

## Clients and Families in Grief

### What Is Providing Support for Clients and Families in Grief?

- › Grief is the emotional, physical, social, philosophical, spiritual, and cognitive response to loss. Grief can result from a death of a loved one as well as from other losses, including loss of health, miscarriage, and the loss of the feeling of safety after a trauma. Mourning is the outward expression of grief. Supporting clients and families who are experiencing grief involves helping them understand the emotions and behaviors commonly experienced during grief and providing support and interventions to assist them in coping with their loss
- › *What:* The grief reaction can be sorted into four domains: feelings, cognitions, behaviors, and physical sensations. Grief support consists of assisting clients and families with progression through the stages, phases, or tasks of grief (depending on the grief model being utilized) and with adjustment to life following a loss. Grief can be categorized as
  - Uncomplicated when it involves what are considered typical feelings, behaviors, and actions associated with loss
  - Anticipatory when it occurs before the actual loss or death
  - Complicated when the person has difficulty progressing through the stages of loss and grief; complicated grief can become chronic, have a delayed onset, manifest as an exaggerated or abnormal response to loss, manifest as an absence of grief or an inhibited grief response (sometimes referred to as absent grief), or manifest as a masked response to loss
  - Disenfranchised when the loss is not recognized or acknowledged by society, family, or other supports (e.g., the loss of a same-sex or transgender partner; death of a loved one who had dementia or another chronic, long-term illness; the loss of a relationship partner outside of marriage)
  - Ambiguous when the loved one is physically present but cognitively or psychologically is absent
  - Integrated when the client has adapted to the loss, satisfaction with life returns, and the grief is incorporated as a part of a permanent response to the loss
- › *How:* Grief support is provided by actively listening and allowing clients and families to discuss their emotions. If appropriate for the setting, the social worker can provide individualized or family counseling to address grief issues. Grief support may also include providing clients and families with information on support groups and other resources in the community that will help in processing their grief
- › *Where:* Support can be provided for the clients and families in grief in any setting where healthcare is provided, including inpatient, outpatient, and home-care settings
- › *Who:* Social workers are primarily responsible for assessing the needs of clients and families in grief and for providing individualized support and counseling, including requesting a referral to other sources of support (e.g., a facility chaplain, a clergy person, a mental health clinician specializing in grief counseling)

### What Is the Desired Outcome of Providing Support for Clients and Families in Grief?

- › The desired outcome of grief support is for clients and families to acknowledge their loss or pending loss and accommodate and integrate it into their regular life functioning healthily. The desired outcome is not that they will move on or forget the loss but that they

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will include the loss and its impact on their day-to-day functioning so that the loss does not continue to have negative effects

## **Why Is Providing Support for Clients and Families in Grief Important?**

- › Clients and families require support as they progress through the stages of grief to accept the loss and move forward in life
- › Helping clients and families to establish and reach individualized goals during the grieving process has a positive impact on the quality of life
- › Early and appropriate interventions reduce clients' and families' risk for complicated grief

## **Facts and Figures**

- › Theories on grief often view the grieving process as consisting of specific stages or tasks. When experiencing grief, patients and families often move forward and backward between stages of grief over a period of many years without following a particular order until acceptance of the loss is achieved (Yancy, 2014)
- › Providing care to a loved one who is terminally ill is stressful and time-consuming. More than 100 hours a week on average are expended by a caregiver when his or her loved one is at the end of life (Hebert et al., 2008)
- › Caregivers who felt they were not properly prepared for a loss experience higher rates of depression, anxiety, and complicated grief (Hebert et al., 2008)
- › Complicated grief is present in the first year of grieving for 10–20% of individuals who experience a loss (Ghesquiere et al., 2011)
- › In a study of 61 caregivers of clients in a vegetative state, researchers found that those who relied on social support, positive attitude, and a problem-oriented approach to cope experienced lower levels of anxiety, depression, family strain, and prolonged grief and those who used avoidance-based coping strategies experienced higher levels of anxiety, depression, family strain, and prolonged grief (Cipoletta et al., 2014)
- › Researchers who studied 64 parents who experienced the loss of a child concluded that high levels of avoidance and depression and lower levels of cognitive reframing (a technique to change stressful and often inaccurate thoughts to more accurate and less rigid thoughts) were associated with prolonged grief symptoms (Harper et al., 2014)
- › In a study of women in Thailand who were grieving after termination of their pregnancies, researchers found that the women's grief decreased (as measured by a grief questionnaire) after they had been a part of an informational and emotional support group which consisted of group therapy as well as telephone support. The results indicate that support groups can be an effective way of alleviating grief (Sriarporn et al., 2017)
- › Losing a family member in traumatic circumstances (e.g., suicide, homicide) has been linked with significantly increased rates of suicide ideation in surviving family members – in one study, 42% of family members reported suicidal ideation following a traumatic death (Williams et al., 2018)

## **What You Need to Know Before Providing Support for Clients and Families in Grief**

- › Loss creates the need for a change or adjustment in the affected person
  - In the healthcare environment, hospitalization, disease, disability, and death are all forms of loss; these forms of loss all involve the loss of
    - Privacy
    - Control over one's physical body, which can negatively affect social status, self-esteem, relationships, and finances
    - The daily physical presence of a loved one
- › Common emotions experienced during the grieving process include
  - Denial
  - Anger
  - Anxiety
  - Sadness or depressive symptoms
  - Numbness
- › Grief responses vary from person to person and can be affected by
  - Gender
  - Cultural and spiritual factors
  - Stage of the life of the bereaved (e.g., child, adolescent, young adult, middle-aged, older adult)
  - History of previous losses and whether those losses were deaths, job loss, divorces, etc.
  - Presence of additional stressors (e.g., financial, familial, substance use, alcohol use)
  - Physical or mental illness

- › Clients and families in grief may react to losses with intense emotions or behaviors common to grief. If the social worker is unprepared for or uncomfortable with these reactions, he or she may fail to acknowledge the grief that is present. The social worker should
  - Acknowledge the loss
  - Actively listen to the client and family
  - Acknowledge the emotions experienced by the client and family
  - Reinforce that these emotions are normal and expected
- › When supporting the grieving clients and families, it is important to
  - Provide a quiet, private area for the client and family members to meet
  - Sit with the client and family members and be comfortable with the silence
  - Establish eye contact if culturally appropriate
  - Convey a desire to communicate with the client and family members
  - Validate the feelings of clients and families by repeating and confirming what the social worker sees and hears when appropriate
  - Recognize that clients and families often find comfort in familiar coping strategies (e.g., ask the client and family what has provided comfort in the past during difficult times)
- › For most individuals, acute grief transforms over time into integrated grief (i.e., they can integrate the reality and emotional pain of their loss and move forward with their lives). For some, however, the grief state persists to the point of debilitation. In persons with complicated grief (also called *prolonged*, *traumatic*, and *pathological grief*), painful emotions, including nonacceptance of the loss, are so long-lasting and severe that individuals are unable to resume their normal daily activities
  - The *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition (*DSM-5*), added proposed criteria for “persistent complex bereavement disorder” to the chapter on Conditions for Further Study.
    - Persistent complex bereavement disorder is clinically significant bereavement that causes distress in social, occupational, or other important areas and is inconsistent with cultural, religious, or age norms. Symptoms must have persisted for at least 12 months (6 months for children)
    - Criteria specify preoccupation with the deceased and the circumstances of his or her death, intense sorrow, and a persistent yearning for the deceased as well as 12 other criteria that describe reactive distress to the death and disruption of social functioning and personal identity

## **Social Work Responsibilities in Providing Support for Clients and Families in Grief**

- › The following preliminary steps should be performed before administering the bereavement risk assessment:
  - Establish the client’s privacy
  - Determine if the client/family requires special considerations regarding communication (e.g., due to illiteracy, language barriers, deafness); make arrangements to meet these needs if they are present
  - Explain the nature and purpose of completing a bereavement risk assessment and answer any questions
  - Express interest in discussing the client’s and/or family’s loss and offer them an opportunity to speak
- › Complete a bereavement risk assessment. Utilize a formal screening tool, if provided by the facility, or conduct an informal risk assessment by examining the following areas and assessing whether they are risk factors or protective factors
  - Family relationships – positive and negative
  - Caregiver role
  - Mental health issues
  - Coping mechanisms
  - Substance or alcohol use
  - Suicidal ideation or expression
  - Family members’ concerns about whether they can cope with the loss of their loved one
  - Spirituality
  - Competing demands (e.g., work, parenting)
  - Financial stressors
  - Physical limitations
  - Other non-death losses (e.g., divorce, job loss, moves)
  - Previous bereavement
  - Social support systems
    - Present or absent

- Whether client or family will be willing to access these supports
- Cultural factors
- Language barriers
- Relationship with the client or with the deceased
- Spirituality/religion
- Positive belief in self and ability to cope with impending loss
- › If the social worker is going to be providing individualized and/or family counseling, see *What Social Work Models Are Used with Providing Support for Clients and Families in Grief*, below
- › Makes referrals for any services indicated by assessment
- › Documents in the client's record according to facility guidelines:
  - Assessment findings
  - Interventions performed
  - Client's response to the interventions
- › Social workers should be aware of their own cultural values, beliefs, and biases and develop knowledge about the histories, traditions, and values of the client and family. They should adopt treatment methodologies that reflect the cultural needs of the client and family
- › Social workers should practice with awareness of and adherence to the social work principles of respect for human rights and human dignity, social justice, and professional conduct as described in the International Federation of Social Workers (IFSW) Statement of Ethical Principles, as well as the national code of ethics that applies in the country in which they practice. For example, in the United States, social workers should adhere to the National Association of Social Workers (NASW) Code of Ethics core values of service, social justice, dignity and worth of the person, importance of human relationships, integrity, and competence. Become knowledgeable of and practice the NASW ethical standards as they apply to clients and families dealing with grief (NASW, 2017)

## **Other Interventions That May be Necessary Before, During, or After Providing Support for Clients and Families in Grief**

- › Increase or decrease the frequency of interventions depending on the client's response to changes in the loved one's medical condition
- › After a loss, the family/caregiver may experience additional changes, transitions, and additional losses that may complicate their grief. The social worker needs to recognize this risk. Help individuals identify, express, and experience their grief to limit or reduce the negative impact of the additional stressors of role changes and transitions
- › Give clients or families experiencing disenfranchised grief permission to grieve openly. The social worker needs to recognize these losses as legitimate and validate the sense of loss and grief experienced by clients or family members
- › The social worker may need to utilize the Geriatric Depression Scale, specifically tested for older adults, to identify depressive symptoms during grief in older adult patients or families

## **What Social Work Models Are Used with Providing Support for Clients and Families in Grief?**

- › The Kübler-Ross model of grief, developed for diagnoses of terminal illness, is widely accepted which has a theory that grief is experienced in five stages and not always linear in progression. This model may apply to individuals who are still living but are in the final stages of terminal illness or to the grieving process of families
  - Denial takes place when the client or family cannot accept the terminal nature of the illness or are in disbelief that their loved one has died
  - Anger can be self-directed or expressed against medical staff, the social worker, the world, etc.
  - Bargaining, which can be internal or spiritual, occurs when family members make promises or pray about what they will do if they or their loved one is spared
  - Depression, which may share some or all of the signs and symptoms of major depression, may be experienced connected to the impending loss or actual death
  - Acceptance is a coming to terms with the approaching loss or actual death and moving forward with living
- › Rando's grief reactions model divides grief into three phases
  - Avoidance may include shock, disbelief, and denial that one's loved one is dying or has died
  - Confrontation is the phase of intense grief reactions as the bereaved person recognizes and realizes over and over that his or her loved one is dead

- Accommodation takes place when the bereaved reenters the world socially and emotionally
- › Bowlby's phases of mourning were developed specifically in response to the parental loss of infants
  - Numbness or feeling as if what is happening is not real
  - Disbelief may be accompanied by a sense that the parents/family are trying to reverse the outcome, dispute the diagnosis, or argue against the expected fatal outcome
  - Disorganization and reorganization occur when the truth of the situation is recognized, and the parents/family align to their new self, roles, and situation
- › Worden's task-based model focuses on individuals and their unique experiences of grief. This model is best suited for an intuitive griever. An intuitive griever might feel his or her grief in waves of emotion. He or she may be actively looking for support and help with expressing his or her emotions, such as
  - Accepting the reality of the loss: either an actual loss or death or the impending loss that is present with a terminal diagnosis
  - Working through the pain of grief involves acknowledging the emotional, behavioral, and physical pain associated with the loss. Adjusting to a new environment is made up of three adjustments
    - Internal adjustment of self
    - External adjustment to the environment
    - Spiritual adjustment
  - Emotionally "relocating" the deceased helps the family to maintain a connection with the loved one but still move forward in life
- › Silverberg's 3-A grief intervention model was developed for caregivers of persons with dementia but can be applied to other grief situations, especially anticipatory grief situations
  - Acknowledging the loss but also acknowledging the grief that is present, whether it is anticipatory grief or grief after a death
  - Assessing the therapy client, whether an individual or family and determining his or her grieving style (intuitive versus instrumental) while also assessing his or her level of denial
    - Intuitive is detailed in Worden's model
    - Instrumental grievers experience their grief physically and cognitively. They are less likely to seek support and more likely to bury themselves in activity or a cause which is a more covert representation of grief
  - Assisting the client or family in accepting respite and letting go of the guilt that comes with taking a break from caregiving or taking a break from grief
- › Grief support may take the form of individual or group therapy
  - The social worker conducting individual supportive grief therapy will use one or more of the models listed above to perform a bereavement assessment, provide active listening, and help the individual to process his or her grief. The social worker's tasks will be to
    - Reduce isolation
    - Discuss the individual's perceptions of his or her grief
    - Allow for expression of that grief
    - Monitor physical, psychological, and emotional symptoms
    - Monitor for needs or anxieties related to the anniversary of the loss
    - Help the individual to honor old rituals related to his or her loved one but create new rituals
    - Include family members and community resources when planning care or networking for the individual
    - Recognize and encourage his or her resiliency and spirituality, if important to the individual
  - Group therapy is most commonly time-limited, with a start date and end date, and often is for a specific type of loss (e.g., sudden versus expected, child versus an adult, spouse, parent, etc.). Groups are closed to new members until the end date is reached (e.g., a group that will meet for 2 hours once a week for 6 weeks with no fewer than 6 members but no more than 12). The social worker should seek a commitment from his or her client to come to the first group session and after the first session encourage the client to agree to attend the remaining sessions. The social worker should also:
    - Establish ground rules (e.g., no interrupting, being respectful, no cell phones, confidentiality)
    - Listen and validate while providing grief education to the group
    - Educate the group on the importance of silence and that it is ok not to have someone always talking
    - Participants need to attend the initial session. Any referrals after the group starts must wait for the next session

## Red Flags

- › Clients and families who experience loss and fail to acknowledge the loss or show emotions are exhibiting absent grief and may require referral to a mental health clinician who is a grief specialist
- › Family strain or ruptured family relationships may interfere with the ability to provide appropriate support during the grieving process
- › In some cultures, establishing eye contact is not considered therapeutic and does not convey caring

## What Do I Need to Teach the Client and the Client's Family?

- › Educate client and family that progressing through grief is not always a linear process through stages, phases, or tasks but instead may consist of progressions and regressions
- › Encourage individuals to seek continued grief support, outside of the healthcare setting, by attending grief support groups, talking with clergy, and/or seeing a mental health clinician, who specialize in grief
- › Normalize the grief process for the client and family so that they do not feel abnormal or alone in their grief experience
- › Educate the client and family on grief triggers. Trigger events are intense emotional experiences brought on by sights, sounds, smells, locations, or family events in which the loss is felt strongly. Teach that these should not be viewed as setbacks in one's grief processing

## DSM -5 Codes

- › 296.xx, Major Depressive Disorder
- › 309.81, Posttraumatic Stress Disorder

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