



HHS Public Access

Author manuscript

Bereave Care. Author manuscript; available in PMC 2018 August 03.

Published in final edited form as:

Bereave Care. 2013 ; 32(3): 117–123. doi:10.1080/02682621.2013.854544.

Family focused grief therapy: a versatile intervention in palliative care and bereavement

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Abstract

A diagnosis of advanced stage cancer is a difficult life event for the entire family. Previous studies have demonstrated the negative psychosocial outcomes associated with the burden of caregiving in conjunction with dysfunctional family relations. Family Focused Grief Therapy (FFGT) is a time-limited intervention that has been shown to be effective in aiding dysfunctional families through the promotion of family functioning, communication, cohesiveness, and conflict management. This paper outlines the content of FFGT therapy and highlights its unique aspects as well as the challenges of providing therapy to different types of families in the context of palliative care. FFGT shows promise as an effective intervention applicable across multiple settings in the future.

Keywords

bereavement; family; grief; palliative care

Introduction

When a family member is diagnosed with advanced cancer, the effects are not confined to the dying patient; they are felt throughout the entire family. During this time, family members often struggle with the balance of providing care to their loved one, while internally coping with the emotional distress of his or her impending death. As family members most often become the primary caregivers during palliative care (Del Gaudio, *et al* manuscript unpublished) the family environment is particularly relevant to this experience.

The impact of family functioning

When a well-functioning family receives the diagnosis of advanced cancer, members work together to share caregiving duties, lend support to one another, and grieve and move forward together in the face of bereavement (Kissane & Bloch, 1994). A dysfunctional

family, however, may unwittingly handicap these processes. Moreover, our prior work has shown that the family environment can affect the onset of, or perpetuate, psychosocial morbidity which may accompany the ill member's transition to palliative care or occur following bereavement (Kissane, Bloch & Dowe *et al.*, 1996). Thus, a family-focused approach as part of care received by patients and families receiving an advanced cancer diagnosis is crucial if we are to foster healing and treat (or prevent) psychosocial morbidity in this context.

To target families that may benefit from further support, a typology of 701 Australian families coping with cancer in the palliative care setting was empirically-derived using the Family Relationships Index (FRI) (Moos & Moos, 1994). The FRI was administered to screen for randomised clinical trial (RCT) eligibility for a trial testing the efficacy of a family-focused psychosocial intervention. The typology was based on members' perception of relational functioning within the family environment.

Five types were identified. Two are well-functioning, with adaptive psychosocial outcomes following bereavement. In the well-functioning families, called 'supportive' and 'conflict-resolving', cohesion and mutual support are high (Kissane, Bloch & Dowe *et al.*, 1996). Two other types are dysfunctional, and many of their members report morbid psychosocial outcomes. These families, termed 'sullen' and 'hostile', engage in maladaptive, dysfunctional interaction patterns (ie. lower cohesiveness, lower expressive communication, and greater interpersonal conflict). Hostile families are chaotic and help-rejecting, while sullen families carry the highest rates of depression, yet show willingness to accept help (Kissane *et al.*, 2003). The fifth type, called 'intermediate', shows moderately-reduced cohesiveness (Kissane, Bloch & Dowe *et al.*, 1996), with its members also at heightened risk of poorer psychosocial outcomes (Kissane, Bloch & Onghena *et al.*, 1996).

Regarding specific morbid outcomes, family members of 'at-risk' families (ie. hostile, sullen, and intermediate) reported significantly higher levels of depressive symptoms and higher levels of global psychological morbidity (including somatisation (ie. experiencing psychological distress as physical symptoms), obsessive-compulsive behaviour, interpersonal sensitivity, depressive symptoms, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism). Members of dysfunctional and intermediate families also reported poorer social adjustment across domains of housework, work, social and leisure activities, relationships with children and extended family, and overall social functioning – regardless of partnered/marital status (Kissane *et al.*, 2003). Compared with intermediate families, the more dysfunctional types also carried poorer social functioning across domains of housework, social and leisure activities, and overall social functioning. Finally, members of these two more dysfunctional types who reported elevated depressive symptoms also reported poorer relationships with their children (Kissane *et al.*, 2003). These data illustrate the decline in psychosocial functioning from well-functioning, to intermediate, and finally to dysfunctional family types. In this line of research, 50% of families in the palliative care setting were shown to resemble the two well-functioning types, while 15–20% carried features of the two dysfunctional types. The rate of dysfunctional features was observed to increase to 30% during early bereavement, before returning to pre-bereavement levels of 15–20%. This increase in the prevalence of dysfunctional features to 30% was largely due to the

effects of bereavement on intermediate families. In the palliative care setting (prior to bereavement), intermediate families comprised approximately 30% (Kissane *et al*, 2003). Overall, this typology permits routine screening with the FRI to identify families ‘at risk’ of morbid psychosocial outcomes. In sum, we recommend screening, followed by preventative and continued psychosocial care, for families identified as belonging to dysfunctional (ie. sullen and hostile) and intermediate family types.

Family-focused grief therapy: An intervention for ‘at risk’ families

The typology above guided the conceptualisation and design of Family-Focused Grief Therapy (FFGT). FFGT is a prophylactic intervention targeted to patients and families belonging to ‘at risk’ families coping with terminal cancer. The intervention prioritises the family as the natural context in which distress due to illness and loss is expressed and metabolised. Research spanning the last two decades has provided a strong empirical basis for intervening early with the distressed family simultaneously coping with bereavement, and mobilising relational resources to ensure the long-term adaptation of its members. FFGT is a relatively-brief, manualised and transportable therapy that can be competently delivered by clinicians of various psychosocial disciplines. Working with the family as a whole often enables recognition of individual members’ emotional needs, and therefore is an approach that easily complements other support modalities. The continuity of care prior to and following the adverse life event (in this case, loss of a loved one from illness) is a unique aspect of this therapy, and presents an opportunity for families to change the course of their adaptation.

A description of FFGT’s course is offered here. Delivery of the therapy is standardised with a manual, extensive training and supervisory support (Chan *et al*, 2004). Therapists have been masters and PhD-level clinicians with post graduate training as family therapists (Del Gaudio *et al*, 2011). In addition, therapists are trained specifically in Family Focused Grief Therapy at a one-day workshop utilising role-play exercises. Fidelity to the treatment model is further ensured through weekly supervisions, during which therapists receive a feedback report highlighting areas of low and high fidelity (Del Gaudio *et al*, 2011).

Assessment sessions

Therapy begins with engagement, an integral domain by which therapists build rapport with the family and gather background information regarding the patient’s illness and family functioning. During the assessment phase, comprised of sessions one and two, it is customary for the therapist to inquire about expectations for the sessions. This allows each family member to voice his/her concerns and provides the greatest likelihood of merging the hopes of family members and promoting understanding among members (Kissane & Bloch, 2012). During the assessment phase, prompting the family to tell the story of the patient’s illness as it pertains to the family’s functioning and coping is an important exercise. At this time, the therapist is able to collect data on the coping styles and emotional reactions of individual family members as well as gain insight into how the family has been managing the patient’s illness (Kissane & Bloch, 2012).

One of the major goals of the assessment phase is to learn about the ‘3 C’s’ of the family relationship: communication, cohesiveness, and conflict (Kissane & Bloch, 2012). These three aspects of family functioning have driven our classification system and have been found to be particularly relevant to familial relations. The therapist seeks to assess communication utilising questions such as (Kissane & Bloch, 2012 p. 39):

‘What is it like when you try to tell your family about important things?’

‘Do you talk much as a family about X’s cancer?’

‘Do you feel you are able to get your ideas across and be heard when speaking with your family?’

These inquiries reveal the degree of honesty in communication between family members and the mechanisms that block it. In assessing cohesiveness, the therapist assesses how the family is able to work as a team through asking questions about how the family is able or unable to support the patient together (Kissane & Bloch, 2012 p. 40):

‘Has the patient’s illness brought you closer together as a family or further apart?’

‘How well do you team together to help X?’

‘How do you feel about X’s illness? What’s it like when you try to share your feelings? Are you a family that expresses feelings?’

Through discussions of cohesiveness the therapist is able to recognise family strengths as well as recognise and clarify observed patterns within the family. In addition, the therapist identifies the conflict that exists within the family. This can be a sensitive subject, therefore, it is necessary for the therapist to normalise conflict within families and observe the frequency of conflict and degree of resolution within this particular family. The therapist may ask questions such as (Kissane & Bloch, 2012 p. 41):

‘How do you handle differences of opinions? Are individuals encouraged to have their own opinions or is consensus valued above all else?’

‘Which family members forgive, which resolve, and which hold resentments?’

In addition to asking questions outlined above, FFGT therapists utilise genograms to gain insight into family relationship patterns, grief patterns, blocks, and significant life events. This exercise aids families in exposing vulnerabilities and patterns and ties these into the family’s current concerns (Kissane & Bloch, 2012). As the assessment phase concludes, the therapist presents a summary of identified strengths and weaknesses to promote treatment plan formulation. An example of this task is shown in the quote, extracted from an FFGT session, below:

‘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 optimise 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.’

Intervention sessions

In the subsequent intervention phase, supporting this focused agenda, the frequency of meetings is tailored to the family's strengths and needs as well as to the health and well-being of the cancer patient. With these considerations, meetings often occur every three or four weeks and are frequently held in the home as the patient becomes too ill to travel during the palliative care phase. The transportability of the therapy becomes particularly advantageous at this time. Meetings in the inpatient setting are invaluable for utilising potential crises as opportunities for transition and change.

During the intervention phase, therapists review the family's concerns elucidated in the assessment phase, bolster the family's strengths, and further the discussion of family coping and grief. At each intervention session the therapist assesses the '3 C's' and prompts family members to summarise the family's progress in terms of the identified key concerns. It is imperative that, as well as identifying barriers to change and further problems, that the therapist praises accomplishments and any improved family cohesion as a means to bolster the family's efforts to achieve change (Kissane & Bloch, 2012).

Therapists examine how each member is coping with the topics that present themselves as the patient's illness progresses such as: suffering, coming to terms with the pending death, and saying good-bye. The review of communication, cohesiveness, and conflict in the intervention phase often take on new forms as new issues such as grief and bereavement are often presented during this phase. Once bereavement has occurred, therapists observe reactions to grief and promote communication of feelings as opposed to problematic patterns of stoicism and avoidance (Kissane & Bloch, 2012). Promoting this type of shared grief is also helpful in building cohesiveness within the family. Therapists frequently attend funerals to foster the therapeutic connection, while signaling their deep regard for the deceased and the bereaved. Continuation of therapy following bereavement ensures continuity of care and builds on the family's relationship with direct knowledge of the deceased – whose wishes and motives can direct subsequent sessions (Kissane & Bloch, 2012). Active sharing of family grief is normative during bereavement work. The construction of new meaning, fresh roles and relational changes is sought.

Consolidation and termination sessions

As signs of resolution emerge, the length of time between sessions is increased to once every two months, then once every three months, and therapy termination is openly prepared for. These latter sessions include relapse prevention strategies aimed at maintaining change and the consideration of future approaches to sustain current direction and momentum (Schuler, Zaidler, & Kissane, 2012). A common exercise is to invite the family to express features of behaviour that might be problematic in the future and to consider how they might handle these in the future.

During this stage of therapy, it is likely that that family is coping with the loss of their loved one. As opposed to other bereavement work in which the therapist has never met the bereaved, the continuity of care by FFGT therapists can prove to be advantageous in terms of reminiscing and achieving family goals. FFGT therapists have knowledge of not only the

family but the lost loved one and therefore can express the words and sentiments of the deceased and powerfully bring them into therapy with the bereaved (Kissane & Bloch, 2012).

The termination of therapy provides a special opportunity for the therapist to share his/her personal feelings for the benefit of the family (Kissane & Bloch, 2012). Saying good-bye can generate genuine feelings of sadness, which may be both appreciated and reaffirming for the family. The therapist expresses his/her confidence in the ability of the family to maintain changes and to take responsibility for continuing their work together in the future.

Therapy challenges by 'at risk' family type

While the process of FFGT can be incredibly rewarding, it is often challenging for therapists to provide therapy to intermediate, sullen, and hostile families. Overall, therapists working with hostile families exhibit the lowest fidelity ratings compared to those working with sullen or intermediate families (Del Gaudio *et al*, manuscript unpublished). In contrast, sullen families make more progress from one session to another. These families remain committed to changing their problematic patterns and moving forward, allowing for reflection and praise for the progress the family has made. [Quotations provided from audio recordings of FFGT sessions]

'So I think that you're telling me that you actually moved into a thoughtful and very constructive direction to avoid a squabble lining up...and thus moving strategically to a mature resolution of the squabble.'

The intense and enduring conflict within hostile families is at times troubling and distracting to therapists:

'Initially, I found [R's] anger stop me. I did not know how to react, I felt somewhat challenged. I felt that he was saying, "You can't make it better, no one can! Or maybe even, "And don't try."'

This conflict not only creates discomfort, but hinders the family's progress throughout the course of therapy:

'When the session becomes very intense [S] becomes upset and wants to leave. The tension becomes high and then my concern for the session to be productive becomes compromised. Both sisters lack the ability to hear each other and listen. It also appears that they have not talked in between session so it's not apparent that they have made much progress.'

During sessions with hostile families, interactions can be volatile and aggressive, requiring the therapist to put out new fires again and again, rather than dedicating time to reflect and normalise the conflict:

'I want to stop because right now, [P], rather than again thinking of it as [J] coming on to you and saying that this is her fault, think about it relationally: what's happening and how can it be done different so you don't have to get so distressed that it escalates to violence? You don't have to be so distressed that the kids are withdrawing and struggling. This is a hard enough time.'

[Quotations provided from audio recordings of FFGT sessions]

Whether hostile (or highly dysfunctional) families can be helped by this model remains unanswered. They will be hardest to engage and clinicians should respect the wishes of very fractured families to not meet at all. Miracles are uncommon. An unwitting therapist could cause harm through over-enthusiastic efforts to bring very dysfunctional family members together in the same room. A golden rule here is to respect the family's established wisdom about what is safe. We have learnt that a key goal with the more dysfunctional families is to create safety, which usually means containing destructive conflict, inviting the family to reframe what is behind their disagreement and move to a more constructive and mutually cooperative stance. Where difficult families cooperate with this direction, progress can be made; where a family will not cooperate, they usually withdraw from family work.

The efficacy of family-focused grief therapy

Efficacy determined by the initial RCT

Evidence of the efficacy of FFGT was first demonstrated in an RCT of 81 families (353 individuals; (Kissane, McKenzie, Bloch *et al*, 2006)). Families were randomly assigned in a 2:1 ratio to receive either the intervention ($n=53$ families) or standard palliative care ($n=28$ families). Forty (75%) of the families allocated to intervention completed the therapy. The number of sessions provided was not predetermined in this study, and averaged close to four per family (range 0–13). Participating family members completed measures of distress and family functioning at enrollment (baseline) and then at six months and 13 months post-loss. Although perceptions of family functioning remained unchanged, FFGT was associated with a significant reduction in individual members' distress after 13 months of bereavement. Significant reductions in both distress and depressive symptoms were especially prominent for the 10% of family members most distressed at baseline, with a trend toward improved social functioning for this subgroup.

A current test of the efficacy of FFGT

A second RCT to test the efficacy of FFGT for American 'at risk' families (ie. hostile, sullen, and intermediate types) is underway. A primary aim of the second RCT is to determine what dosage of therapy is needed to promote adaption and prevent morbid outcomes in bereavement.

Procedure/measures—Families were randomised to three treatment arms: 10 sessions of FFGT ($n=57$ families), 6 sessions of FFGT ($n=58$ families), or standard palliative care ($n=55$ families). Families completed questionnaires on the same schedule as the initial RCT, described above with largely similar content areas assessed. This second RCT was funded by the National Cancer Institute and was ethically approved by the Institutional Review Board (Protocol #05–120).

Participants—A total of 170 families (including 620 individuals) signed a statement of informed consent and consented to participate in the study. Initial FRI responses classified 19% of enrolled families as the hostile type, 50% as sullen, and 31% as intermediate. Of the

620 family members enrolled, 21% are patients, 18% are spouses, 38% are offspring, and 23% are of another relation (eg. siblings, friends) with least two family members involved in the patient's care per consenting family. The majority of patients were diagnosed with advanced/Stage IV gastrointestinal (66%), skin (12%), and breast (5%) cancers. For all families, the patient's oncologist had prognosticated that the patient would survive one year or less.

Preliminary findings—As this second trial is nearly complete, we describe interim process and outcome data here. First, regarding outcome data, trends showing reduced psychological distress emerged in a preliminary data analysis conducted for the institution's patient safety data review board. Lower depressive symptomatology was reported by family members receiving any FFGT compared with controls (eg. mean Beck Depression Inventory (BDI) (Beck & Steer, 1993) scores for subjects ($n=213$) were $M=14.6$ ($SD=9.1$) at enrollment, and $M=9.4$ ($SD=7.6$) at six months of bereavement; mean BDI scores for families in standard care were $M=13.5$ ($SD=8.9$) at baseline, and $M=11.2$ ($SD=10.2$) at six months of bereavement). Moreover, for the 15% with highest distress scores on the Brief Symptom Inventory-global scale (BSI) (Derogatis, 2001), linear mixed effects models (Raudenbush, Bryk, & Congdon, 2002) comparing depressive symptomatology trajectories across intervention conditions (adjusted for baseline levels) showed statistically-significant decreases in depression scores for those receiving any FFGT (Schuler *et al.*, 2012)

The potential of this model of therapy to prevent complicated grief disorder (CGD) is also suggested by this recent trial, in which the Complicated Grief Consensus Criteria (Prigerson *et al.*, 2009) was used to compare the prevalence of CGD amongst family members who had reached bereavement. Examination of the first 174 participants at six months post-loss yielded CGD rates of 16% amongst those receiving any FFGT compared with 25% among controls.

To evaluate processes by which FFGT may promote change, family members reported their perceived degree of their family's communication expressed during each session. Data were collected for 58 families (196 individuals) across the first four sessions of therapy. These data were pooled across the six- and ten-session arms since manualised session content is similar across these arms. Changes in communication across sessions were examined using linear mixed effects modeling (Raudenbush *et al.*, 2002). Although variations were observed across individuals' trajectories, results suggested that, on average, family members perceived a significant overall increase in communication across these sessions ($\beta=1.26$, $se=0.18$, $t=7.07$, $p<.001$; (Zaider & Kissane, 2009).

Our reflection on unique and versatile aspects of FFGT

In tandem with our prior work (eg. Kissane *et al.*, 2003), preliminary data from our current tests of the efficacy of FFGT are encouraging. Here, we reflect on the distinctive intervention characteristics that may bolster FFGT's promise as an efficacious intervention for 'at risk' families coping with advanced cancer.

At the end of life, dying patients become less ambulatory and caregiving burden increases. Thus, sustaining families' engagement in therapy can be challenging. FFGT has, in response, evolved into a versatile model of support that can be delivered in the outpatient setting, at the hospital bedside, or in the home. Although therapists can struggle to clarify and maintain the structure of therapy when it occurs outside of the consulting room (Del Gaudio *et al*, 2011), the flexibility and transportability of this model have become essential to its feasibility. We have written at length elsewhere about guidelines for the safe conduct of therapy in the home (Kissane & Bloch, 2002). The willingness of the therapist to travel to the family home demonstrates the therapist's empathy and acknowledgement for the difficult time that the family is experiencing.

In addition to sustaining families' engagement in therapy, sessions taking place within the family home allow for the participation of family members who are initially opposed to therapy. Often the reluctance toward therapy is bred from a web of misconceptions and fears for these individuals. The ability to witness the work being done close by (where the unwilling relative is often in a neighbouring room) and choose to join the rest of the family in therapy are invaluable. If these sessions take place in an office outside of the home, these family members will not have this same opportunity to join in, heal, and evolve with the rest of their family.

Family Focused Grief Therapy has shown promise as an intervention that can be delivered across multiple settings and with sensitivity to families' cultural needs. FFGT therapists are able to approach families of different cultures with an air of respect and curiosity (Del Gaudio *et al*, 2012). The spirit of this approach promotes appreciation amongst the family and their willingness to share their customs and traditions. This ability to accommodate and relate to members of different cultures allows therapists to build stronger relationships, and also gain insight into the values that are reflective of both family functioning and coping (Del Gaudio *et al*, 2012).

Additional challenges of intensive, longitudinal family therapy trials in palliative care

A longitudinal study of this magnitude, targeting 'at risk' families in the throes of loss, inevitably presents challenges. Many challenges were expected; one of these has been, of course, difficulty retaining the full sample. This challenge has been cited in numerous longitudinal palliative care studies (eg. Bordeleau *et al*, 2003). In our study, the challenge is exacerbated by the inclusion of both patients and family members. Many families enrolled in the study consist of members residing in different homes and/or cities, which affect data collection and therapy attendance. In these cases, the strategy of utilising the diligent family members to encourage others to complete questionnaires or attend treatment is not as effective.

Summary and future directions

Family Focused Grief Therapy is a unique and versatile, time-limited intervention delivered to 'at risk' families during palliative care and bereavement. FFGT appears to be successful

in fostering open communication, supporting the sharing of grief and protecting against depression. The true value of this therapy however, is its mobile and accommodating nature. The ability for therapy sessions to take place in the family home allow for participation of immobile patients as well as integral family members that did not initially consent. Although this model may present challenges, the continuity of care preceding and following the patient's death offers a helping environment for the family to cope and move forward as a supporting and cohesive family unit.

Acknowledgements

The study has been funded by the National Cancer Institute grant number 5R01CA115329-06. A special thank you to the clinical research staff of the Family Focused Grief Therapy study, particularly Dr Talia I Zaider for her contributions and review of this paper. In addition, we would like to thank the FFGT families who volunteered to share their personal experiences during caregiving and bereavement with us, without your contributions this meaningful research would not be possible.

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