

A STATEMENT OF ASSUMPTIONS AND PRINCIPLES CONCERNING PSYCHOSOCIAL CARE OF DYING PERSONS AND THEIR FAMILIES

INTRODUCTION

The dying and their families face numerous psychological issues as death approaches. In writing these assumptions and principles we hope to counteract the tendency to focus too much on physical and technical care, to stimulate readers to test the following assumptions against their own experience, and to incorporate them into their work.

By psychosocial we mean the emotional, intellectual, spiritual, interpersonal, social, cultural, and economic dimensions of the human experience. Assumptions and principles for spiritual care and bereavement have already been developed by other work groups of the IWG.

By family we mean those individuals who are part of the dying person's most immediate attachment network, regardless of blood or matrimonial ties. The family, which includes the dying person, is the unit of care. By caregivers we mean those professionals and volunteers who provide care to dying persons and their families. We have separated the dying person, the family, and caregivers for the purposes of discussion only. Many of these assumptions and principles apply equally to dying persons and their families. They may not apply to all cultures and belief systems.

These assumptions and principles may seem self-evident, but should not be seen as generalities. They are ideals which we should strive to maintain, and thus they need to be translated into daily acts and clinical interventions that serve to meet the needs of dying persons and their families.

DYING PERSONS

Assumptions

Principles

89. Dying persons may choose to acknowledge or not to acknowledge their impending death. Caregivers must recognize and respect the person's right or need to deny or not to communicate about his/her impending death. Caregivers may be helpful to family members and others in understanding/accepting the dying person's position which may change with time.
90. Dying persons can communicate about their impending death in different cultural ways encompassing verbal, non-verbal, or symbolic ways of communicating. Caregivers must seek understanding and knowledge of the dying person's cultural and lifestyle experiences. Caregivers need to be astute to non-verbal and symbolic ways of communicating and recognize these modalities may be more significant to the dying person than what is explicitly expressed.
91. Dying persons have the right to information about their changing physical status and the right to choose whether or not to be told they are dying. Caregivers need to be sensitive and perceptive to the different ways the person may be requesting information about his or her condition.

92. Dying persons may be preoccupied with dying, death itself, or what happens after death.

93. Dying persons can have a deep-seated fear of abandonment. They may therefore continue treatment for the sake of the family or physician rather than in the belief that it will be of personal benefit.

94. Many dying persons experience multiple physical and psychological losses before their death.

95. Dying persons exhibit a variety of coping strategies in facing death.

The caregiver team needs to be aware of the dying person's concerns and fears in order to provide care which is responsive and supportive.

Caregivers can be helpful to the dying person in identifying feelings that may affect treatment decisions. Caregivers may also be helpful in opening communication between the dying patient and family or physician which may more clearly reflect the patient's goal for treatment.

Caregivers may be helpful in facilitating expression of grief related to the multiple losses of terminal illness. Caregivers may also be helpful in supporting the dying person's need for continued autonomy, satisfying roles and activities, and meaning despite these losses.

Caregivers need to be able to recognize the utility of adaptive coping mechanisms and be tolerant of the patient or family's need to use or abandon them. Caregivers can help to foster an environment which encourages the use of more effective ways of coping by accurately addressing the dying person's psychosocial concern.

96. Dying persons generally need to express feelings.

97. Dying persons communicate when they feel safe and secure.

98. Dying persons may find it helpful to communicate with others who are terminally ill.

99. Dying persons' communication about death concerns may be inhibited by a number of psychosocial and culturally determined expectations.

Dying persons should not be isolated but should be given the opportunity to communicate.

Caregivers should strive to create an environment in which communication can be facilitated, paying special attention to physical comfort, symptom management, physical surroundings, privacy, confidentiality, adequate time, acceptance of feelings, and shared expectations.

Opportunities for patient interaction should be encouraged, such as peer or professionally facilitated support groups, social functions, or designated areas within treatment settings where patients may informally gather.

Caregivers can be helpful in breaking through the barriers to communication which inhibit the dying person's true expression of feelings.

100. Dying persons have a right to be acknowledged as living human beings until their death.

101. Dying persons' psychological suffering may be greater than their physical pain or discomfort.

102. Dying persons may have difficulty in dealing with multiple family members who have different or conflicting needs.

Caregivers need to facilitate an awareness that dying persons are still able to sense their own surroundings even when they seem severely impaired. Caregivers should encourage behavior, touch, and communication which continue to demonstrate respect for the dying person.

Caregivers should recognize and attend to the psychosocial component of suffering.

Caregivers need to be aware of the dynamics within each family and recognize the importance of dealing with individual members as well as the family unit. Caregivers should be sensitive to the presence of conflicts between family members and may need to maintain a position of neutrality in order to be effective.

ISSUES FOR FAMILIES

Assumptions

103. Families have fundamental needs to care and be cared for.

104. The need to care and the need to be cared for sometimes conflict.

105. People vary in their coping abilities and personal resources. Moreover, competing priorities may hamper the amount and quality of care people are able to give.

106. The approach of death may disrupt the structure and functioning of the family.

Principles

Families should be encouraged to provide whatever care they can. Caregivers should not supplant the family in the caregiver role except where the family lacks physical or emotional resources, knowledge, or desire to provide care. By providing care to family members, they may be better able to care for the dying person.

Those who sacrifice their own needs for care in order to care for others need to be encouraged to accept help for themselves. Some need to receive care before they can give care.

Caregivers should not impose their own expectations on a family's ability to care. Caregivers may need to explore with the family what is reasonable for each to provide.

Many families need counseling and support to prepare for the dying person's death and its consequences.

107. Families need to have information about a dying person's condition although in cases of conflict the person's wish for confidentiality must be respected.

108. Families often need to be involved with the dying person in decision making.

109. Families have a right to know that their affairs will be shared only with those who have a need to know.

110. Family members need to maintain self esteem and self respect.

111. Sexual needs may continue up to the point of death.

The dying person and caregiving team share the responsibility for informing the family about the person's condition, depending on his or her ability to participate. Whenever possible the dying person and appropriate caregiver(s) need to agree on the source and extent of information given to families.

Guided by the dying person's wishes, caregivers can be helpful in facilitating joint decision making.

Confidentiality must be maintained at all times and its meaning taught to all caregivers.

Caregivers should show respect at all times. Caregivers do this by paying attention to family wishes, feelings, and concerns.

Caregivers should acknowledge dying persons' and their partners' need to express their sexuality both verbally and physically, with easy access to privacy without embarrassment.

112. Families coping with terminal illness frequently have financial concerns. Caregivers need to assure that families have access to informed advice and assistance on financial issues. These issues represent present or anticipated problems that may or may not be realistic.
113. Faced with death, the family may imagine that changes will be greater than they are. Caregivers can often help to diffuse the intensity of fears with information and support.
114. Families have a need and right to express grief concerning the impending death and multiple losses associated with the illness. Caregivers can be helpful to families by encouraging the expression of grief and communication with the dying person about their shared losses.

ISSUES FOR CAREGIVERS

Assumptions

115. Caregivers need education and experience in addressing the psychosocial needs of dying persons and their families.

Principles

A combination of specialized courses in death and dying and clinical practicums in care of the terminally ill and their families may help to prepare caregivers to deal with the physical and psychosocial needs of dying persons.

116. Caregivers need to be aware of the dying person's and family's psychosocial frame of reference in acknowledging and coping with impending death. Caregivers need to be sensitive to the dying person's and family's current willingness to acknowledge the reality of their situation. Caregivers must not impose their own expectations for how dying persons face death.
117. Caregivers bring their own values, attitudes, feelings, and fears into the dying person's setting. Caregivers must recognize that they cannot take away all the pain experienced in the dying process. Caregivers need to be reassured that it is not a lack of professionalism to display and share emotions. Caregivers need to be aware of the way in which their coping strategies affect their communication of emotional involvement with the dying person and family.
118. Caregivers are exposed to repeated intense emotional experiences, loss, and confrontation with their own death in their work with dying persons. Caregivers need to receive adequate support and opportunity to work through their accumulated emotions. Caregivers working with dying persons need to have developed sound motivation, emotional maturity, versatility, tolerance, and a special ability to deal with loss.

119. Caregivers dealing with families and groups sometimes experience conflicting needs and requests about communication and confidentiality.

Caregivers need to be prepared to deal with complex family dynamics and to assist the family in resolving their own conflicts.

120. Caregivers may sometimes not communicate with each other about their own needs and feelings.

Caregivers need to be tolerant, caring, and non-judgmental with each other in order to promote cooperation which will benefit the person's care.

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