Dose-effectiveness RCT of preventive family therapy in advanced cancer: benefits for the bereaved

David W Kissane,[1,2,3] Talia I Zaider,[1,3] Yuelin Li,[1,3] Shira Hichenberg,[1] Tammy Schuler,[1] Marguerite Lederberg,[1] Lisa Lavelle,[4] Rebecca Loeb,[1] and Francesca Del Gaudio.[1]

[1] Department of Psychiatry & Behavioral Sciences, Memorial Sloan-Kettering Cancer Center, New York, NY, USA
[2] Department of Psychiatry, Monash University, Victoria, Australia
[3] Department of Psychiatry, Weill Medical College of Cornell University, New York, NY, USA
[4] Ackerman Institute for the Family, New York, NY, USA

National Cancer Institute RO1 grant number: CA 115329 awarded to D.W. Kissane

Family-centered care

- Preventive for families 'at risk': starts in oncology when advanced cancer status clear
- Screening can recognize dysfunction
- Key role for psychosocial care team

SCREENING TO DETECT HIGH RISK FAMILIES

- Family Relationships Index (FRI) Well validated scale (1981) - 12 item, true-false, pencil & paper
- 3 subscales:
  - cohesiveness 4 items
  - expressiveness 4 items
  - conflict 4 items
- Score up to 12: sum of cohesion + express + reversed conflict
- Sensitivity to detect family dysfunction 100%; depression 88% (Edwards & Clarke, 2005)
- Sensitivity to detect dysfunction 86% (Kissane et al, 2003)

Screening with 12-item FRI

[Family Relationships Index, Moos & Moos, 1974]

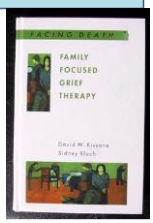
Study of 1809 US cancer patients (Schuler et al. 2014)

Family type	Number	%
Well functioning families = approx two thirds		
Supportive families	814	45
Conflict-resolving families	418	23
Families at some risk of poorer outcome = one third		
Low communicators	375	21
Uninvolved families	101	5.5
Conflictual families	101	5.5

Category	5 Family types	Rates	Features
Well functioning	Supportive	33%	Cohesive, Grieve well
Australian Family Typology 1996	Conflict Resolving	20%	Tolerant of difference, Adaptive
Low communicating	Intermedi-ate	33-20%	Mid-range, Some morbidity
Dysfunctional	Sullen (Uninvolved)	9-18%	Muted anger, Most depressed
	Hostile (Conflictual)	6-12%	Conflictual, fractured, chaotic

Proof of concept: Family-focused care to 'at risk' families in palliative care & bereavement

Kissane et al, 1998, 2002, 2006

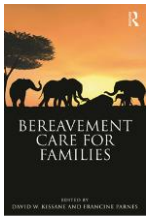


- **Melbourne RCT for 81 families, 333 individuals**
- **Initial efficacy study**
- **Participation rate 44%**

- Main effect: significantly reduced BSI-Distress in FFGT arm at 13 months bereavement
- Outcomes: significant reduction in BDI Depression and improved Social Adjustment
- 16 therapists; 5 sites – 2 hospitals & 3 home care Services

Effectiveness RCT: Family-focused care to 'at risk' families in palliative care & bereavement

- New York RCT for 170 families, 620 individuals
- Screened 4188, ineligible 2700 (65%), eligible 1488 & enrolled 620 (42%)
- 32 therapists, 5 sites – 2 hospitals & 3 home care services
- **Dose UC v 6 v 10 sessions FFGT**
- **Stratified by 3 levels dysfunction:**
  - **low communicators (intermediate)**
  - **less involved (sullen)**
  - **conflictual families (hostile)**



Family therapy to high risk families in advanced cancer setting

Kissane et al, JCO, 2016

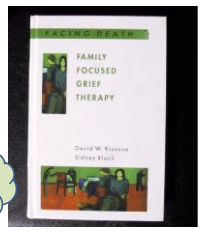

JOURNAL OF CLINICAL ONCOLOGY ORIGINAL REPORT

Randomized Controlled Trial of Family Therapy in Advanced Cancer Continued Into Bereavement

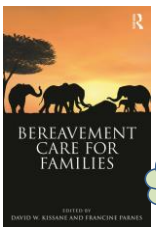
- **10 sessions of family therapy to high risk families prevents development of Prolonged Grief Disorder (PGD)**
- **15.5% PGD in controls at 13-months bereavement**
- **3.3% PGD in 10-session arm at 13 months of bereavement**
- **P=0.048**
- **Low communicating and conflictual families helped; families with low involvement resistant.**

Our intervention – Family-focused grief therapy:

Resilience-promoting & meaning-affirming family work, delivered over 6-10 sessions over as many months, which optimises supportive communication within the family, and begins with dying patient present & continues into bereavement



2002 Open Uni Press



2014 Routledge

Consensus Criteria for Prolonged Grief Disorder (or Complicated Grief) – ICD-11

Prigerson et al, 2007

A. Bereaved > 6 months

B. 1 of 3 symptoms of separation distress: (1) intrusive thoughts; (2) pangs of sorrow or grief; (3) yearning for person lost

C. 5 of 9 symptoms: (1) role confusion or diminished sense of self; (2) difficulty accepting loss; (3) avoidance of reminders; (4) loss of trust; (5) bitterness; (6) difficulty moving on; (7) numbness; (8) meaninglessness/empty; (9) stunned/shocked

D. Functionally impaired (social, occupational, domestic)

E. Not better accounted for by MDD, GAD, PTSD, Substance Disorders or General Medical Condition

Impact of FFGT on "Prolonged Grief Disorder" caseness – ICD-11

CGI[a] Caseness	Time	Standard Care % (n/total)	FFGT 6-session % (n/total)	FFGT 10-session % (n/total)	GEE effects[b]
	Baseline	CGI data not collected pre-death			Treatment main effect Wald Chisq = 8.31, df = 2, p = 0.016
	6 months bereavement	19.3 (11/57)	12.3 (13/106)	8.9 (9/101)	
	13 months bereavement	15.5 (13/84)	12.1 (15/124)	3.3 (4/122)	

[a]CGI caseness applied criteria for Prolonged Grief Disorder. [b]Test statistics were based on a GEE model of CGI caseness as a function of 5 covariates: study stratification factors (site and family type), treatment assignment, time (e.g., 6 months vs. 12 mos), and a fifth covariate of a treatment by time interaction. The Wald Chi-square statistics were from the Wald test for the treatment by time interaction.

Impact of FFGT on BDI depression

Family type	Treatment	Baseline	6 mo Bereavement	13 mo Bereavement	Effect Size d BL-6 mo	Effect Size d BL-13
Low Communicating	Standard Care	13.3 (7.7)	12.1 (10.6)	10.9 (11.2)	-0.13	-0.25
	FFGT 6 s	13.6 (6.6)	11.6 (7.1)	12.8 (9.0)	-0.29	-0.10
	FFGT 10 s	7.7 (7.1)	7.0 (6.8)	6.6 (6.5)	-0.10	-0.16
Uninvolved	Standard Care	12.2 (8.9)	11.5 (10.6)	8.8 (8.6)	-0.07	-0.39
	FFGT 6 s	12.0 (8.6)	10.1 (7.7)	9.7 (9.1)	-0.23	-0.26
	FFGT 10 s	14.3 (9.6)	13.6 (9.5)	11.0 (9.3)	-0.07	-0.35
Conflictual families	**Standard Care**	**16.8 (11.5)**	**12.4 (8.6)**	**11.9 (7.8)**	**-0.43**	**-0.50**
	FFGT 6 s	**14.2 (9.6)**	**11.0 (7.1)**	**10.2 (9.8)**	**-0.38**	**-0.41**
	FFGT 10 s	**10.3 (7.0)**	**6.0 (6.9)**	**5.7 (6.8)**	**-0.62**	**-0.67**

BDI analysis used data from 417 family members nested within 151 families.
Treatment effect: Wald Chisq = 0.67, df = 2, p = 0.714
Family type effect: Wald Chisq = 9.75, df = 2, p = 0.008
Treatment by Family type interaction: Wald Chisq = 0.97, df = 4, p = 0.914

Impact of FFGT on BDI depression caseness

Caseness[a]	Time	Standard Care % (n/total)	FFGT 6-session % (n/total)	FFGT 10-session % (n/total)	GEE effects[b]
BDI	Baseline	18 (23/125)	21 (33/156)	17 (26/155)	Baseline to 6 months Wald Chisq = 2.63, p = 0.105
	6 months bereavement	20 (15/74)	10 (12/116)	16 (19/116)	
	13 months bereavement	21 (20/97)	14 (19/138)	11 (15/136)	Baseline to 13 months Wald Chisq = 3.92, p = 0.047

[a]BDI caseness was defined by combining cases with severe BDI scores ≥29 and moderate BDI scores ≥ 20, respectively.
[b]Test statistics were based on a GEE model of BDI caseness as a function of 5 covariates: study stratification factors (site and family type), treatment assignment, time (e.g., 6 months vs. baseline), and a fifth covariate of a treatment by time interaction. **The Wald Chi-square statistics were from the Wald test for the treatment by time interaction (e.g., 6 months vs. baseline and 13 months vs. baseline).**

Why might FFGT impact more on PGD than MDD?

Prolonged Grief Disorder

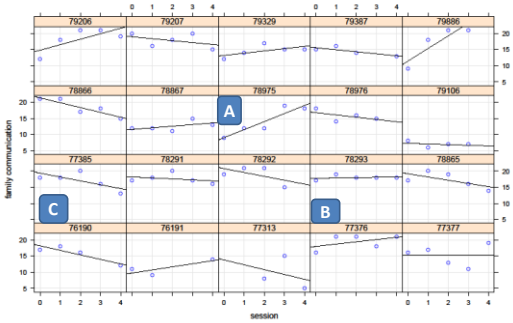
- Disorder of attachment
- Family relational processes impacted

Major Depressive Disorder

- More biological disorder of neurotransmitter abnormalities and pruning of neuronal dendrites in limbic circuits
- Has secondary effects on relationships

FAMILY COMMUNICATION ACROSS SESSIONS OF THERAPY

(A) patterns of improvement, (B) maintenance of effective communication and (C) reduction of communication. Zaider et al. unpub.



Association between Family Functioning and Preparedness

	Fixed Effects			
	β	*SE*	*t*	*p*
Intercept	11.16	1.68	6.66	.02
Cohesiveness	0.13	0.49	0.28	.78
Expressiveness	-0.44	0.36	-1.22	.22
Conflict Management	-0.80	0.29	-2.61	.01*

Note. Analysis based on a random intercept model; *β* = regression coefficient; *SE* = standard error of the regression coefficient; *t* = t statistic

Relationship between Family Functioning and Life Completion

	Fixed Effects			
	β	*SE*	*t*	*p*
Intercept	12.74	2.44	5.21	0.00
Cohesiveness	0.24	0.71	0.34	0.73
Expressiveness	1.26	0.52	2.43	0.01*
Conflict management	0.98	0.42	2.30	0.02*

Note. *β* = regression coefficient; *SE* = standard error of the regression coefficient; *t* = t statistic

Theoretical models underpinning family work

Attachment theory

- Bonds between members
- Style of relating across generations

Social cognitive theory

- Assumptive world views of family-as-a-whole
- Meaning of roles in family

Group adaptation

- Tension between constructive & restrictive views of the family-as-a-whole

Harness resilience

- Affirm strengths & robustness
- Focus on dual processes of grieving loss and restoring living

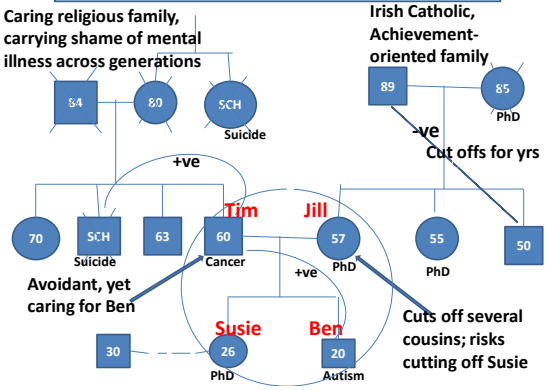
Attachment style

1. Secure
2. Insecure anxious
3. Insecure avoidant
4. Insecure disorganized

FAMILY PATTERN

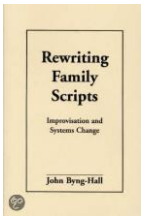
1. Well functioning (supportive or conflict resolving)
2. Low communicators
3. Less involved
4. Conflictual, chaotic

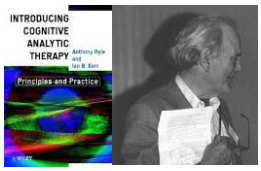
Relational patterns across generations



Family patterns

- Family scripts (Byng-Hall, 1985)
- Reciprocal roles (Ryle, 1990)
- Schema modes (Young, 1994)





In clinical practice, can we identify 'at risk' families?

Ask 3 questions about family relationships:

1. **How openly and effectively do you communicate?**
2. **What is your family's teamwork like?**
3. **How do you manage differences of opinion and conflict in your family?**

3 C's: Communication, Cohesion, Conflict

Section

Brief comments on how to deliver family therapy in advanced cancer

FAMILY FOCUSED [GRIEF] THERAPY (FFGT)

Kissane et al, 1998, 2002

- **Brief (6-10 sessions) Family Therapy**
- **Started in palliative care with cancer patient present and their "fictive kin" or "psychological" family**
- **Continued into bereavement**
- **Targeted at families "At Risk" of morbid outcome/complicated bereavement**

FAMILY FOCUSED GRIEF THERAPY (FFGT)

- **GOALS:**

1. To optimise family functioning
- **increase cohesiveness**
- **increase communication**
- **reduce conflict**

2. Promote coping, sharing of grief & mutual support

Identifying family 'concerns'

Language

Avoid "problems"

Agendas?
Needs?
Issues?
Concerns?

Issues

Openness of communication?
Teamwork?
Differences?

FAMILY FOCUSED GRIEF THERAPY (FFGT)

- **PROCESS:**

1. Affirm family's strengths & active coping
2. Make patterns of family functioning explicit
3. Encourage family to take responsibility for change

RULE: Find Family Strengths

Resilience-based model

What do you like about the family?
What are their successes & accomplishments?
Have certain values been prominent?
Is there a motto or cultural tradition to note?

Goal: balance any concerns about the family with your sense of their strengths

Golden rule: If you haven't found aspects to affirm, things you like, meaningful stories, Spend more time!

FAMILY FOCUSED GRIEF THERAPY (FFGT)

- **THE THERAPIST:**

1. **A collaborative therapeutic alliance is central.**
2. **Open, explicit approach to exploration of FF & grief about change / loss.**
3. **Interventions occur through circular & strategic questioning and affirmation of efforts directed at change.**

FAMILY FOCUSED GRIEF THERAPY (FFGT)

- **PRAGMATICS:**

1. **All relevant family members invited, including the ill patient.**
2. **Time-limited & therefore focused.**
3. **Two sessions (weekly / fortnightly) for assessment; 2-6 sessions for active intervention (fortnightly / monthly); consolidation (2-monthly); termination (3-monthly).**

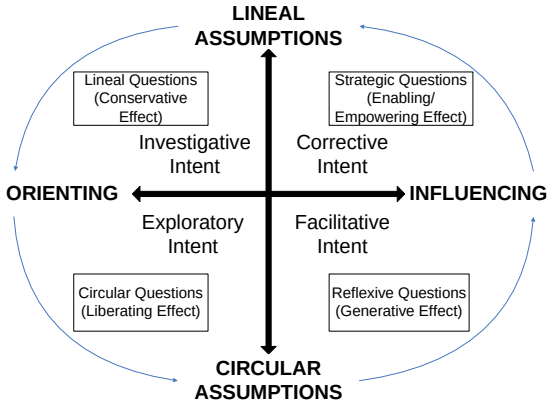
Higher order questioning skills

after K Tomm, 1988, Interventive interviewing

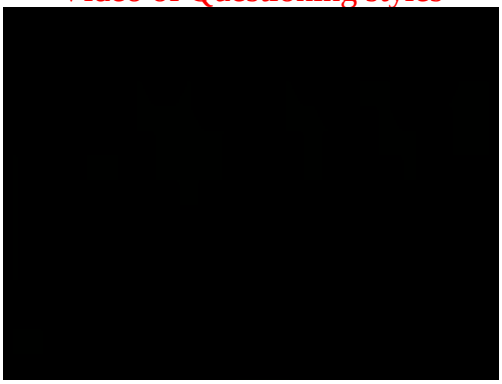
- **Linear questions: asked directly of a person - promotes 1 on 1 conversation**
- **Circular questions: each person is asked to provide opinions about the perceptions of and relationships between others – invites reflection and draws family's attention**
- **Strategic & Reflexive questions: these can embed potential solutions into the language of the question or generate hypotheses & stimulate problem solving or reflection**

Memorial Sloan-Kettering Cancer Center

comskil



Video of Questioning styles



Technique of offering Summary comments to Family

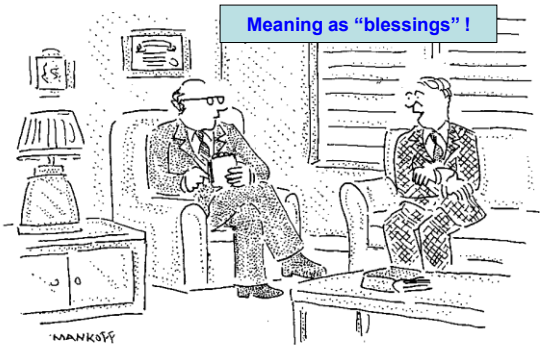
- These help to pace the meeting & to bring the family to potential consensus around the issues under consideration

- Include all or as many members in the summary comment: affirm strengths alongside concerns
- Reflect differences in a balanced manner
- Maintain neutrality if possible
- Embed a suggestion, hint or way forward in the summary to see if consensus about this can be achieved

Video re use of summary comments

Reconstructing family meaning through FFGT

- Transgenerational mapping of patterns of relating & ways of coping with loss
- Affirming strengths seen in family stories & promoting family resilience
- Defining the value of the ill or deceased member to their family. How can their legacy prevail?
- Family mottos, traditions or metaphors (Janice Nadeau, 2006)



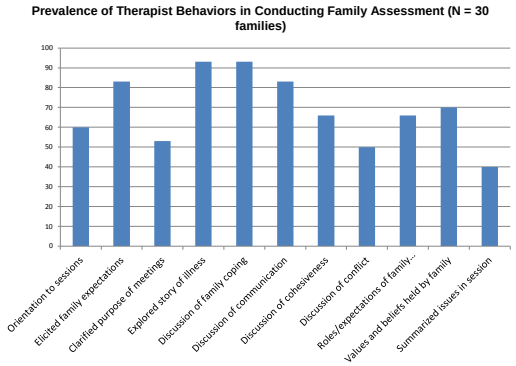
"I do count my blessings, but then I end up counting those of others who have more and better blessings, and that pisses me off."

The course of FFGT

1. **ASSESSMENT:** story of illness, family functioning & genogram [1-2 weeks].
2. **ENGAGEMENT:** agree on "issues or concerns" - cohesion, communication, conflict [end of assessment].
3. **FOCUSED TREATMENT:** grief, problem solving, conflict resolution [1-4 sessions over months].
4. **CONSOLIDATION:** affirmation of change in family functioning [1-2 sess].
5. **TERMINATION:** + future orientation.

Basic components of each session during active treatment

- Begin with greeting & orientation
- Review illness & its treatment [or death/grief]
- Review prioritised concerns - the focus
  - Communication, cohesiveness, conflict
- Consider palliative care themes & needs
- Affirm progress over time, reminding family of its strengths
- Shared grief work, consolidation of FF
- Conclude sessions with summary + future



Therapist competence in Melbourne-based FFGT RCT

- Strong therapeutic alliance in 94%
- Affirmation of family strengths in 90%

- Planning of therapy comprehensive: 81%

- Focus on agreed themes in 76%
- Comprehensive sharing of grief in 78%
- Termination of therapy well executed in 92%

Therapist behaviors in USA study*

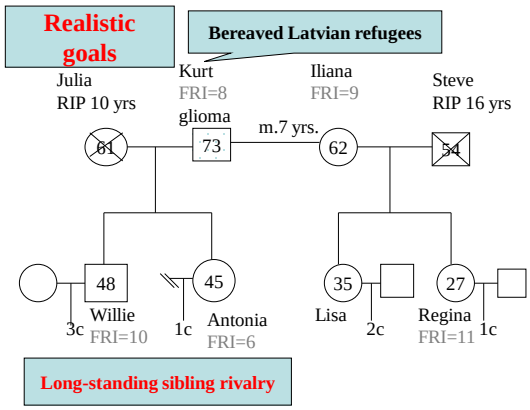
	Del Gaudio et al, 2012
Invite story of illness	>90%
Invite story of death, funeral, grief	>90%
Discussion of family's coping	>90%
Exploration of communication	>84%
Exploration of family cohesion	>70%
Review of values & beliefs	70%
Exploration of conflict	50%
Joined with family over expectations	>80%
Focused family with summaries	50%

*Not all behaviors are relevant to all families

Setting realistic goals

Given the <u>time-limited</u> & <u>focused</u> nature:

- **don't try to modify long-standing personality difficulties.**
- **consider entrenched patterns carefully.**
- **limit time spent on individual crises.**
- **be pragmatic in identifying goals.**
- **focus on the family, its functioning, the illness and related grief issues.**



Maintaining family's sense of safety

- **Containment of active conflict in the session**
  - **Look for soft emotions behind hard emotions**
  - **Consider advantages & disadvantages of conflict**
  - **Pattern discerned across generations**
  - **Promote active search for alternative solutions**
  - **Time out, Focus on process rather than content**
  - **Agreeing to disagree / respect / acceptance**
  - **Forgiveness / tolerance**
- **Avoid alignment with one family member to detriment of others, unless an individual needs support temporarily**

"You can't buy forgiveness with airline miles, Charles."

Empathic responses in family therapy

- **Individual therapy: 1 on 1…..empathy occurs in linear exchange from therapist to patient.**
- **Family therapy: when distress is seen, therapist uses circularity via questions to help other members to offer empathy to the distressed person, thus promoting mutual support.**

Mapping the illness psychosocially
J Rolland, 2005

•What care-giving tasks does the illness bring the family?
- **Where is the burden? The stress?**

•Can we strive for communion and agency?
- **Where is the shared connection?**
- **Can the family be empowered?**

•Can the family "give illness a place at the table?" Can they "keep the illness in its place?"

Genograms: family trees help

What to focus on?

- 3 generations, names & ages
- Quality of marriages
- Coping with loss/death
- History of illnesses
- Strengths of family

Who is the family?

- The 'psychological' family
- The 'fictive' kin
- Whomever the patient says it is

Summarize the patterns evident from one generation to next – balance strengths & challenges

Talk about death & dying

- Ask about the Seriousness of illness
- Ask about Prognosis
- Name protective behaviors
- Circularity to draw out diverse views
- Gain permission to consider hypothetical timelines
- Therapist needs to look for opportunities to pursue death talk, although group may appear avoidant.

Unfinished business

Common themes

- Care provision
- Emotional challenge of suffering - meaning
- Reminiscence and celebration - meaning
- Unfinished business
- Intimacy - meaning
- Discussing death
- Saying goodbye
- Good death or disappointment
- Cultural & religious practices - meaning
- Particular needs, including children
- Historical influences on the family - meaning
- Shared family grief & coping

FFGT: ENDING THERAPY

- Affirm family of their positive progress & remind them of the place for continuing work against 'old patterns' in the future.
- Acknowledge loss
- Look to future priorities
- "Help always available if needed"
- Message of confidence

Conclusions

- Difficult families can be helped: conflictual, more so than uninvolved families.
- Time heals the low communicators.

- Prolonged Grief Disorder prevented – modest impact;
- Not surprisingly, impact on depression more modest

- 10 sessions better than 6
- Noteworthy that
  - 42% engaged in RCT;
  - 91% commenced FFGT,
  - 82% completed half and
  - 50-64% completed all sessions

Therapists can be readily trained

FFGT shows considerable promise