

Complicated Grief

Risk factors, interventions, and resources for oncology nurses

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BACKGROUND: When a loved one dies of cancer, complicated grief (CG) may occur because of the trauma associated with family caregivers' perceptions of their loved one's suffering, either from advanced cancer or from side effects of cancer treatment.

OBJECTIVES: This article provides an overview of CG and existing interventions for family caregivers who may be at risk for CG following the loss of a loved one and the implications for oncology nurses who provide emotional support and guidance.

METHODS: Current evidence related to the treatment of CG and information to assist with identification of individuals at risk for CG are presented, as well as resources for oncology nurses who encounter individuals who are at high risk for, or who are experiencing, CG.

FINDINGS: Although therapy interventions for CG have been shown to be effective forms of treatment, these therapies are not widely available and often require an extended treatment period to yield results. Oncology nurses can provide early interventions, such as referrals to supportive care services and mental health professionals to facilitate effective treatment.

KEYWORDS

grief; family caregivers; patient education; end-of-life care; integrative therapies

DIGITAL OBJECT IDENTIFIER

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GRIEF IS PART OF THE HUMAN EXPERIENCE and a normal reaction to the death of a loved one. Although the pain of loss may never completely subside, most individuals adjust to life without the deceased and develop a new sense of normalcy over time. For others, the grief process becomes prolonged. Individuals who have difficulty accepting the death and assimilating into life without the deceased experience what is known as complicated grief (CG), or prolonged grief disorder (Shear, 2010).

CG may occur in as many as 40% of family caregivers who lose a close family member to cancer (Guldin, Vedsted, Zachariae, Olesen, & Jensen, 2012). For some, symptoms of CG can occur before the patient dies when family members are struggling to accept the cancer diagnosis and impending death (Tomarken et al., 2008). CG disproportionately affects older adults, with more than 25% of older adults experiencing CG, compared to only 5%–7% of the general population (Newson, Boelen, Hek, Hofman, & Tiemeier, 2011; Shear, 2010). CG is associated with numerous psychological problems, including loneliness, social isolation, anxiety, clinical depression, cognitive impairment, and post-traumatic stress disorder (PTSD) (Ghesquiere, Shear, & Duan, 2013; Shear, Ghesquiere, & Glickman, 2013). Compounded losses of multiple close family members and friends, increased likelihood that the deceased will be a spouse or partner, and financial burdens associated with the loss may lead to a higher incidence of CG among older adults (Ghesquiere et al., 2013; Newson et al., 2011).

Oncology nurses often form close relationships with patients and their family caregivers, both of whom depend on them for guidance and emotional support during cancer treatment (Guldin et al., 2012). Therefore, oncology nurses are positioned to direct family caregivers to appropriate grief services, as well as to deliver continued emotional support and guidance. This article provides information to assist with identifying individuals at risk for CG, discusses current evidence related to treatment for CG, and provides resources for oncology nurses who encounter individuals who are at high risk for, or who are experiencing, CG.

Risk Factors

Although anyone can experience CG, certain risk factors may elevate the likelihood of CG occurring. Manifestations of CG include (a) intense longing; (b) loneliness, emptiness, or lack of meaning in life; (c) recurring thoughts of wanting to join the deceased; and (d) intrusive thoughts about the deceased that interfere with functioning (Shear et al., 2011). Individual signs and symptoms of CG also may include feelings of guilt over the death; constantly replaying the circumstances of the death in their mind; imagining

that they could have somehow prevented the death if they had done something differently; and feeling numb, shocked, or in disbelief over the death. The nature of the relationship to the deceased, personality traits, coping style, psychiatric history and comorbidities, and socioeconomic factors all contribute to the risk of CG.

Relational Factors

The closer the relationship to the deceased, the more likely it is that the individual will experience CG. Spouses and parents are particularly vulnerable to symptoms of CG. Spouses may be highly inter-dependent on each other and share a close relationship and a lifetime commitment. Widowed parents with young children may face additional stressors that can lead to depression and increased psychological distress (Yopp, Park, Edwards, Deal, & Rosenstein, 2015). Because parents normally do not expect a child to precede them in death, feelings of guilt and existential suffering may ensue. Older adults may experience multiple losses in a short period of time that compound grief and delay recovery (Newson et al., 2011).

Personality Traits and Coping Style

Personality plays a key role in how an individual grieves, internalizes the grief, and integrates understanding and meaning about the loss of a loved one (Piper, Ogrodniczuk, Joyce, & Weideman, 2011). An individual's psychological adjustment process, combined with attachment style and coping capability, can help determine whether he or she is at a higher or lower risk of experiencing symptoms of CG (Piper et al., 2011). Although more well-adjusted individuals would be expected to cope better with grief and loss, the literature does not clearly support this relationship (Mancini, Sinan, & Bonanno, 2015; Piper et al., 2011). Personality traits identified as correlates for poorer coping strategies and prolonged emotional distress include anxiety, insecurity, lower levels of self-esteem, and higher levels of negative cognition (Boelen, van den Bout, & van den Hout, 2006; Piper et al., 2011).

Despite inconclusive research regarding a causal relationship between personality and severity of grief, personality does factor into the level of distress some individuals experience when dealing with grief and the length of time required for the grief symptoms to resolve (Piper et al., 2011). The literature presents a compelling argument that an individual's level of worry and anxiety, along with his or her attachment style, plays a role in the ability to effectively adapt after a loss (Schenck, Eberle, & Rings, 2015). For example, securely attached individuals tend to adapt and resolve their grief more effectively than those with a more anxious attachment style (Piper et al., 2011). Those with higher anxiety-related attachment styles may experience difficulty moving through the grief process, managing emotions, and adjusting after a loss (Piper et al., 2011). Individuals with anxious attach-

“Grief is a culture-bound experience that occurs within an individual’s social-cultural environment.”

ment styles are also prone to prolonged emotional distress and display maladaptive avoidant behavior, causing them to suppress emotions that could result in psychosomatic symptoms (Mancini et al., 2015).

The negative cognitions associated with the previously mentioned attachment styles create beliefs of not being able to live without the deceased individual, feeling worthless without the presence of the deceased person, and feeling like life no longer has meaning (Boelen et al., 2006). These negative cognitions cause bereaved individuals to dwell on their loss rather than to focus on problem- or emotion-specific solutions (Mancini et al., 2015). Negative cognitions play a significant role in prolonging emotional distress and serve as the target for therapeutic interventions to help bereaved individuals dispute and restructure their maladaptive thoughts and beliefs (Boelen et al., 2006; Piper et al., 2011). Behavioral interventions that support the lessening of negative cognitions and avoidant behaviors serve as protective factors in resolving grief and loss (Mancini et al., 2015).

Individuals who experience CG during their bereavement tend to exhibit greater dependency behaviors, focus primarily on negative cognitions about the deceased, are highly emotional, experience a greater degree of loneliness, and hold negative perceptions about the support they will receive if they reach out to others for help (Boelen et al., 2006; Mancini et al., 2015; Piper et al., 2011). Individuals who demonstrate greater levels of resilience during their bereavement hold a more favorable view of the support they can expect from others, rely more on their support systems, openly share their feelings, and worry less about available support when needed (Mancini et al., 2015).

Additional protective factors that lead to more adaptive bereavement include spiritual and religious practices or rituals, prior adaptive psychological well-being, personal and financial control, and no co-occurring losses (Mancini et al., 2015; Piper et al., 2011). These protective factors predict less negative cognition and higher rates of perceived wellness (Boelen et al., 2006).

However, bereaved individuals with insecure attachment styles may demonstrate unwillingness or inability to engage with community and social support networks (Piper et al., 2011).

Studies conducted by Mancini et al. (2015) and Schenck et al. (2015) concluded that individuals with insecure attachment styles remained more focused on negative cognitions about the deceased than those with secure attachment styles. Findings also revealed a higher level of CG symptoms among bereaved individuals with insecure attachment styles. Those bereaved individuals who displayed CG symptoms demonstrated greater levels of separation distress (Piper et al., 2011; Schenck et al., 2015). Grief integration is necessary to find meaning in the loss and to find ways of maintaining a sense of closeness with the deceased (Schenck et al., 2015), resulting in adaptive coping that strengthens resilience (Mancini et al., 2015).

Psychiatric Comorbidities and Differentiation

As with many primary mental health disorders, comorbidities are common among individuals suffering from CG. This includes when CG is considered the primary disorder, as well as when CG is secondary to mental health disorders that share symptom overlap. For example, individuals presenting for care with a primary diagnosis of CG exhibit elevated rates of comorbid anxiety disorders, especially PTSD (48% current, 52% lifetime) and panic disorder (14% current, 22% lifetime) (Simon, Shear, et al., 2007). In nontreatment settings, approximately 15% of bereaved individuals also meet the diagnostic criteria for PTSD (O'Connor, 2010). Similarly, individuals with CG present with psychological characteristics often found in individuals with anxiety disorders, such as experiential avoidance (Boelen, van den Bout, & van den Hout, 2010) and intolerance of uncertainty (Boelen, 2010). Considering reverse directionality, high rates of comorbid CG have been documented in individuals with a primary diagnosis of major depressive disorder (Kersting et al., 2009; Sung et al., 2011). Consistent with this temporal relationship, a history of prior trauma or loss and a history of mood and anxiety disorders also predict greater likelihood of developing CG (Lobb et al., 2010).

Although significant symptom overlap exists whether CG is primary or secondary to PTSD, each disorder has its own unique features (O'Connor, 2010; O'Connor, Lasgaard, Shevlin, & Guldin, 2010). Whereas PTSD is characterized typically by fear, horror, anger, guilt, or shame, combined with an anxious hyperarousal and exaggerated reactivity, the experience of CG is marked primarily by yearning, loss, or emptiness (Alexander & Litz, 2014). CG symptoms include an intense longing for the deceased and distress over the loss of the relationship, which is not a central component of PTSD (O'Connor et al., 2010). To further differentiate, when experiencing PTSD after a loss, intrusive thoughts fixate on the death event itself, leading individuals to avoid internal and external reminders of the death event specifically, rather

than reminders of the deceased. On the other hand, in CG, individuals may experience intrusive and involuntary thoughts about diverse aspects of the relationship with the deceased, including positive content that the bereaved longs for, and avoidance is mostly limited to stimuli that serve as reminders of the reality or permanence of the loss (Alexander & Litz, 2014). However, the cardinal symptom of emotional numbness since the time of the loss is shared by both CG and PTSD (Alexander & Litz, 2014). Common comorbidities and similar symptom overlap between CG and other mental health disorders add to the challenge of identifying optimal treatments.

Psychotherapeutic Interventions

The normal grief process is a fluid process that most individuals can resolve without the intervention of healthcare professionals (Waller et al., 2016). Oncology nurses should consider referring individuals experiencing normal grief to support groups, grief counseling, and spiritual care services (Ghesquiere et al., 2013), which are offered through hospice and palliative care programs throughout the United States (Centers for Medicare and Medicaid Services, n.d.). When grief is prolonged, and the grief-stricken individual is unable to reconcile the grief and adjust to life without his or her deceased loved one, psychotherapeutic interventions are warranted (Wittouck, Van Autreve, De Jaegere, Portzky, & van Heeringen, 2011).

Support groups and bereavement counseling offer psychosocial support throughout the grief process and educate participants about normal grieving patterns; however, little evidence suggests

FIGURE 1. PSYCHOTHERAPY MODALITIES

COGNITIVE BEHAVIORAL THERAPY

- Form of psychotherapy that explores how thought patterns affect an individual's attitudes, feelings, and behaviors

COGNITIVE RESTRUCTURING

- Form of cognitive behavioral therapy that focuses on identifying negative, ineffective, or disruptive thought patterns and replacing them with more positive ones to encourage behavioral change

EXPOSURE THERAPY

- Form of cognitive behavioral therapy in which individuals confront a traumatic event through cognitive re-exposure and learn how to process emotions associated with the event

INDIVIDUAL INTERPERSONAL THERAPY

- Form of psychotherapy that focuses on interpersonal issues that can contribute to emotional distress to reduce symptoms, improve functioning, and enhance social support

Note. Based on information from Foa et al., 2008; Interpersonal Therapy Institute, 2017; Mills et al., 2008; National Alliance on Mental Illness, 2017.

that psychosocial support is effective in preventing or treating CG (Ghesquiere et al., 2015). Because bereavement programs are widely available and facilitated by mental health professionals, they may be helpful in identifying individuals who require treatment for CG.

Despite an abundance of hospice and palliative care programs offering support groups and counseling for grieving individuals, only a small percentage of people use these services (Steiner, 2006). Online groups offer similar benefits, increased access, and lower associated costs (Lubas & De Leo, 2014) which may encourage usage. However, healthcare providers have expressed concerns about the safety, oversight, and confidentiality of online programs (Lubas & De Leo, 2014; Wells, Mitchell, Finkelhor, & Becker-Blease, 2007).

Early palliative care interventions for family caregivers, delivered by advanced practice nurses via telephone while the patient is in advanced stages of malignancy, may reduce depression and CG, but require further study (Dionne-Odom et al., 2016). A writing intervention, called Finding Balance, allows bereaved caregivers of patients with cancer to reflect, process emotions, and find balance through specific writing activities (Holtlander et al., 2016). These promising new interventions, developed and evaluated by nurse scientists, aim to guide nursing practice in specific interventions to alleviate grief; however, more research is needed to evaluate their effectiveness in CG.

A 2011 meta-analysis of interventions for CG, which pooled data from 14 randomized, controlled trials testing interventions to prevent or treat CG, determined that treatment of CG significantly improved grief-related symptoms, whereas prevention interventions have not demonstrated consistent efficacy (Wittouck et al., 2011). The studies of CG interventions presented in the meta-analysis were published from 1990–2007 and included studies of cognitive behavioral therapy, individual interpersonal therapy, and a combination of the two (see Figure 1). The interventions ranged in length from 12–20 weeks and were conducted by trained mental health counselors and therapists.

Katherine Shear, MD, a faculty physician in the School of Social Work at Columbia University, has been instrumental in moving the science of grief therapy forward. Shear and her research team developed a 16-session psychotherapeutic intervention for individuals with CG that has demonstrated efficacy in three large randomized, controlled trials involving more than 600 participants (Shear et al., 2014, 2016; Shear, Frank, Houck, & Reynolds, 2005). The Complicated Grief Treatment intervention is a structured psychotherapy program, designed to be implemented by licensed mental health professionals (Shear et al., 2014). Complicated Grief Treatment has also demonstrated efficacy in a group setting, which affords a more economical option and higher access to treatment (Supiano & Luptak, 2014).

FIGURE 2.
RESOURCES FOR GRIEF SUPPORT

ONLINE RESOURCES

PsychCentral® Grief Quiz: A brief self-assessment to determine if a bereaved individual is experiencing complicated grief symptoms

- <http://psychcentral.com/quizzes/grief-quiz.htm>

HelpGuide.org: Coping with grief and loss

- www.helpguide.org/articles/grief-loss/coping-with-grief-and-loss.htm

GoodTherapy.org's top 10 websites for grief and loss

- www.goodtherapy.org/blog/best-resources-2012-top-10-grief-loss-0104137

Mindfulness and Grief: Meditation and journaling for grief

- <http://mindfulnessandgrief.com>

The Grieving Heart: For hope and support after loss

- <http://thegrievingheart.info>

The Center for Complicated Grief

- <https://complicatedgrief.columbia.edu>

BOOK RESOURCES

Mindfulness and Grief: With Guided Meditations to Calm Your Mind and Restore Your Spirit by Heather Stang

- <http://mindfulnessandgrief.com/mindfulness-and-grief-book>

Recommended grief-related books to provide support after loss

- <http://thegrievingheart.info/griefbooks.html>

Pharmacologic Interventions

Depression and CG frequently co-occur, and preliminary evidence suggests that antidepressants factor into treatment of CG (Bui, Nadal-Vicens, & Simon, 2012; Glickman, Shear, & Wall, 2016; Hensley, Slonimski, Uhlenhuth, & Clayton, 2009; Simon et al., 2008; Simon, Thompson, Pollack, & Shear, 2007; Zisook, Shuchter, Pedrelli, Sable, & Deaciuc, 2001). Pilot studies have demonstrated positive effects of selective serotonin reuptake inhibitors on CG (Hensley et al., 2009; Simon, Thompson, et al., 2007; Zygmunt et al., 1998); however, a clinical trial involving 395 people with CG found that providing citalopram (Celexa®) and Complicated Grief Treatment in combination reduced depression-related outcomes, but did not lead to specific improvements in CG when compared to Complicated Grief Treatment plus placebo (Shear et al., 2016).

Implications for Nursing Practice

In practice, except for hospices, family caregivers are not considered targets of oncology nursing care, and healthcare providers and hospitals are not reimbursed for administering care to family caregivers. Therefore, nurses may find providing support to them after the death of the patient to be challenging. Nevertheless, oncology nurses are well positioned to identify family caregivers who are at the greatest risk for CG and should remain alert to the

possibility. Oncology nurses should stay abreast of available community resources so that family caregivers experiencing CG, or those at risk for CG, can be referred promptly to support groups, grief counseling, or spiritual support services. Nurses can provide direct support for those struggling with grief by offering condolences, demonstrating concern, and allowing family caregivers to express their feelings. Individuals may be open to discussing feelings and concerns or they may be reluctant. If concerns about the potential for self-harm arise, nurses have an ethical obligation to obtain immediate mental health services for that individual. Figure 2 provides online resources that can help support individuals experiencing CG. Many hospices provide free bereavement services regardless of whether the individual experiencing the loss was involved in that hospice. Often, pastors are trained in managing grief, so referring family caregivers to their local faith community leader may be helpful.

Education

Nursing education has very little focus on the issues of loss and grief for family caregivers and even less focus on CG. Therefore, nursing educators should incorporate assessment and management of CG at all levels of the nursing curriculum and conduct educational research to measure the efficacy of adding CG-related content. Cancer centers and oncology units should offer continuing education focusing on CG to keep practicing nurses up to date on the latest findings from research, as well as to provide education and support to assist nurses who might be experiencing grief themselves.

Research

Although Complicated Grief Treatment has been shown to be an effective treatment for CG symptoms, it is not widely available and typically requires a relatively lengthy treatment period (16 weeks) (Shear et al., 2014). Future studies should focus on efficient ways of delivering treatment for CG and other effective forms of psychotherapy to more individuals. To date, few studies have evaluated psychotherapeutic interventions specifically for CG in loved ones of patients who have died from cancer. The experience of family caregivers and close family or friends during diagnosis and treatment, as well as near the end of life, may influence their response following the loss and have unique effects on the grief process. Targeting psychologic symptoms, like trauma, depression, and loneliness, may be useful for individuals experiencing prolonged or complicated grief. Preliminary evidence suggests that nurse-led interventions may have a role in alleviating CG in caregivers of patients with cancer, but more research is needed to support such interventions (Dionne-Odom et al., 2016; Holtslander et al., 2016). Grief is a culture-bound experience that occurs within an individual's social-cultural environment. Research studies that inform behavioral health and medical practitioners must include family, social, cultural, and environmental

IMPLICATIONS FOR PRACTICE

- Recognize the risk factors associated with complicated grief (CG) to ensure that family caregivers receive prompt interventions.
- Support family caregivers experiencing CG by offering condolences for their loss, providing referrals to grief counseling or supportive services, and allowing family caregivers to express their feelings about the loss.
- Provide efficient palliative care, symptom management, and patient and family education during the cancer trajectory to help prevent experiences of CG in family caregivers.

constructs when developing intervention programs (Schenck et al., 2015).

Conclusion

Oncology nurses often encounter individuals who are suffering with, or who are at risk for, CG. Prompt recognition and referral to supportive services and mental health experts can help facilitate early and effective treatment. Current evidence suggests that psychotherapy and pharmacologic treatments may be helpful in alleviating CG symptoms. Providing effective palliative care, symptom management, and patient and family education during the cancer trajectory may help to prevent CG. Acknowledging the loss, engaging in active listening, and allowing family caregivers to express their feelings and tell their story are important ways that oncology nurses can intervene in CG.

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QUESTIONS FOR DISCUSSION

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Journal club programs can help to increase your ability to evaluate the literature and translate those research findings to clinical practice, education, administration, and research. Use the following questions to start the discussion at your next journal club meeting.

- Name two psychological problems associated with complicated grief (CG).
- What are some of the characteristics found in individuals at risk for CG?
- What are your initial interventions for individuals experiencing CG?
- What resources have you mobilized in your practice to support individuals experiencing CG?

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