FAMILY DYNAMICS IN SERIOUS ILLNESS

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Objectives

• Understand the impact of illness on families
• Recognize the importance of family involvement
• Describe the importance of family assessment and communication
• Appreciate the role of family functioning and its effect on death, dying, and bereavement.
• Learn the common elements of a systemic approach in working with families.
Outline

• Families in palliative care
• Family systems and families in crisis
• Family communication
• The dimensions of fading away
Families and Palliative Care
What is the family?

- A network of attachments
- With a past and a future
- Exists within a social and cultural context
- Families are places where one has powerful experiences
• We are all experts on families – we all come from families!
• The families we help are all different from us
• Work with families can be throughout any part of the illness journey.
The Family

• “A dynamic social system subject to change and influenced by historical, cultural, and contemporary forces” (Kissane and Block, 2002)
• “The family, in practice, is whoever its members say it is” (Kissane and Block, 2002)

- Nuclear
- Extended
- Family of origin
- Adopted
- “social” family

- Friends
- Neighbors
- Work colleagues
- Community (religious, etc.)
• “constantly interactive” and “mutually reinforcing” (Davies & Steele)
• Members may be helpful or resistant
• Family is the unit of care in PC
Impact of Terminal Illness

- Stable patterns may shift
- Role changes
- Social isolation/practical
- Personal confusion/life cycle
- Exhaustion/lack of fun
- Invasion by outsiders
- Loss of control
- Fear, uncertainty, and loss
- Communication breakdown
See the family as a resource for change: not impeding the change

- “Normal” families come in all shapes and sizes.
- Can they begin to deal effectively with the problems they face?
- How can we help create change?
- We need to **discover** and use their resources
Clear Assessment

• An effective assessment is key to establishing an appropriate care plan for the patient and family.
• Family assessment starts when a new patient is referred
• All members of the team work with the family

• *Maximize listening skills, minimize quick judgments.*
• Coping mechanisms, other changes?
• Impact of illness on partnership?
• Other vulnerable individuals?
• Personal histories?
• Myths?
• Past coping?
• Accept support?
• Hopes for the future?
• Available resources (financial, practical support, etc)
Family Systems and Families in Crisis
• The family, including the patient, should be the unit of care.
• Support with grief begins before the death
• Grief is a family event, and it is likely to be influenced by:
  • attachments that exist within the family
  • the quality of the relationships between family members
  • adaptation and functioning
The whole is greater than the sum of its parts!

A set of relationships that act, react, interact
Balance, equilibrium, homeostasis

- Family = a system where one part is dependent on another part to work and for the whole to operate smoothly.
- Each member knows his or her role and relies upon each other to work as an integrated team.
- In everyday life, families have to keep comfortably afloat and keep sailing along.
• Most cope with generally harmonious relationships.
• They surmount daily problems
• For each family, their “pattern” or “system” will work for them most of the time.
• Offering the family unit stability and predictability
• Ensuring the family’s comfortable survival
• The illness of one family member will affect the whole family; in turn, the family’s response will affect the patient.

• Some families keep a façade so as not to let other people in or allow others to help them.
• The crisis of death is the ultimate threat to the family unit
• What happens to the system when one of its members is going to die?
• The family is thrown into a psychological crisis! Into a situation in which it has never previously coped
• How does the system survive this new situation?
• Families tend to hold onto familiar defense mechanisms.
• If these fail to be efficient, they may need to adapt to new means
• It is not always recommended to make major changes in the family; they have worked well for so many years, now is not the time for major change, unless necessary.
Every crisis represents a novel situation in which novel forces, both internal and external, are involved. (Caplan, 1965)
• Illness, dying, and death does not automatically resolve differences in families.
• We need to become “empathically attuned” to several people in the room
• Importance of assessment
• Respectful partnerships with families
• Transparency in clinical decision-making
• Trained professionals: use skills of counsellor, psychologist, social worker, etc.
The Transition of Fading Away

• Redefining
• Burdening
• Struggling with paradox
• Contending with change
• Searching for meaning
• Living day by day
• Preparing for death
How you can
Task of Professionals

• To ensure a clear and adequate flow of information
  • To give opportunity for questions to be asked

• To acknowledge emotional pain
  • To facilitate its expression and sharing
  • To reassure about unfamiliar emotions

• To help family decide what is important to them
  • To give them confidence/resource to act on it
  • To support them in practicing new behaviors
- Normalize the experience: “many people share similar reactions to this kind of news”
- Use active listening skills to facilitate grief work: “of all that is happening to you right now, what is the hardest part to deal with?”
- Create a safe place for self-disclosure, and build a trusting relationship “No matter what lies ahead, you will not be alone”.
• Develop a collaborative relationship to establish a mutual plan of care: “what would help you the most right now?”
• Respect any use of denial in the service of coping with harsh realities: “It must be hard to believe this is happening”
• Assess the coping styles: “When you have experienced difficult times in the past, how did you get through them?”
• Reinforce strengths. “It looks like you are doing a great job”
• Maximize a sense of control and autonomy “It seems you really have a handle on this”
• Assess the need for information. “What do you know about the illness?”
• Check the need for clarification: “What did you hear?” or “Summarize in your own words how you understand your situation now.”
• Avoid medical terminology
• Mentor people who have had little experience with the health care system. Coach them in conversations with their physicians and teach them ways to navigate the complex health care system.
• Observe changes in family members’ roles and responsibilities (e.g. breadwinner becomes caregiver; homemaker works outside the home)
• Assist in identifying coping strategies
• Assist in identifying and expressing their values to guide them in decision-making
• Identify communication ground rules and seek to improve communication between family members: “is it ok to discuss this subject?”
• Involve them. Give them something to do.
• If in hospital setting, allow them to care for patient
• Preference is for home setting: more involved
• More family members involved, the better the bereavement outcome
• Help the family through: support, education, planning ahead
• Maintain hope
• Hope shifting

• Offer information: objective, concise, clear, open communication. What should they anticipate? Discuss issues family may hesitate to ask.
• Acknowledge varying coping responses
• Take a break to reload!
Conclusion

• Each family is unique and comes with its own life story
• Listen to the story. Understand them, build trust.
• Help them recognize their role in the family
References

