

SUBSTITUTE DECISION MAKING AT END OF LIFE

Slide 1: Faculty/Presenter Disclosure

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List all relationships/affiliations with for-profit and/or non-profit organizations.

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- Grant/Research Support: organization name NONE
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Slide 2: LEARNING OBJECTIVES

1. At the conclusion of this presentation, participants will be able to identify strategies to assist substitute decision makers in coping with end of life challenges
2. At the conclusion of this presentation, participants will be able to understand the complex challenges of meeting the complex demands of advanced directives in end of life substitute decision making
3. At the conclusion of this presentation, participants will be able to help family members dealing with end of life challenges help clarify the role of medical professionals in assisting families in end of life decision making challenges

- Engaging with substitute decision makers at a time when things are relatively stable facilitates planning according to previously held values (ethical fading)
 - Reality is those conversations are hard to implement when confronted with choices it's hard to maintain clarity of thinking at such times
 - For example, decision for family members to administer more morphine but reality brings confusion –need for doctors to be explicit about direction
- High potential for family conflict at transition points

FEELINGS ABOUT DEATH

- Forced to confront our own mortality
- Forced to confront our unpreparedness
- Fear of unknown
- Feeling of helplessness

REALITY VERY DIFFERENT THAN THEORY

- If patient prepared an advanced directive most don't know where they are and most doctors don't know they exist or what's in them
- British study published in Lancet in 2004 found that about 40% of hospitalized patients lacked the mental capacity to make decisions because they were unconscious, delirious, demented or had other cognitive impairment
- Surrogates often base their judgments on considerations other than what the patient wants

SUBSTITUTED JUDGMENT

- Patient centered decisions: focus on sick person's wishes and interests
- Might recall past conversations of what the person wanted and/or a general knowledge of the person
- What they deemed the patient's best interest– SUBSTITUTED JUDGMENT
 - If the patient were sitting in the room with you what would they want?
 - Beneficence– what appears to be in their best interest?
- Hard to do because patient imagining reality that is different when faced with it
- Study of when people are faced with reality of their quality of life when they requested a DNR they often change their mind because they find more meaning and happiness at such extreme times

- Not that you're denying what person wanted it's you think person would have made different decision if they understood facts better

SURROGATE CENTERED

- Involved a different set of factors– might be based on what they would want in a similar situation (as in “golden rule”)
- Might be guided by their religious beliefs which might be accepting of death or fighting against it

SOURCES OF FAMILY CONFLICT

Community Survey

N=1,478

Sources of Conflict

Source	Somewhat	Very Much
Communication	38%	11%
No Time	36%	11%
Financial	31%	11%
In-laws	27%	10%
Sexuality	27%	10%
Work too much	26%	8%
Spouse unprepared for marriage	25%	8%

The Default Setting

- The default setting is to think that all families are like your family of origin- the reality is that every family is different and that one's spouse's family, almost by definition will seem different
- Key is not to see this as better or worse- rather as variation on the theme of normal. Once one pathologizes this difference as a "defect" one's spouse is likely to respond by seeing this issue as one of divided loyalties and a non-productive defensiveness and escalation of conflict is likely to follow.

Cultural Issues

- Marrying into culture unique to that family
 - European Jewish families may be more likely to be enmeshed- but there are often unique cultural nuances that define rules and expectations in Sephardic families, Ashkenazi families or based on family history such as first generation Americans, or families who are headed by children of holocaust survivors

Accommodation vs Instant Family Member

- It is easy to forget that in dealing with our parents we have the benefit of decades of learning to accommodate to the emotional needs, demands and unique idiosyncrasies of our parents. Often our accommodation to their personalities is so much a part of us that we don't even realize how we have molded our behavior to minimize conflict and maximize effective communication
- Bring a high level of empathy to your family member spouse who doesn't have the benefit of this experience and is often expected to "instantly" master this complex and often inscrutable code of conduct

Getting Used to Differing Family Styles

Dimensions that families differ on:

- Hierarchy:
 - Rigid Vs. Chaotic
- Intimacy
 - Enmeshed Vs. Disengaged

Hierarchy: Chaotic

- **Hierarchy: Challenges Posed by In-laws With a Chaotic Rule Structure**

- Can range from rigid to chaotic. Chaotic families might pose difficulty for son-in-law or daughter-in-law regarding issues such as:
 - Sense of time
 - Sense of discipline
 - Formality
- Sources of such conflict might be expecting them for dinner and having them come very late or not at all, or perhaps a style of disciplining or supervising grandchildren in a manner that might seem like neglect to a more disciplined young parent

Hierarchy: Rigid

- Families with rigid hierarchy are more likely to:
 - More likely to get upset at a perception of overly lax style
 - In turn their approach to end of life substitute decision making might be viewed as too controlling, overprotective or rigid

Intimacy

- Enmeshed:
 - Put on a sweater, I'm Cold
 - Your pain is mine if you're happy I am
- Can cause problems regarding “psychological allergy” to closeness brought about by end of life challenges and enforced time together which can lead to feeling smothered

Disengaged:

- A disconnected interpersonal style Can easily seem uncaring to family members who for reasons of temperament have a warmer emotional temperature

Family rulebook

- Their playbook- nobody gives you the real set of rules until there is a penalty on the play
 - Don't you know can't go to this house without flowers
 - Need open communication with medical staff to educate medical team about culture of family

Setting Limits

- Clarifying rules and expectations
 - Define and set boundaries concerning feelings, thoughts and expectations
 - Insure you are on same team and that you preemptively develop a signal or password if necessary signaling when it is time to end a visit, distract or intervene

CRITICISM

- **Explore with spouse a coping plan for dealing with your frustration caused by differing styles**
- **If medical team is subject to family members criticizing other family member, just listen. Making comments other than asking clarifying questions can heighten conflict**

Name the Monster

- GENERAL APPROACH IS TO validate without necessarily agreeing

Validate

- Research that more husband accepts wife's viewpoint the more she sees his
- Ashrei- ishur

Empathy: Perspective Taking

- Try to see other person's point of view
- Recognize “disenfranchised grief” that daughters in law and sons in law often experience
- Constantly put one's self into other person's shoes

TYRRANY OF THE SHOULD

- Assume that if family member is distant and cold may be because she is a distant and cold woman- tyranny of the shoulds
- Rav Nachman: They have nothing against me – only against the person they think I am– and he deserves it

A Man hears what he wants to
Hear and Disregards the Rest

NEED TO FIND SOMEBODY FAMILY MEMBER TRUSTS TO MINIMIZE
DISTORTION

Humility: “A Man Hears What he Wants to Hear and Disregards the Rest”

- ▶ The Talmud tells of an incident experienced by Rabbi Illish, who, while being held in captivity, heard a raven calling to him. Rabbi Illish asked a man who was imprisoned with him what the bird was saying and the man, who knew the language of birds, answered: “Illish, run away, Ilish run away”. Not believing the raven, a bird that is considered untrustworthy, Rabbi Illish ignored the advice. Later, a dove came and called out to him – again he asked his fellow prisoner to translate - and the man again answered that this bird, too, was warning: “Illish, run away, Ilish run away.” Rabbi Illish heeded the second warning and successfully escaped.

You Can't do this Alone

▶ Rabbi Chaim Shmuelewitz, asks, why was it necessary for Rabbi Illish to ask the man to interpret when he, himself, understood what the raven and dove were saying? He answers that Rabbi Illish understood human nature, and the temptation to hear what you want to hear. Rabbi Illish, who was looking for a sign that it was safe to attempt to escape didn't trust himself to hear the birds accurately. He understood that he needed to rely on another person to confirm that he was understanding the message accurately.

▶ *Gitin 45a*

▶ *Sichos Musar, (2004) Maamar 80, page 348, Israel*

▶ Rabbi Akiva Eiger, *Gilyon HaShas, Gittin 45a*