Family Conflict at the End-of-Life

What do we Know and How Can we Help?

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Outline & Overview

- Defining terms
- Rationale for understanding family conflict at the end-of-life
- Findings from recent research
- Implications for “best practices” to address family conflict

Defining Terms

What is Family?

- “People in a committed relationship from which they shape a sense of identity”
  (Kissane & Bloch, 2002, p. 2)
- Whoever its members say it is
  (Kissane & Bloch, 2002, p. 48)

Family conflict defined

“Interpersonal tension or struggle among two or more persons (within the family) whose opinions, values, needs or expectations are opposing or incompatible”
(Kramer et al., 2006, p. 794)

What is Family Conflict Important to Understand?

Rationale
Clinical Guidelines

Mandates

Families increasingly involved in:
• Pain and symptom management
• Care coordination
• EOL decision making (Lorenz et al., 2004)
• When conflict is present, proxy decision makers less likely to make decisions consistent with elder's wishes. (Parles et al., 2011)

Conflict Common & Matters
• At end of life -
  – 35% - 57%
  (Boelk & Kramer, 2012; Kramer et al., 2006, 2010a).
• “What matters most in EOL”
  – Unresolved issues/conflicts
  – In top 4 (out of 28) of importance among seriously ill patients
  Hayland et al. (2006)

Conflict Exacerbates Suffering
• Of Patient
  – 95% of Bio-ethics consults = conflict
  (Neveloff-Dubler, 2005)
  – Longer tx side-effects
  (Kim & Morrow, 2003)
  – Aggressive tx - nursing home
  (Copel, 2004)

Conflict Exacerbates Suffering
• Of Family Members
  – CG burden & depression
  (Heyland et al., 2006; Strawbridge & Wallhagen, 1991)
  – Complicated grief

Professionals Struggle
• Report feeling:
  – ill prepared to address conflict
  (Back & Arnold 2005; King & Gull 2006)
  – less successful addressing care needs when conflict present
  (Kramer & Yonker, 2011)
What We Need to Better Understand: A Recent Research Agenda

• What is the nature of family conflict at end of life (what is it about)?
• What precipitates or contributes to conflict?
• What are the consequences?

Findings from Recent Study

Factors Contributing to End-of-Life Conflicts in the Family

Hospice Study
(Boelk & Kramer, 2012)

• Mixed Method Case study
• Designed to replicate & extend Elder Care study to:
  – Advance theory
  – Examine correlates & predictors of conflict
  – Hospice setting
  – Gain both professional and family members perspectives

Methods

• Study Setting
  – Non-profit hospice organization
  – Serving 6 county area
  – Central Wisconsin

Methods continued

• Mixed Methods
  – 10 Focus Groups
  – 161 Family Caregiver Surveys
  – 15 Family Caregiver Interviews
Results

Presence of Family Conflict in 161 admissions
n = 97; (57%)

Presence of Prior conflict;
n = 77 (48%)

Topics of Family Disagreements
(Boelk & Kramer, 2012)

- Caregiving
- The Patient’s Condition
- Treatments & Procedures
- Medication Use
- Life-sustaining measures
- Enrollment Decisions
- Location of Care
- Post-death Decisions
- Family Roles & Responsibilities
- Family Involvement
- Finances & Estate
- Communication
- Spirituality
- Coping

See p. 2 for description

Explanatory Matrix of Family Conflict

(Boelk & Kramer, 2012)

Think about how relevant these various examples are to conflict you have witnessed

FAMILY CONTEXT

- Historical relationship patterns
- Family involvement in care
- Family demands & resources
- Family structure
- Substance use, abuse, dependency
- Advance care planning & promises made
- Faith traditions & belief systems

Illustration

Historical Relationship Patterns – unknown to hospice

My dad always hated me, …never gave me anything but kicks in the ass or a hit in the face…he told me once I was garbage, … I’d always be garbage. You don’t know how many times I often thought, “garbage girl is taking care of you now dad!”…There was sexual abuse in the family that my dad did toward me … and he started in on my sister…to this day I can hardly stand to be in the same room alone with him…but you got to …step up when you’re needed.
CONDITIONS:
“dimensions of a phenomenon that facilitate block or in some way shape actions and/or interactions” (Kools et al., 1996, p. 318)

Decline in Health Status and Functioning
  Acute medical crisis
  Elevated frailty

Admission into Hospice/Death Awareness
Absent Family Members “Coming out of the Woodwork”

CONTRIBUTING FACTORS

Death Anxiety
- Difficulty Integrating Death Awareness

Contributing Factors continued
Incongruent Perceptions of Health Status, Needs & Preferences

Contributing Factors continued
Efforts to Assert &/or Maintain Control

Contributing Factors continued
Communication Constraints

Contributing Factors continued
Efforts to Seek Resolution
Contributing Factors continued

Family Vying for Estate &/or Position

Contributing Factors continued

Role Expectations & Obligations

CONSEQUENCES

Restricted or delayed care planning or implementation

Consequences continued

Patient wishes and/or quality of care jeopardized

Consequences continued

Increased Patient, Family, and/or Team Distress

Consequences continued

Diminished Support for Patient and/or Caregiver
Consequences continued

Severed Family Relationships

“I have tried to pull her back in so many times on behalf of mom and I can’t take the beating anymore emotionally…When she dies…I’m done…she better watch the obituaries, because I’m angry really down deep inside…I have shut the middle sister out…I have cut the cord”

Identifying Elements of the Model

• The Vareka family
• What elements of the model can you identify?

Mrs. Vareka is an 82 year old female with vascular dementia who has been living in her own home with the help of her daughter Jane (age 58) who has been her primary caregiver and Power of Attorney for health care. She requires 24 hour care, 7 days a week. Mrs. Vareka has four adult children; her husband died in a work related accident when the children were young. Martha (age 54) and Joe (age 52) live in the area. Bill (age 62) the oldest son lives in New Jersey. Martha and Jane both have a nursing background and Martha has been actively involved in helping Jane with caregiving and health related decisions and scheduling help as needed.

Following an evaluation to determine the cause of walking difficulty, Mrs. Vareka was recently diagnosed with stage IV lung cancer. After considering various treating options, Jane decided to meet with a hospice admission staff member and invited all of her siblings. Jane reports that during the meeting Bill seemed very agitated and demanded explanations about why chemotherapy and radiation were not being pursued; no one with medical expertise was available to answer his questions about treatment options and/or the futility of treatment. The family was told about hospice services and policies related to palliative care; including an expectation that hospice would be notified of any changes or problems in health status, rather than seeking hospital admission.

Example

Jane decided to enroll her mother in hospice. Following the admission meeting, Jane received a “nasty message” on her answering machine from her sister Martha: “when you do your scheduling next time, you don’t have to schedule me, because I may make the wrong decision and call 911.” Martha no longer speaks to Jane and has not visited her mother since the hospice admission meeting.
How can we Help?
Implications for Best Practices

But First: A Note of
CAUTION

Be Careful of:
Rescuer Syndrome

Rescuer Syndrome
“The belief that we know better than someone else how to resolve their conflict, or are somehow better equipped to do so, leads us to intervene or try to ‘rescue’ them in a way which disempowers them and inhibits their ability to resolve it themselves.”
(Sharland, 2013)

Symptoms
• Criticizing - Condemning
• Taking sides
• Persuading
• Punishing
• Raging
• Wanting to “even the score”

Why Doesn’t it Work?
• Escalates severity - complexity of conflict
• Disempowers
• “Biggest obstacle to supporting others in resolving their conflict.”
(Sharland, 2013)
We are ALL vulnerable to the Rescuer Syndrome

• Must be conscious of its presence
• Learn more effective approaches
  • to conflict resolution

(Sharland, 2013)

“Best-practices” Inquiry Note

• Traditional approach focuses on quantitative research (clinical trials)

• Not useful when little research has been done.

Expanded Approach to Identifying “Best-practices”

Petr & Walter (2005)
• Quantitative Studies
• Qualitative Studies
• Consumer Perspective
• Practice Wisdom

Best Practices Should Address all Phases of Conflict Reduction

<table>
<thead>
<tr>
<th>Phase</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conflict Prevention</td>
<td>Monitoring and/or intervening to stabilize a potential conflict before it escalates</td>
</tr>
<tr>
<td>Conflict Management</td>
<td>Minimizing the escalation of conflict</td>
</tr>
<tr>
<td>Conflict Resolution</td>
<td>Encouraging reconciliation of differences</td>
</tr>
</tbody>
</table>

William Ury

Anthropologist, extensive experience addressing family conflict, labor strikes, wars, corporate battles

It takes two sides to fight but a third side to stop.

Conflict Prevention Roles
### Conflict Prevention Roles

<table>
<thead>
<tr>
<th>WHY CONFLICT ESCALATES</th>
<th>WAYS TO PREVENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frustrated needs</td>
<td>The provider</td>
</tr>
<tr>
<td>Poor skills</td>
<td>The teacher</td>
</tr>
<tr>
<td>Weak relationships</td>
<td>The bridge-builder</td>
</tr>
</tbody>
</table>

(Ury, 2000)

### Example of Stage 1 Conflict
- Mom takes a turn
- Why was the conflict escalating in this situation?

### The “Provider”
Enabling People to Meet their Needs
- Respect
- Control
- Share Resources - Knowledge

(Ury, 2000)

### The Provider: Engage & Disseminate Information to “Identified Family”
- Standard presumption that family members share information
- Offspring differ significantly from their parents in perceptions of family communication

(Kissane et al., 1994)

### Family Member Quotes
"Nobody has reached out to her...and we don’t understand why...They could have reached out to a sibling who is disengaged...she won’t talk to us..."

"I think it would be nice if maybe, like [the social worker]...calling the other kids, and saying “hey, how are you doing? Is there anything you wanna talk about?” Because I don’t know if they would go and initiate it themselves."

### The “Teacher”
Skills to Handle Conflict
- Teach tolerance
- Model communication skills
- Teaching joint problem-solving

"Time’s up. I’m through listening.”

(Ury, 2000)
The “Bridge-Builder”
Forging Relationships Across
Lines of Conflict

• Develop joint projects – feeling of “we”
• Foster genuine dialogues

(Ury, 2000)

Other Conflict Prevention
Approaches and Interventions

Best Practice: Encourage
Advance Planning Conversations

• May align perceptions
• Minimize risk of overtreatment
  • Without conversations, surrogates “tend to make
    errors of over-treatment”

(Moorman, Care, p.812; Wenger, Shugerman & Wilkinson, 2008).

Best Practice: Routine Admissions Screening

• Identify “Families at Risk”:
  – Determine extent to which conflict:
    • Already exists
    • Is amenable to change
    • Whether family desires intervention
  – Determine potential for contributing factors to arise

Best Practice: Family Assessment

• Genograms
  Mapping the family

• Family Relationship Index (see p. 4)
  • Could have one or all family members complete

• Family Conflict at End of Life Scale (p. 4)

Best Practice:  Family Assessment

Family Relationships Index

<table>
<thead>
<tr>
<th>Typology</th>
<th>Functioning and Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supportive (12)</td>
<td>High levels of cohesion</td>
</tr>
<tr>
<td>Conflict Resolvers (10-11)</td>
<td>Effective communication &amp; cohesion; able to resolve conflicts constructively</td>
</tr>
<tr>
<td>Intermediate (8-9)</td>
<td>Tend to have more difficulty as stress increases; well suited to preventive intervention</td>
</tr>
<tr>
<td>Sullen (5-7)</td>
<td>Moderate conflict, moderate cohesion and poor expressiveness; anger muted; high depression/grief, search for help.</td>
</tr>
<tr>
<td>Hostile (0-4)</td>
<td>High conflict, low cohesion, &amp; poor expressiveness, do not seek support.</td>
</tr>
</tbody>
</table>
### Family Types
found in Palliative Care Setting
(Kissane & Bloch, 2002)

<table>
<thead>
<tr>
<th>Type</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supportive</td>
<td>33%</td>
</tr>
<tr>
<td>Conflict-Resolving</td>
<td>21%</td>
</tr>
<tr>
<td>Intermediate</td>
<td>31%</td>
</tr>
<tr>
<td>Sullen</td>
<td>9%</td>
</tr>
<tr>
<td>Hostile</td>
<td>6%</td>
</tr>
</tbody>
</table>

### Best Practice:
Engage “Families at Risk”
Routine Family Conferences

“Of the interventions identified…, the importance of regular, properly managed family conferences or meetings as a mean of preventing and managing EOL conflict has the strongest evidence base”
(CRELS project, 2010, p. 27)

### Purpose of Family Conferences

**Provide and Share Information**
- a. Medical updates
- b. Educate - correct misinformation
- c. Get everyone on "same page"

**Facilitate Decision-Making & Planning**

**Address Affective Needs**
- a. Normalize feelings
- b. Provide opportunities for expression and reconciliation

### Facilitating the Family Conference: The Process

**Excellent Resource:**
“Family Meetings in Palliative Care: Multidisciplinary Clinical Practice Guidelines”
(Hudson, Quinn, O’Hanlon & Aranda, 2008)

See Handout (p. 5):
EPERC: Fast Facts & Concepts #16:
“Moderating an End-of-Life Family Conference

### Elements for Successful Conferences

- Pre-planning
- Common goals & agenda confirmed
- Realistic expectations
- Key team members present
- Designated chairperson
- Awareness of the family struggle
- Use of emotionally supportive behaviors
- Inclusion of all significant family members
- Careful communication (see p. 6)

(Atkinson, Stewart & Gardner, 1980; Curtis et al., 2002; Dugan, 1995; Fineberg, Kaseashima, & Asch, 2011; Hudson et al., 2008; Schmall & Pratt, 1969)
Our Role in Conflict Management
When is it appropriate to take a “Hands Off” approach?

Best Practices Should Address
Two Primary Targets

Best Practice: Adhere to General Principles of Conflict Management
(see p. 7)

- Maintain the palliative perspective
- Maintain flexibility
- Maintain neutrality, transparency and professionalism
- Avoid splitting
- Avoid demonizing
- Set necessary limits

(Holst, Lundgren, Olsen & Ishoy, 2009, p. 40)

Conflict Management Roles
WHY CONFLICT ESCALATES CONTAIN

<table>
<thead>
<tr>
<th></th>
<th>Ways To</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Attention</td>
<td>The Witness</td>
</tr>
<tr>
<td>No Limitation</td>
<td>The Referee</td>
</tr>
<tr>
<td>No Protection</td>
<td>The Peacekeeper</td>
</tr>
</tbody>
</table>

(Jury, 2000)

The “Witness”

- Bear Witness
  - Internal conflict
  - Validate; support

“I feel guilty because I wanted him to die and now he’s dying.”
The “Witness”

• Naming the problem

• Effective means of starting a meaningful
dialog among the conflicted parties.

You seem like you are very angry, can you
talk about what is making you angry? (David
Weissman)

The “Referee”

• Help set limits
• Help establish
rules
• Problem solve
• Consider
reframing

The “Peacekeeper”

• Provide protection
• Interpose

• When might this be
necessary?
• What are the ways
that we may need
to provide
protection or
interpose?

Conflict Resolution Roles
Conflict Resolution Roles

WHY CONFLICT ESCALATES
RESOLVE

Conflicting Interests

Principled Negotiation

Mediation

Injured Relationships

The Healer

(Ury, 2000)

Principled Negotiation

“Interest-based” approach by Fisher and Ury (1983) in “Getting to Yes: Negotiating Agreement without Giving in”.

One of the longest running best sellers in negotiation and business books

Principled Negotiation: Four Principles

1. Separate the people, from the problem

<table>
<thead>
<tr>
<th>People Issues</th>
<th>Problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotions: fear, anger</td>
<td>Patient unable to eat</td>
</tr>
<tr>
<td>Different perceptions</td>
<td>Treatment decisions have to be made</td>
</tr>
<tr>
<td>Communication skills</td>
<td>Patient actively dying</td>
</tr>
<tr>
<td>Relationship issues</td>
<td>Caregiving required</td>
</tr>
</tbody>
</table>

2. Focus on interests, not positions

“Your position is something you have decided upon. Your interests are what caused you to decide” (p. 42).

<table>
<thead>
<tr>
<th>Interests</th>
<th>Positions</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Best” care possible</td>
<td>Demand invasive tx</td>
</tr>
<tr>
<td>To feel respected</td>
<td>Want mom at my house</td>
</tr>
<tr>
<td>To honor wishes</td>
<td>Won’t agree to NH placement</td>
</tr>
</tbody>
</table>

3. Invent options for mutual gain

- Brainstorm (without judgment)
- Both parties
  - Propose options
  - Satisfy other side
  - Review the ideas

4. Use Objective Criteria

- To evaluate the acceptability of a negotiated agreement when interests are opposed or for use in time trial
- Examples:
  - Professional standards
  - “Best practices”
  - Signs of improvement or worsening
**Principled Negotiation**

Fast Facts & Concepts #184
Illustration of principled negotiation involving conflict in medical care at end of life (see p. 10)

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**Conflict Mediation**

“A time-limited, goal focused conflict resolution process”
(Gentry, 2001, p. 45)

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**Mediation:**

- “Sees conflict as inevitable part of life arising from difference”
- Can be responded to destructively or constructively
- Conflict - opportunity for
  - Learning
  - Connection
  - Insight (Sharland, 2013)

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**Mediation: Conflict Resolution Skills Emphasize Communication**

“Good communication cannot guarantee that conflict is ameliorated or resolved, but poor communication greatly increases the likelihood that conflict continues or is made worse.” (Krauss & Morsella, 2006, p. 156)

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**Caution...**

“Communication is not a panacea...in the absence of genuine desire to resolve conflict it is likely to intensify the parties' disagreement as to moderate it.”
(Krauss & Morsella, 2006, p. 155).

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**Mediation Skills**

“The best mediators are those who are able to understand fundamental differences between parties, understand the context and meaning, find common purpose, view the larger picture and bring imagination and creativity to the process”
(Bowman, 2000, p. 18).
Mediation: Effective Conflict Resolution Skills

- Listening
- Summarizing
- Questioning (Sharland, 2013)

Mediation Skills: Listening

“When I ask you to listen to me and you start giving advice you have not done what I asked…” (Anonymous)

- Alliances or Advice
  - escalate or confuse the problem

Mediation Skills: Listening

- Helps family member
  - understand what they feel and think
  - consider what they want
  - enhances sense of control or choice or power over their response
  (Sharland, 2013)

Mediation Skills: Summarizing

- Checking accuracy
- Opportunity to clarify
- Not “interpretation”
  - what actually was said.
  (Sharland, 2013)
Mediation Skills: Summarizing

- Allows speaker to review thoughts/feelings from more detached position
- See things as a whole

(Sharland, 2013)

Mediation Skills: Summarizing

- Don’t assume to know feelings (e.g., “I can see you are angry”)
- Rather ask: “So how do you feel about this?”

(Sharland, 2013)

Mediation Skills: Questioning

- “Open” questions
- Avoid leading questions
  - E.g., “have you tried talking with your sister?”
- They take ownership away from client

(Sharland, 2013)

Conflict Mediation Process
(Also see handout p. 11-12)

Step 1: Identify conflicted parties
Step 2: Understand the stated and latent interests
Step 3: Help parties understand the mediation process
Step 4: Review what you have learned
Step 5: Run the meeting

(Neveloff-Dubler, 2005)

The “Healer”
Repairing Injured Relationships

- Listen and acknowledge
- Encourage
  - Forgiveness
  - Apology

Best Practice: Train and Support Staff

- Implement regular training & support sessions for professionals
  - To enhance awareness
  - To develop competence
  - To problem-solve
  - To debrief