and respect a family's protective urge, and tie the information elicited into the family's presenting concerns. When the family's present behavior is understood in a historical context, blame can be avoided and empathy offered for why such behaviors exist. Sometimes families recognize recurring patterns for the first time, this new insight then empowering fresh choices to change the pattern.

In one family [Case 014], prior experiences of loss were connected to the prevalence of depression in the family:

> Therapist: I can see that was a very unsettling phase of your life, causing tremendous anxiety... It's curious how it is repeated across the generations... those experiences were hard and people have been at risk of depression... depression is not any one person's fault, or a failure on their part... but rather there is a genetic loading which makes them vulnerable...

Successful vs problematic appreciation of family identity

Exploring a family's identity and values provides a frame through which to highlight sources of pride and solidarity. Interventions here included: (1) eliciting a ‘family motto’; (2) identifying roles and expectations of family members; and (3) discussing values and beliefs. Therapists may hesitate to inquire about family values lest the struggle to identify meaningful traditions could highlight deficits. One family [Case 055] viewed it as a difficult task:

> Therapist: Can we think as a family about the motto... and see what you come up with?
>
> Christina [mother]: Do we even care? I don't know why this is important.
>
> Tom [father]: I don't think you're going to get a motto!

When the family is willing to join in, this can be a powerful way to help a family to define itself and reaffirm its strengths and constructive beliefs.

> [Case 088] Therapist: So now you've got three different mottos... be open and honest is the key to success, love and support, and have a good laugh.
>
> Eric [son]: Let's make it simple: ‘open and honest is the key to success, while having a good laugh’.
>
> Fred [patient]: We are a loving family with a good laugh.

Successful vs problematic identification of focus of therapy

A key task for therapists is to achieve consensus on a focus for sessions. This often involves synthesizing complex information to create a clear agenda for continued support. One helpful approach is to summarize the concerns raised, yet only 58% of therapists appropriately did so. Sometimes, there was within-family disagreement on the value and focus of therapy. At other times, therapist and family agendas diverged. Ambivalence about the merit of discussing end oflife concerns is one example [Case 057]:

> Elizabeth [patient]: It's hard. Nobody talks about death... not our favorite dinner topic! We accept it as part of life... I don't see dwelling on death as constructive... You feel like you're jumping the gun in discussing death.

Based on the family's main concerns, therapists were asked to formalize a treatment plan, which was only done well by one fifth of therapists within these first two sessions. Many waited until supervision before returning with a plan in session 3. Successful formulation of a treatment plan typically incorporates each family member's perspective, so that everyone becomes a stakeholder in the process:

> Therapist [Case 014]: We have been identifying your strengths... there is great love and a special way of caring... We've also identified a focus for our work: supporting those who are a concern... one is you, Clare, because of your exhaustion and your hard work in taking care of Anne. Another is you, Susan, because of your closeness to your mother... Does the cultivation of support, then, seem a worthy goal?

If the focus of family meetings remains unclear, the alliance with the therapist is at risk for rupture during subsequent sessions, as occurred with this family:

> Therapist [Case 057]: You are trying to figure out what we are doing here... it is really up to you to do with it what you want... I want the sessions to be helpful, but the way they are going to be helpful is for you guys to decide...

Here the therapist's insistence that the family initiate the agenda ended with them not seeing a constructive way forward in future meetings. Experienced therapists will partner with the family, while bringing their clinical wisdom to the fore in identifying achievable goals.

Finally, the formulation of a summary that integrates the strengths and concerns elicited during a session provided a frame for the work that lies ahead. This was seen in 39% of sessions, as illustrated below [Case 063]:

> Therapist: Let's sum up. What is really impressive is how much love and care there is that generates a real frankness... you declared a number of challenges that have been with you throughout family life... our meeting together gives the chance to optimize the way you connect and understand each other and achieve effective communication... so in the end, we are really supporting the love that is there, and turning that into a powerful force.

Challenges experienced by therapists

As part of their completion of structured process notes, therapists identified particularly challenging moments in each session, as summarized below:

In-home therapy presented unique issues for therapists. Concerns about boundaries, hierarchy and space were challenging when meetings occurred in the home:[19]

> A major difficulty has been the physical set-up of the seating in the living room. I am unable to see all three members as we speak. [Case 064]

> It was difficult to have a session in the family's apartment... given the noise of television and visitors walking in and out, it was very difficult to concentrate. [Case 1505]
>
> ... the family had dinner during the session ... Lynne drank three glasses [of wine]... she got angrier as the session progressed... I wasn't certain how to broach the fact that drinking alcohol wasn't conducive to a constructive discussion. [Case 075]
>
> Maya continually getting up and making phone calls proved very distracting. [Case 090]

Home-based treatment was especially difficult when conflict was prominent, as the therapist risks loss of control and safety:

> Bianca was very angry... and it was difficult to interject... she was saying hurtful things to Carol... Bianca was not remotely apologetic. [Case 054]

When therapists were confronted with expressions of grief, difficult personal feelings surfaced:

> This is personally and professionally challenging as I have limited experience in dealing with death and dying. [Case 042]
>
> I felt uncomfortable asking them to pierce their veil of optimism by contemplating a future hypothetical where she is dead. [Case 074]
>
> When Jackie finished talking, she looked me in the eye and asked, ‘How will I know when it is time?’... My initial reaction was panic... it became clear why we were here. It was hard to sit through the pain and continue to find the balance of my own emotions. [Case 052]

Family therapy in palliative care requires a model that is focused and time-limited. Therapists struggled to achieve a balance between maintaining a focus, while acknowledging longstanding concerns, as noted by one therapist:

> I felt time constraints interfering with constructing the genogram, collecting family stories, and making hypotheses about intergenerational patterns... there was no time to brainstorm or problem solve an issue. [Case 510]

Discussion

The rich qualitative data that emerged here highlight the challenges encountered by clinicians working with families in palliative care. The family is increasingly the primary caregiving system, and carries a burden that can easily be left unaddressed when patient-centered care prevails. There has been increased recognition of the need to support the family-as-a-whole during palliative care. While there is consensus that this is necessary, there have been few clinically based guidelines to inform clinicians as to how supportive therapy should be conducted.[13]

Our study provided insight into how family meetings can assess families who are considered ‘at risk’ for psychosocial morbidity. The families described here scored low on a family

functioning screening measure, reporting difficulties in communication, cohesion and conflict, in addition to varied levels of depression. Overall, therapists were able to adhere to the majority of interventions prescribed, suggesting that FFGT can be applied by therapists practicing in the community. Interventions that were more challenging to implement included: (1) assessing family conflict; (2) constructing a family genogram; and (3) formalizing a treatment plan.

Families with a history of unresolved conflict are prone to increased disagreement and volatility at the end oflife.[20] Relatively few sessions included an early exploration of conflict, even when the capacity for conflict management was rated poorly by several families. As noted by Chan and colleagues,[20] conflict may be more safely explored later in therapy, when the family and therapist have established a stronger alliance and mutual comfort. This latter approach can be constructive if the pattern of conflict is accepted and not representing any unfinished business. When therapists are able to tolerate high levels of conflict, they become more successful in recognizing maladaptive patterns of interacting, a precondition for fostering the family's capacity for mutual support in the aftermath ofloss.

The family genogram proved challenging for many therapists as well. Constructing a narrative based on family history helps the group to contextualize their present concerns, serving as both a therapeutic tool and a data-gathering exercise.[21] A common risk for therapists was becoming overly focused on gathering historical data, without exploring relational themes (i.e., how did your family grieve the loss of this parent?). In several instances, therapists helped families uncover key multigenerational patterns, building awareness of ‘habits’ that had been inherited from prior generations. Byng-Hall conceptualized these patterns as scripts that families follow.[22] This exercise proved challenging when therapists did not sufficiently clarify its rationale or gain ‘buy-in’ from families. Some therapists struggled to link multigenerational information with the current problem.

Formalizing a treatment plan early in therapy was another challenge. When there was discordance within the family about their agenda, therapists had difficulties finding common ground and integrating the various perspectives presented. Sometimes a therapist's own agenda proved incongruent with the family's needs, such as when one therapist encouraged discussion of death and dying without the family's permission. In other cases, treatment planning was absent because the purpose of meeting was already evident to all. Therapists who succeeded in establishing a treatment plan identified family concerns alongside their strengths, and named their motivation to work towards change. Goals directed at open communication, shared teamwork and tolerance of differences proved worthwhile for many families.

Additional challenges derived from conducting therapy in the family's home, where defining boundaries can be difficult.[23] Establishing guidelines at the very beginning empowers the process of therapy - for example, asking participants to turn off cellphones and postpone meals. Christensen[24] recognized that training programs have ignored the special issues raised by working in the home. Another shortcoming of most training programs is the challenge of addressing death and dying. The clinician must contain considerable emotional

pain and grief.[25] While our study highlights some of these challenges, an important future step will be to look statistically at whether the therapist behaviors described are linked to specific therapy outcomes.

Developmentally, palliative care services need to employ appropriately trained social workers or psychologists to deliver family therapy. Commencing this family work before the death of the patient brings the patient's voice into the room and assists recall of their wishes for the family during bereavement. Such continuity of care solidifies engagement of the therapist with the family, thus sustaining support through more difficult periods and assisting with their overall adaptation.

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References

1. Rolland, JS. Families, illness, & disability: an integrative treatment model. Basic Books; New York: 1994.
2. Blanchard CG, Albrecht TL, Ruckdeschel JC. The crisis of cancer: psychological impact on family caregivers. Oncology. 1997; 11:189–202. [PubMed: 9057175]
3. Folkman S, Moskowitz JT. Coping: pitfalls and promise. Annu Rev Psychol. 2004; 55:745–774. [PubMed: 14744233]
4. Pitceathly C, Maguire P. The psychological impact of cancer on patients' partners and other key relatives: a review. Eur J Cancer. 2003; 39:1517–1524. [PubMed: 12855257]
5. Kissane DW, Bloch S, Burns WI, McKenzie D, Posterino M. Psychological morbidity in the families of patients with cancer. Psychooncology. 1994; 3:47–56.
6. National Institutes of Health (NIH). Improving end-of-life care. NIH Consens State Sci Statements. Dec 6–8; 2004 21(3):1–28.
7. World Health Organization (WHO). [12th October, 2011] WHO Definition of Palliative Care. www.who.int/cancer/palliative/definition/en/
8. Fineberg IC. Preparing professionals for family conferences in palliative care: evaluation results of an interdisciplinary approach. J Palliat Med. 2005; 8:857–866. [PubMed: 16128661]
9. Gueguen JA, Bylund CL, Brown RF, Levin TT, Kissane DW. Conducting family meetings in palliative care: themes, techniques, and preliminary evaluation of a communication skills module. Palliat Support Care. 2009; 7(2):171–179. [PubMed: 19538799]
10. Hudson P, Quinn K, O'Hanlon B, Aranda S. Family meetings in palliative care: multidisciplinary clinical practice guidelines. BMC Palliat Care. 2008; 7:1–12. [PubMed: 18197982]
11. Kissane DW, Bloch S, Dowe DL, Snyder RD, Onghena P, McKenzie DP, et al. The Melbourne family grief study, I: perceptions of family functioning in bereavement. Am J Psychiatry. 1996; 153(5):650–658. [PubMed: 8615410]
12. Kissane DW, Bloch S, Onghena P, McKenzie DP, Snyder RD, Dowe DL. The Melbourne Family Grief Study, II: psychosocial morbidity and grief in bereaved families. Am J Psychiatry. 1996; 153:659–666. [PubMed: 8615411]
13. Kissane DW, McKenzie M, Bloch S, Moskowitz C, McKenzie DP, O'Neill I. Family Focused Grief Therapy: A randomized, controlled trial in palliative care and bereavement. Am J Psychiatry. 2006; 163:1208–1218. [PubMed: 16816226]

14. Grunfeld E, Folkes A, Urquhart R. Do available questionnaires measure the communication factors that patients and families consider important at end of life? J Clin Oncol. 2008; 26:3874–3878. [PubMed: 18688055]
15. Wackerbarth SB, Johnson MM. Essential information and support needs of family caregivers. Patient Educ Couns. 2002; 47:95–100. [PubMed: 12191532]
16. Kissane, DW.; Bloch, S. Family Focused Grief Therapy: a model of family-centred care during palliative care and bereavement. Open University Press; Buckingham and Philadelphia: 2002.
17. Chan EK, O'Neill I, McKenzie M, Love A, Kissane DW. What works for therapists conducting family meetings: treatment integrity in family-focused grief therapy during palliative care and bereavement. J Pain Symptom Manage. 2004; 27(6):502–512. [PubMed: 15165648]
18. Dumont I, Kissane D. Techniques for framing questions in conducting family meetings in palliative care. Palliat Support Care. 2009; 7(2):163–170. [PubMed: 19538798]
19. Thomas V, McCollum EE, Snyder W. Beyond the clinic: in-home therapy with Head Start families. J Marital Fam Ther. 1999; 25(2):177–189. [PubMed: 10319291]
20. Kramer BJ, Boelk A, Auer C. Family conflict at the end of life: lessons learned in a model program for vulnerable older adults. J Palliat Med. 2006; 9:791–801. [PubMed: 16752985]
21. McGoldrick, M.; Gerson, R. Genograms in family assessment. Norton; New York, NY: 1985.
22. Byng-Hall J. Scripts and legends in families and family therapy. Fam Process. 1998; 27:167–180.
23. Snyder W, McCollum EE. Their home is their castle: learning to do in-home family therapy. Fam Process. 1999; 38(2):229–242. [PubMed: 10407722]
24. Christensen LL. Therapists' perspectives on home-based family therapy. Am J Fam Ther. 1995; 23:306–314.
25. Gamble, SJ. Self-care for bereavement counselors.. In: Webb, NB., editor. Helping bereaved children: a handbook for practitioners. Guilford; New York: 2002. p. 346-362.

Table 1

Sample demographics and baseline functioning.

	Total		Patients		Spouses		Offspring		Other (e.g., siblings)	
	n	%[a]	*n*	%[a]	*n*	%[a]	*n*	%[a]	*n*	%[a]
Number	299	100	62	21	54	18	109	36	74	25
	Mean (SD)		**Mean (SD)**		**Mean (SD)**		**Mean (SD)**		**Mean (SD)**	
Age (years)	43.8 (17.6)		56.2 (12.6)		56.7 (11.9)		33.2 (12.6)		50.4 (17.9)	
	n	%[a]	*n*	%[a]	*n*	%[a]	*n*	%[a]	*n*	%[a]
% Female	182	61	36	19	23	13	71	39	52	29
% Caucasian	235	79	50	21	47	20	89	38	49	21
% Married	170	57	48	28	48	28	37	22	37	22
Family Functioning	**Mean (SD)**		**Mean (SD)**		**Mean (SD)**		**Mean (SD)**		**Mean (SD)**	
Total FRI[b]	8.13 (2.13)		7.88 (2.26)		8.09 (2.20)		7.51 (2.12)		8.27 (2.02)	
Expressiveness	2.27 (1.15)		2.31 (1.15)		2.22 (1.18)		2.28 (1.13)		2.24 (1.16)	
Cohesiveness	3.46 (0.80)		3.26 (0.86)		3.33 (0.89)		3.35 (0.79)		3.54 (0.67)	
Conflict Resolution	2.40 (1.23)		2.31 (1.32)		2.54 (1.08)		1.88 (1.54)		2.49 (1.34)	
Depression BDI[c]	13.21 (9.25)		16.07 (9.60)		13.96 (8.45)		12.40 (9.38)		11.82 (8.60)	

Note:

[a]Percentages may not add to 100 due to rounding

[b]Family Relationships Index = Expressiveness + Cohesiveness + Conflict Resolution

[c]Beck Depression Inventory

Table 2

Prevalence of therapist interventions during assessment phase of FFGT.

Interventions	Prevalence
Engagement	
Orient to therapy	78%
Explore family expectations	70%
Clarify purpose of therapy	64%
Explore family's understanding of illness	97%
Discuss family coping in response to pt.'s illness	97%
Engage less vocal members	92%
Relational Assessment	
Teamwork and cohesion	76%
Communication	76%
Conflict resolution	35%
Family Genogram	
Genogram rationale	43%
Identify patterns of relating	89%
Identify patterns of expressing grief	72%
Link patterns across generations	66%
Discuss family history across three generations	80%
Family Identity	
Elicit family motto	34%
Clarify roles/expectations	65%
Identify values and beliefs	62%
Focus of Therapy	
Present summary of concerns	39%
Develop formalized treatment plan	20%
Establish goals of therapy	58%
Identify family strengths	67%