Family Conflict at the End of Life:

Research and Implications for Best Practices

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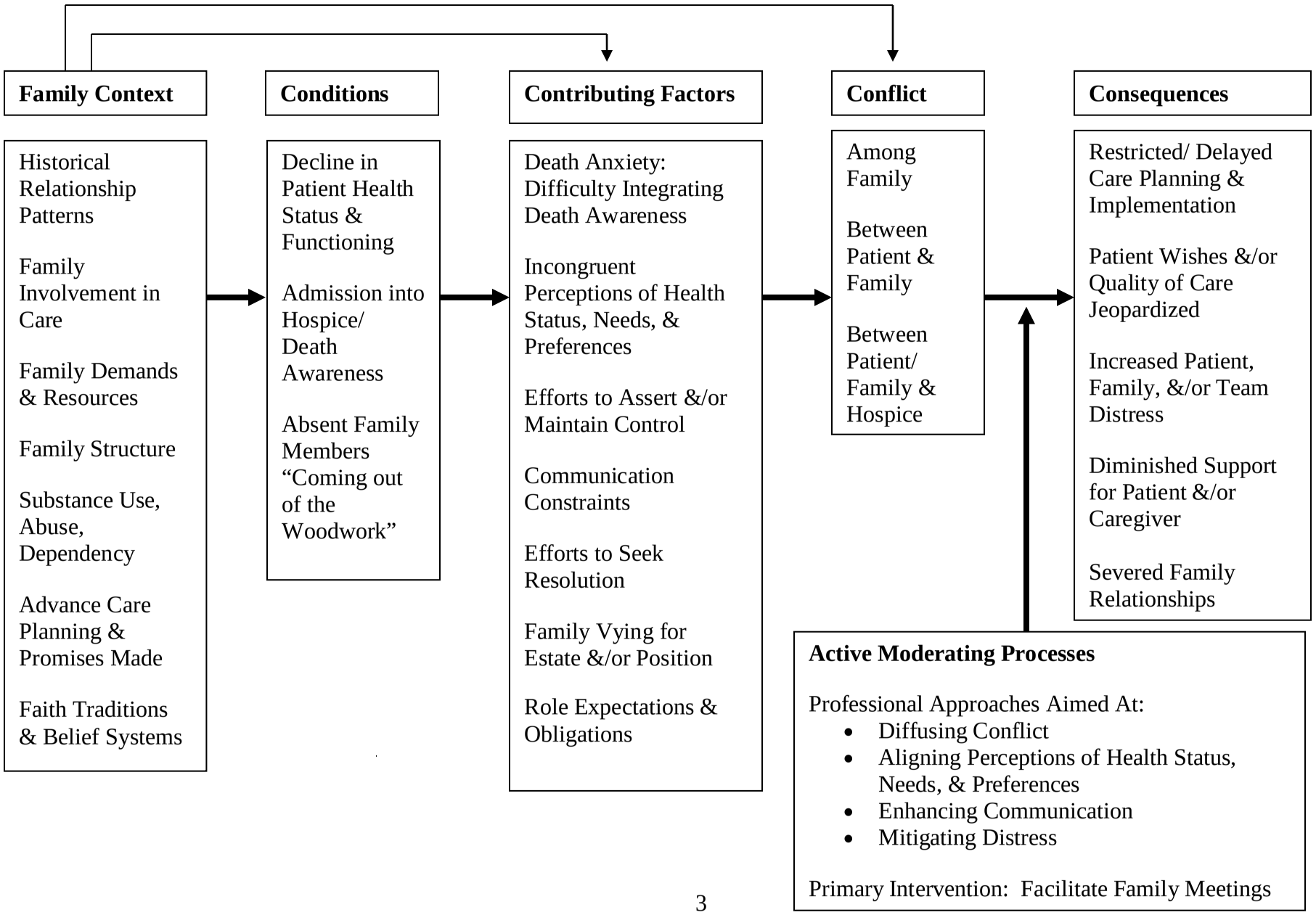
Topics of Family Disagreements (Boelk & Kramer, 2012)

Topic	Description
Caregiving	How to provide, what type/level of care is needed, quality of care, who gives better care, what to feed or not feed the patient
The Patient's Condition	Participation in activities, patient activity level
Treatments & Procedures	Fighting disease versus "giving up," treating or not treating infections, what tests/procedures the patient should/should not have, use of the ambulance, use of emergency room
Medication Use	What medications should/should not be given, Sedation versus keeping patient alert
Life-sustaining Measures	Artificial hydration/nutrition, ventilation, code status, prolonging life versus comfort measures
Enrollment Decisions	Involvement of outside help (including hospice)
Location of Care	Where the person lives and receives care
Post-death Decisions	Funeral planning, burial, handling of cremains
Family Roles & Responsibilities	Who is making decisions, how workload is shared, who will take leave from work, who will patient live with, who will be main contact person, who will serve as power of attorney
Family Involvement	Visiting/not visiting patient, who is providing care and who is not doing their fair share
Finances & Estate	Money, distribution of property/possessions/estate/inheritance
Communication	What to tell the patient, what to tell the children
Spirituality	Appropriate faith traditions & rituals
Coping	Who is coping/not coping appropriately

Figure 1. Explanatory Matrix of Family Conflict at the End-of-Life (Boelk & Kramer, 2012)



Assessing Family Relationships

"*Family Relationships Index"* developed by Rudolf H. Moos and Bernice S. Moos, 1981)

Please read each statement below, and place a tick in the column marked TRUE if you think the statement is true of your family, or tick in the column marked FALSE, if this statement is not true of your family.

	TRUE	FALSE
1. Family members really help and support one another		
2. Family members often keep their feelings to themselves.		
3. We fight a lot in our family.		
4. We often seem to be killing time at home.		
5. We say anything we want to around the home.		
6. Family members rarely become openly angry.		
7. We put a lot of energy into what we do at home.		
8. It is hard to 'low off steam' at home without upsetting somebody.		
9. Family members sometimes get so angry they throw things.		
10. There is a feeling of togetherness in our family.		
11. We tell each other about our personal problems.		
12. Family members hardly ever lose their tempers		

Scoring Rules:
Cohesiveness = 1 True + 4 False + 7 True + 10 True.
Expressiveness = 2 False + 5 True + 8 False + 11 True
Absent Conflict = 3 False + 6 True + 9 False + 12 True
FRI = cohesiveness + expressiveness + absent conflict scores.

Typology of families reported by Kissane and Bloch (2000). Family deemed "at risk" if score is 9 or less.

Typology	***FRI Scores***
Supportive	12
Conflict resolvers	10-11
Intermediate	8-9
Sullen	5-7
Hostile	0-4

"Family Conflict at the End-of-Life" (FC-EOL) scale (developed by B. J. Kramer)

As you think about the decisions that you and your family are facing regarding your care (or the care of _____), please answer the following questions:

	Please check one answer box per question.				
How much do any family members…	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
a. Disagree or argue with one another?	☐	☐	☐	☐	☐
b. Feel resentment toward one another?	☐	☐	☐	☐	☐
c. Feel anger toward one anther?	☐	☐	☐	☐	☐
d. Insult or yell at one another?	☐	☐	☐	☐	☐

FAST FACTS AND CONCEPTS #16: "Moderating an End-of-Life Family Conference"

Author(s): Bruce Ambuel PhD and David E Weissman MD

Background At some point during the course of a terminal illness, a meeting between health care professionals and the patient/family is usually necessary to review the disease course and develop end-of-life goals of care. Learning the process steps of a Family Conference are an important skill for physicians, nurses and others who are in a position to help patients and families reach consensus on end-of-life planning.

Family Conference Process Steps

1. **Why are you meeting?** Clarify conference goals in your own mind. What do you hope to accomplish?
2. **Where:** A room with comfort, privacy and circular seating.
3. **Who:** Patient (if capable to participating); legal decision maker/health care power of attorney; family members; social support; key health care professional
4. **Introduction and Relationship Building**
   Introduce self & others; review meeting goals; clarify if specific decisions need to be made.
   Establish ground rules: each person will have a chance to ask questions and express views; no interruptions; identify legal decision maker; and describe importance of supportive decision making.
   If you are new to the patient/family, spend time seeking to know the "person"—ask about hobbies, family, what is important in her or his life, etc.
5. **Determine what the patient/family already knows.** Tell me your understanding of the current medical condition? Ask everyone in the room to speak. Also ask about the past 1-6 months—what has changed in terms of functional decline, weight loss, etc.
6. **Review medical status.** Review current status, prognosis and treatment options. Ask each family member in turn if they have any questions about current status, plan & prognosis. Defer discussion of decision making until the next step. Respond to emotional reactions (See Fast Facts #29, 59).
7. **Family Discussion with a Decisional Patient**
   Ask the patient, What decision(s) are you considering?
   Ask each family member, Do you have questions or concerns about the treatment plan? How can you support the patient?
8. **Family Discussion with a Non-Decisional Patient.** Ask each family member in turn What do you believe the patient would choose if the patient could speak for him or herself? Ask each family member What do you think should be done? Ask if the family would like you to leave room to let family discuss alone. If there is consensus, go to 10; if no consensus, go to 9.
9. **When there is no consensus:** Re-state: What would the patient say if they could speak? Ask: Have you ever discussed with the patient what he or she would want in a situation like this? If you, as a clinician, have a firm opinion about the best plan of care, recommend it simply and explicitly, and explain why.
10. **Wrap-up:** Summarize consensus, disagreements, decisions, & plan. Caution against unexpected outcomes. Identify family spokesperson for ongoing communication. Document in the chart – who was present, what decisions were made, follow-up plan. Don't turf discontinuation of treatment to nursing. Continuity – Maintain contact with family and medical team. Schedule follow-up meetings as needed.

See related *Fast Facts*: Delivering Bad News (#6, 11); Responding to Patient Emotion (#29); Dealing with Anger (#59), Conflict Resolution (#183, 184).

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Citation: Ambuel B and Weissman DE. Moderating an end-of-life family conference, 2nd Edition. Fast Facts and Concepts. August 2005; 16. Available at: http://www.eperc.mcw.edu/fastfact/ff_016.htm.

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FAST FACTS AND CONCEPTS #183: Conflict Resolution I: Careful Communication

Author(s): Adam Kendall MD, MPH and Robert Arnold MD

Background Conflicts about medical care occur frequently at the end of life. These conflicts threaten therapeutic relationships and lead to patient, healthcare provider, and family dissatisfaction. Conflict between the patient/family and physician may arise from simple factual misunderstandings about medical care. Frequently, however, conflict is driven by a patient's or family's emotions such as feeling unheard or ignored, as well as having goals that conflict those of the medical team. In these instances, attempting to convince a patient or family through providing additional medical information will not work. This Fast Fact provides an alternative approach to conflict resolution based on understanding a patient's or family's story, attending to their emotions, and establishing shared goals. A subsequent *Fast Fact* (#184) will focus on conflict resolution employing the techniques of Principled Negotiation.

1. Learn the patient's and family's story

- Begin discussions with a genuine curiosity to learn what they perceive to be the course of events during the illness.
- Explore the context of the patient's illness narrative with attention paid to their relationships with doctors, their sources of medical information, and their life goals (see *Fast Fact* #26)
- Avoid presenting agenda items for a meeting that are defined by the medical team's priorities. Instead, focus on the patient's and family's concerns.
- If a patient or family is asking for treatment against the recommendation of the medical team, focus on the context of the request. Have they been let down by the medical system in the past? Have they found that others in their family have benefited from the treatment they request?
- Find out how they want information presented to them. Do they want specific benefits and risks? Do they want written information?

2. Attend to emotions

- Conflict can cause strong emotions in healthcare providers including guilt, anger, and resentment. Acknowledge these emotions to yourself and other professionals, but strive to prevent them from interfering with your interactions with the patient and family.
- Patient and family emotions such as grief, disappointment, and anger are to be expected in these situations. Compassionately acknowledge and address these emotions as they arise, and allow the patient and family to express what is making a situation frustrating for them (see *Fast Facts* #29, #59). When people are emotionally stressed, they may have trouble cognitively processing information. Empathically attending to emotions often allows a patient or family to move on to understanding medical information.
- If a family is focusing on what they believe was an error in care, be transparent about where a mistake may have been made (see *Fast Facts* #194, 195). Apologize. Even if it was not an error, one can acknowledge how frustrating the situation is. Saying "I can tell that this situation is frustrating for you," is not an admission of error—it is empathic.

3. Establish shared goals for treatment

- Use the patient's core values as a foundation for developing a treatment plan. "I would like to know more about your mother and what her values have been during her life."
- Ask about a patient's goals including what they would want if they were dying or if there were no curative treatments available for their condition.
- When there are requests for ineffectual treatment, describe instead where the medical team can make a difference for the patient, in relation to their goals. "Please correct me if I'm wrong, but it sounds like your mother really values her independence and freedom from being in pain. Let's try to figure out how we can best help her achieve these goals."

Providing medical information to patients and families may seem at first to be the most natural approach to resolving conflict. Addressing the underlying roots of conflict will have a longer lasting effect. The above approach emphasizes resolving conflict through finding mutual trust and shared goals between physicians, patients, and families.

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Citaton: Kendall A, Arnold R. Conflict Resolution I: Careful Communication. Fast Facts and Concepts. July 2007; 183. Available at: http://www.eperc.mcw.edu/fastfact/ff_183.htm.

GENERAL PRINCIPLES OF CONFLICT MANAGEMENT

Arresødal Hospice's Principles of Management of Intra-Familial Conflicts

Principle	Suggestions
Maintain the palliative perspective	Consider the possibility and implementation of palliative management strategies in certain subtypes of family dysfunction and (if favorable circumstances allow) to extend beyond this, incorporating a more long term outlook for future rehabilitee of the surviving relatives.
Maintain flexibility	Take into account the strengths, psychological resources, level of intellect and emotional state of conflicting family members before deciding whether to use interpretive or supportive techniques. Be prepared to reflect over strategies that have not been optimal and modify as necessary
Maintain neutrality, transparency and professionalism	Current information for all staff members involved through mono- or multi-disciplinary meetings is essential. It is important to handle conflicting family dynamics in an open, transparent and professional way, not to be unexpectedly absorbed as an active part of the conflict and avoiding covert behaviors. The principle of neutrality applies to this strategy in that involvement in long-term prior conflicts is to be avoided.
Avoid splitting	Avoid, or at least identify and understand, splitting between members of staff by recognizing the families with conflicting dynamics may display completely opposing attitudes within short periods of time which can be challenging to staff. In the worst case scenarios, relatives in conflict my project their issues onto others in a way to control fragmented or distressed parts of themselves.
Avoid demonizing	Encourage and enable staff to share awkward, challenging and/or negative feelings brought on by sudden or inadvertent involvement in conflicting family dynamics.
Set necessary limits	Limits need to be identified and maintained consistently if behaviors of family members threaten the integrity or safety of the patient, other relatives, staff or the palliative-therapeutic relationship.
Intervention	Encourage staff members to maintain the professional/personal balance through multidisciplinary discussions, counseling and prompt debriefing.

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

FAST FACTS AND CONCEPTS #184: Conflict Resolution II: Principled Negotiation

Author(s): Adam Kendall MD, MPH and Robert Arnold MD

Background When conflicts about medical care persist despite gaining mutual trust and a deep understanding of goals (see *Fast Fact* #183), it may be effective to use principled negotiation. Principled negotiation is an approach to resolving conflict that avoids power struggles and unwanted compromises. The following is an illustration of the steps that are involved. Within each step, we will refer to a case example: a family who is requesting artificial feeding against medical advice for their father who is dying from end-stage dementia.

1. **Separate people from the problem.** Identify the fundamental problem, separating that from individuals'—on both sides—intentions and culpability.

- The problem is not that the family members are "in denial" that their loved one is dying or "uneducated" when they do not hear the medical team's recommendations.
- The problem is not that the family is acting out their frustration by making unreasonable demands.
- Nor is the problem that the medical team and hospital are trying to withhold treatment from the patient or "giving up" on him.
- The problem is that the patient *is* dying, no longer able to eat properly, and that artificial nutrition does not improve quality or quantity of life in this situation.

2. **Focus on interests.** Listen to requests and demands but try to look into underlying interests. In addition, express the intentions and goals of the medical team.

- The family wants what is best for the patient. Their intent may be to provide comfort and to build up the patient's strength, and to prevent a painful starvation.
- The medical team wants to provide the best medical care for the patient. Their intent may be to avoid an intervention that has no clear benefit for the patient, may cause harm, and may not have been desired by the patient.

3. **Invent solutions.** Avoid contrasting different philosophies of medical care. Instead, propose a plan of care that meets a family's expectations without detracting from good medical care. Consideration could be given to:

- Meeting the family's goals of providing food by allowing for the patient to taste home cooked meals.
- A short trial of tube-feeding with the plan to continue only if the overall quality of life for the patient improves.
- A trial of attentive oral feeding with a plan to reconsider tube feeding if the patient appears to be hungry or otherwise suffering.
- Solutions that do not promote mutual interests are: placing a feeding tube without a plan to measure its success or failure at meeting a goal, arranging for another medical team to take over the patient's care, or referring the case to an ethics committee.

4. **Outline objective criteria.** If a time trial is being pursued, agree upon what the deciding factors would be in determining a trial's success. Provide objective information to substantiate medical recommendations.

- Establish signs of improvement or worsening such as functional ability, weight, ability to interact, and level of consciousness.
- Establish criteria for harm such as infections, restraint or sedative use, hospitalizations or emergency department visits.
- Consider providing publications from organizations that advocate for patients and families, and are not associated with physicians or hospitals.
- Provide opinions or guidance from individuals outside of the conflict. These could include social workers, case managers, chaplains, or therapists.\

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