## SPECIAL CONSIDERATIONS FOR FAMILIES

### How Can Health Care Professionals Help Families at a Time of Loss?

- In end of life care, the family of the dying person is a critical focus in the care processes
  - Caregivers for the patient need care and support themselves
  - Involved in making critical decisions that influence the dying person's end of life care, well-being, and the time and mode of death
- Understanding family responses to dying and death
  - Tasks of the bereaved family (from Walsh & McGoldrick, 1991)
    - Shared acknowledgement of the reality of the loss
    - Shared experience of the pain of the loss
    - Reorganization of the family system without the deceased
    - Investment of energy in other relationships
  - The timing of the loss in the family life cycle contributes to the family response to the loss
    - Some losses are untimely (e.g., death of a child) and especially difficult to accept
    - Multiple losses may overwhelm family with demands of adjustment, both practical and existential
    - Families with young children differ in their grief response to those with adult children who live apart from the parents
    - Families experiencing concurrent life changes (birth of a child coupled with death of a parent) will have special needs
    - Deaths in families that have experienced divorce and remarriage will present their own challenges to the family members

### When Family Members Conflict

- Family conflict may disrupt the care of the patient and result in complicated bereavement for its members
- Often a highly stressful situation for health care professionals
- Important to keep in mind that death has an impact on a family ***system*** as well as the individual members
- As a health care professional, you may have little information on the family history even if one member has provided some information
  - You have received information from only one perspective
  - The perspective may be quite different when presented by other family members

**The Experience of One Family** Mr. A is a 70-year-old Japanese American man diagnosed with metastatic prostate cancer. He is married with two adult sons living with their families in the area. He and his family are practicing Buddhists. Mr. A is an Aikido master and his students are located around the world. His cancer now is widely spread with metastatic disease in his bones contributing to severe pain. During his last clinic visit, you observe that his functional status is poor. He requires assistance to dress and to walk.

Mr. A has expressed a desire not to be sedated in order to be clear mentally and fully aware of his experiences. His pain, however, is refractory to medication. His quality of life is severely impaired and he is not able to sit up or sleep because of the pain. His wife and sons are very concerned.

Mr. A is very weak. Mrs. A reports that he has not moved from his bedroom for the past three days. She states that during the last few weeks, many of his former Aikido students have called from around the world and a number have traveled to visit with him. Their home health nurse calls to say that the family is able to spend very little time with Mr. A because of the visiting students who have occupied his time and energy. The nurse expresses concern that the family is being deprived of their last time with Mr. A and that this may interfere with the grief process.

Mr. A has been hospitalized close to the end of his life and is comatose. His wife and sons have been sitting in his room with him. Other family members are present in a waiting room down the hall. Mr. A and his wife previously have identified his eldest son as the surrogate decision maker. His son has agreed to a do not resuscitate order. This is written and placed in his medical record. His youngest son and several other family members approach you and express concern about the do not resuscitate order they have seen on his chart. In this discussion, Mr. A's brother becomes angry that the decision was made by Mr. A's elder son without consultation with senior family members. He threatens legal action.

You have been Mr. A's physician throughout the course of his illness and have come to know Mr. And Mrs. A quite well. They have come to rely on your skill as a physician and trust you in guiding his medical care. In turn, you have developed great respect and regard for this man and his wife. They are clearly suffering at this time and it is difficult for you to see their pain. Mr. A's brother and younger son have expressed anger with your care and have made it clear that they do not appreciate your decision-making. During the past year, a number of your patients have died and you have experienced several personal losses, including the death of a member of your immediate family. As you return to your office after an evening visit with Mr. A and his family, you feel emotionally drained.

Mr. A is close to death and his wife is with him. His wife appears to be very anxious about Mr. A's breathing and the changes in the color and temperature of the skin of his fingers and toes. She has made repeated requests for suctioning of the secretions of his throat and chest. She has been observed to be crying quietly at his side.

**Perspectives…** The story of Mr. A and his family demonstrates a number of family concerns and conflicts in end of life care—the needs of the patient versus the concerns of the family, family member needs and concerns versus considerations of friends, conflicts within the family. The experience of Mr. A and his family also raises cultural considerations.

As a health care professional how would you address the different needs of Mr. A and his family? How might you work with the family to reduce the conflicts among the family members? What other needs are implied in this story? Would your needs and concerns as Mr. A's physician, nurse, chaplain, counselor conflict with those of Mr. A and his family? What kinds of interventions might be useful to help Mr. A, his wife, sons and other family members?

**Assessing Families Anticipating or Experiencing Loss**

- Who are the family members?
    - Who lives with the patient—spouse or partner, children, elders?
    - Critical to consider variation in family composition: Many families differ from what might be thought of as the traditional family unit—husband, wife, children
        - Gay, lesbian, or bisexual families
        - Families blended due to remarriage after divorce or death of one or more partners
        - Adult children caring for parents
- Who is in the extended family?
    - Are there important significant others that are like family members (e.g., close friends, clergy, nanny)?
    - Are there children?
    - Are there dependents other than children?
- How do the family members relate to each other?
    - Flexible versus rigid roles
    - Close versus distant relationships
    - Open versus closed communication
    - Affectionate versus reserved communication
- Who are the main decision makers in the family?
- How does the family make decisions together?
- What family members have been designated by the dying person to play a role in decision making in end of life care?
- Are there divisions among family members?
    - Is there hostility or conflict among subgroups?
    - Is there a scapegoat?
- How do the family members relate to outsiders such as health care professionals or the end of life care team?
- What is the families experience with other losses?
    - Recent losses?
    - Rituals?
    - Coping?
- What other stresses or life changes is the family experiencing?
    - Marriages
    - Births
    - Illnesses
    - Relocations
    - Financial changes
- What are the resources that this family has to cope with losses?

- Spiritual and religious beliefs, faith?
- Strong community of friends and extended family members?
- Psychological resilience, optimism among some or all family members?
- Openness to receiving help and support from others?
- Financial resources?

**Defusing Family Conflict**

- Understand that bereavement is one of the most stressful events that the family experiences
  - In contemporary society in the United States, many families live far from their extended families and are isolated socially in their communities
  - The losses of a family are magnified—the family experiences both the loss of a member and the loss of the family unit has it has been known
- Understand the family and its members—their previous experiences, their beliefs, their concerns about the dying process
- Be sensitive to the family as a system—the responses of each member have an impact on the entire group
- Recognize that family members may have diverse perspectives in the same situation
- Avoid aligning with one member or group in the family when possible
  - Listen respectfully to family members without passing judgment or taking sides
  - Allowing family members to express their concerns can go along way to prevent or defuse conflicts
  - Using different members of the end of life care team to provide support for each individual family member can help the individuals in the family to feel that their perspective and concerns are understood
- Educate the family about the process of care and the process of dying
- Organize family/staff conference or meeting so that different points of view can be discussed, concerns and questions can be raised, and family can be educated together
- Encourage family members to take care of themselves
  - Help the family arrange respite care
  - Provide financial counseling or assistance
- Allow family members to express painful emotions, including anger and hostility
- Verbally recognize the contributions of each family member to the life of the dying person and to their care at the end of life
- Verbally acknowledge the stressfulness of the end of life experience and the grief of the family member
- Provide help for family members in resolving conflicts and in seeking closure with the dying person

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