

Grief and Chronic Disease

Description/Etiology

Grief, defined as a reaction to a major loss characterized by a period of sorrow, emotional numbness, and, in some cases, guilt and anger, is a normal, healthy response that usually diminishes as the grieving person accepts their loss. Chronic disease refers to any illness that is incurable, requires special assistance to manage, and interferes with the affected individual's long-term functioning; examples of chronic diseases are arthritis, multiple sclerosis, heart disease, and obesity. Chronic disease affects all areas of an individual's life, often resulting in functional limitations; financial stresses; social isolation; increased dependence on others; decline in positive self-image; and mental health issues. Individuals with a chronic disease and their caregivers may experience grief with each loss associated with the disease, such as lost abilities, activities, and relationships.

Chronic sorrow is a term that is used frequently when discussing grief related to chronic disease. The constant presence of the illness serves as a continual reminder of the changes and limitations that face the client and the involved family members. These changes also present continual challenges to the individual's self-identity and self-esteem, which can deepen the grief reaction. The uncertainty that accompanies periods in which exacerbations, remissions, and complications take place also causes psychosocial distress. For purposes of treatment it is important to differentiate between grief and depression in persons with chronic disease. Depression treatment may include medication, whereas those experiencing grief can often benefit from social support. Grief may or may not be addressed with antidepressant medications. It is also possible that antidepressant medications may interfere with medications needed for the management of the chronic disease.

The effects of chronic disease extend beyond the affected individual and influence overall family functioning. A common social work perspective utilizes a family-systems model. This is a strengths-based approach in which the clinician examines the family relationships and works to ensure that interventions meet the needs of everyone involved, not just those of the identified client. In the case of multiple sclerosis, in which age of onset is in the 30s and 40s, special attention should be paid to children in the family who may have become caregivers at an early age and may be grieving loss of childhood.

Chronic disease is dynamic: although most chronic diseases worsen over time, individuals often experience phases of improvements and setbacks. Various theoretical models have been developed that acknowledge that adaptation to chronic disease progresses in adults through several phases. The social worker needs to be aware that grief interventions may need to take place within each of these phases. Symptoms leading to diagnosis, diagnosis, and one's initial adjustment to the diagnosis make up the crisis phase; there may be a return to this phase if medical setbacks occur. In the chronic phase the client is living with the disease and coping with symptoms, including times of symptom flare-up in diseases such as asthma, lupus, and multiple sclerosis. For diseases that are progressive and incurable, such as Parkinson disease and Alzheimer disease, this is a time of inexorable progression. The third phase, which is not present for all chronic diseases, is the terminal phase, when death becomes the inevitable outcome. Children with chronic disease may experience the same three phases yet at times may also be vulnerable to additional stress, such as when the child changes settings (e.g., from home to hospital), when a parent is absent (e.g., because of their own illness; divorce; deployment), and during times of developmental change for the child (e.g., becoming a more independent adolescent).

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Intense, prolonged grief that causes significant impairments and psychosocial distress is known as complicated grief. Complicated grief often affects the family members and caregivers of chronically ill individuals after their deaths. Variables that affect the likelihood of developing complicated grief include the location of care and death for the individual (e.g., home, hospital, nursing home), type of illness, intensity of care that was provided, perception of how the ill person was treated by staff, and perception by the family of their experiences with staff (e.g., was staff respectful, was there adequate communication). Inadequate social support systems, poor physical health, and preexisting depression or anxiety increase the risk of complicated grief.

Facts and Figures

There were an estimated 55.4 million deaths worldwide in 2019, of which 74% were attributed to noncommunicable diseases. The three leading causes of death were heart disease (16%), stroke (11%), and chronic obstructive pulmonary disease (6%) (WHO, 2020).

In the United States, there were 2,854,838 deaths in 2019; the two leading causes of death, heart disease and cancer, were responsible for approximately 44.1% of deaths. Other chronic illnesses in the top 10 causes of death were respiratory disease, stroke, Alzheimer disease, diabetes, and kidney disease. Cancer was responsible for 10.9% of deaths of children ages 1–9 and 5.4% of deaths of adolescents and young adults ages 10–24 (Heron, 2021). In 2018 diabetes was diagnosed in an estimated 13.0% of Americans 18 and older (U.S. CDC, 2020); asthma was diagnosed in 7.0% of children younger than 18 and in 8.0% of adults older than 18 in 2019 (U.S. CDC, 2021).

Risk Factors

The stressors that accompany chronic illness are risk factors for grief. Financial stressors resulting from healthcare costs and, for some, an inability to work place individuals with chronic illness at risk for loss of housing, marital stress or divorce, loss of savings, bankruptcy, and inability to pay for necessary treatments and medications. Some individuals with chronic diseases have limited family or social support and must manage their care on their own. As the disease progresses, their safety may be at risk. Others with chronic illnesses may become isolated because of immobility or financial constraints, leaving them unable to keep medical appointments or meet other basic needs. Decreased self-esteem can lead to symptoms of depression, which may lead to a grief reaction. This may cause further complications and leave individuals feeling overwhelmed and isolated. The family and caregivers of chronically ill individuals also are at risk for grief and complicated grief related to the chronic disease.

Signs and Symptoms/Clinical Presentation

- › Psychological: Sense of loss for the person one was or wanted to be pre-diagnosis, sadness, stress, hopelessness, denial, anger, fear, shame, low self-esteem, feelings of worthlessness, feelings of stigma, loss of meaning, guilt, resentment
- › Behavioral: Changes in sleep patterns, changes in eating habits, aggressive behaviors, non-adherence to medical treatment plan, poor organization of life, inability to engage in previous activities, self-isolation
- › Physical: Somatic complaints resulting from disease such as pain, headaches, chest pain, shortness of breath, exhaustion. Physical changes resulting from disease or treatments such as hair loss, weight gain or loss, amputation. Need to use assistive technology such as insulin monitors (internal or external), wheelchairs, walkers, hospital beds. Dependency on others for ADLs

Social Work Assessment

› Client History

- Biopsychosocial-spiritual assessment of client and family to understand the client and family's understanding of where the client is with regard to the progression of his or her illness and his or her treatment plan. Assessment of the client's support system and resources: emotional, service-oriented (i.e., related to the practical needs of the disease such as transportation, disease management), and financial
- Psychoeducation assessment of what the client understands about his or her disease progression and symptoms to assist with future planning and development of support services
- Assessments for depression and suicide risk may be necessary to determine if individuals are at risk for self-harm

› Relevant Diagnostic Assessments and Screening Tools

- Screening for signs of excessive grief and depression can be used if client is at risk for these. These tools include the Burke/NCRCS Chronic Sorrow Questionnaire, Beck Depression Inventory (BDI), and the Extended Grief Inventory (EGI).

Clinicians using a depression screening tool need to be prepared to distinguish between depression and grief and treat the client accordingly

- For advanced chronic illness a mini mental state examination (MMSE) may be necessary to assess the client's capacity to make their own decisions and provide self-care
- The Millon Behavioral Health Inventory (MBHI) is a 150-item self-report measure that assesses coping styles, psychogenic attitudes, and psychosomatic complaints and includes a prognostic index
- The Psychosocial Adjustment to Illness Scale (PAIS) is a 46-item tool that combines a psychiatric interview with self-report to assess the client's psychological adaptation to their illness. Subscales include healthcare orientation, vocational environment, domestic environment, sexual relationships, extended family relationships, social environment, and psychological distress
- The Sickness Impact Profile (SIP) is a 136-item tool with 12 subscales that includes measures related to physical and psychosocial impact of illness
- The Reactions to Impairment and Disability Inventory (RIDDI) is a 60-item self-report tool that examines eight classes of psychosocial responses to illness
- Parents of chronically ill children can complete the Coping Health Inventory for Parents (CHIP), a 45-item scale that measures parents' coping ability when a child is seriously or chronically ill

› **Laboratory and Diagnostic Tests of Interest to the Social Worker**

- Blood tests, PET scans, MRIs, CT scans, and other tests may be necessary to monitor progression of chronic disease and monitor medications. Review of medical records will help determine services needed to assist client and family with disease and life management
- Alcohol and drug screening may be necessary to monitor use of opiates or other addictive medications as well as nonprescribed substances

Social Work Treatment Summary

The grief feelings of individuals with chronic disease and their families may fluctuate depending on where the individual is in their disease trajectory. The severity of symptoms of a chronic illness and their impact on daily living varies by individual, age, and disease. When considering treatment options for grief the social worker must choose the treatment that matches the individual's physical and emotional state and disease progression. Cognitive behavioral therapy can help individuals reframe their beliefs about the losses resulting from chronic disease and be proactive in their care and life. Individual psychotherapy or person-centered therapy can address any historical or present issues that prevent the individual from dealing with feelings of grief and loss. Group counseling helps to normalize the disease process and provide insight and strategies for dealing with decline. In general, interventions that are supportive, psychodynamic, and that offer insights regarding the client's affect are more useful in the earlier stages of a chronic illness, when the focus is on adaptation. Interventions that are more directive and goal-focused (e.g., cognitive-behavioral therapy, coping skills training) are more useful to clients who are further along in the disease process.

When the client is the caregiver of an individual with a chronic disease, Rando's six processes of mourning can form a framework for intervention. The social worker utilizing this model should recognize losses related to the advancement of the disease, explore the caregiver's reactions to separation from the ill individual (e.g., physical, emotional, relational, intellectual), encourage recall and reflection, encourage the release of old attachments and assumptions about what might have been and focus on the present state, explore what is hindering adjustments, and educate on how the caregiver can reinvest in new goals, dreams, and attachments.

Social workers should be aware of their own cultural values, beliefs, and biases and develop specialized knowledge about the histories, traditions, and values of their clients. Social workers should adopt treatment methodologies that reflect their knowledge of the cultural diversity of the communities in which they practice.

Internationally, 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) Global Social Work 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; and become knowledgeable of the NASW ethical standards as they apply to clients with grief related to chronic disease and practice accordingly.

Problem	Goal	Intervention
Client is feeling overwhelmed by newly diagnosed chronic illness; has begun to experience grief related to anticipation of losses that will occur and future course of the illness	Increase client's level of understanding and acceptance of diagnosis and disease	Psychoeducation counseling can assist client to learn about his or her disease and come to terms with life changes; person-centered therapy may assist with adaptation. Explore client's feelings and emotions related to diagnosis. Assist client in processing these emotions
Client is experiencing grief feelings of anger, injustice, and resentment about diagnosis	Increase client's acceptance of disease and empower them to manage the disease	Individual psychotherapy, cognitive-behavioral therapy, or bereavement counseling will help process the client's feelings and normalize the experience. Group therapy enables the client to be among others with similar diagnoses and benefit from shared knowledge
Client is feeling sense of loss and grief over changes in lifestyle or functioning	Validate client's feelings of loss and normalize feelings	Individual or group counseling to help support and normalize feelings
Client is experiencing depression and suicidal ideations	Reduce feelings of depression and help client reinvest in life. Reduce severity of suicidal ideation	Assess for level of depression and suicide ideation. Refer to inpatient care if indicated. Refer to individual or group counseling to help process feelings of depression and teach redefinition of self within the context of individual's disease progression
Client is exhibiting signs of substance use as he or she tries to cope with the physical and psychological impact of the illness	Reduce substance use or abstain from substance use dependent on situation	Refer to substance treatment. Advocate for detoxification if needed. Refer to appropriate support groups to maintain reduced use or sobriety
Family of client is experiencing feelings of anticipatory grief and loss related to chronic disease	Process feelings of grief and loss, improvement in negative symptoms	Increase family's feelings of being supported, help family members develop coping skills, and normalize sense of loss; group counseling in age-specific groups that provide education and support to help normalize grief experience and teach coping mechanisms

Applicable Laws and Regulations

- › Social workers, mental health clinicians, and other healthcare professionals are bound by the “duty to warn,” which states that they must inform the proper authorities if a person is found to be a danger to themselves or others. Each U.S. state has its own version of duty to warn, as do other countries. It is up to the social worker to be familiar with the regulations in their place of practice. Social workers should also familiarize themselves with the processes related to involuntary detainment for mental health evaluation and stabilization
- › Client may bring up the topic of physician-assisted dying or “right to die” laws. Right-to-die legislation may be referring to refusal of treatment, voluntary euthanasia, and/or physician aid in dying for terminally ill individuals. Social workers need to be knowledgeable of local laws and court decisions in their state or country regarding this topic. Currently, nine U.S. states (i.e., Oregon, California, Colorado, Hawaii, Maine, New Jersey, New Mexico, Vermont, Washington), and Washington, D.C. have specific legislation related to the right to die. Montana has eliminated prosecution of physicians who prescribe the needed medications. Internationally, laws regarding assisted dying have been passed in some Australian states (in effect in Victoria and Western Australia, not yet in effect in Tasmania and South Australia), Belgium, Canada, Colombia, Germany, Luxembourg, the Netherlands, New Zealand, Spain, and Switzerland; the content of these laws and regulations varies from country to country
- › Each country has its own standards for cultural competency and diversity in social work practice. Social workers must be aware of the standards of practice set forth by their governing body (e.g., in the United States the National Association of Social Workers, in England the British Association of Social Workers), and practice accordingly

Available Services and Resources

- › Organizations that support, educate, and advocate for affected individuals and their families exist for most chronic diseases. Internet searches and local resource agencies can assist with references. In addition, many organizations offer bereavement programs that cater to entire families throughout the progression of diseases such as cancer. Check local listings or local social services agencies for programs in the community

Food for Thought

- › Clinicians need to be able to recognize the difference between depression and preparatory grief. Part of preparing for one’s death is mourning the losses that accompany end of life, but this process may be mistaken for depression. Key differences are
 - Preparatory grief comes and goes, whereas depression involves a persistent state of sadness
 - Clients experiencing preparatory grief can progress and work through the grief
 - Preparatory grief is less likely to include poor self-image; if poor self-image is present, it is proportionate to the changes the client is experiencing due to the illness
 - A grieving individual may still have hope and experience pleasure
 - An individual experiencing preparatory grief may still respond positively to reentering society, whereas a depressed individual may consistently avoid social interactions
- › Individuals with chronic diseases such as type 2 diabetes, HIV/AIDS, and chronic obstructive pulmonary disease may be at risk for disenfranchised grief (i.e., grief that is not recognized by society) because of the stigma associated with these diseases
- › Chronic illness frequently affects physical appearance; clients may be coping with body image issues as a result
- › Social workers need to recognize that a client or family who displays hope or an optimistic outlook is not necessarily denying the reality of the illness
- › Social workers need to be aware of the grief processes that will be present when the caregivers are minor children caring for a parent with a chronic disease. These young caregivers may be coping with grief related to loss of childhood, feelings of abandonment, and isolation

Red Flags

- › Feelings of grief and loss that are unaddressed can compromise an individual’s ability to manage their disease. Nonadherence to one’s care plan can in time lead to more severe disability and even death
- › Feelings of depression (episodic or pervasive), hopelessness, isolation, shame, guilt, and worthlessness; loss of pleasure in activities; grief; and stress all are symptoms that may be experienced by someone coping with a chronic disease. These emotions can increase the risk of suicidal ideation. Clients with chronic disease need to be monitored and screened for suicidal risk

- › Disability and chronic disease have distinctly different definitions but are sometimes combined in prevalence figures. Social workers using data for client education must ensure that chronic diseases which do not entail physical limitations were not combined with physical disabilities in research studies

Discharge Planning

- › Ensure that client has a clear understanding of their disease so appropriate services can be arranged at discharge
- › Identify and address any needs that are immediate or urgent
- › Work with the client and family on developing a disease management program that includes medical interventions (e.g., regular doctor appointments, monitoring of symptoms and medications)
- › Assist the client and family in finding personal meaning within their chronic disease
- › Work with client on adaptive coping skills to apply to physical, social, educational, or vocational settings
- › Arrange for emotional and grief support for the client and family (e.g., referral to support groups or individual, family, or group counseling)
- › Refer to appropriate community resources (e.g., in-kind assistance, transportation, housing, financial help)
- › Be respectful and nonjudgmental if client and/or family are displaying an optimistic outlook in the face of a serious illness

References

1. BASW. (2021). BASW Code of Ethics for Social Work. Retrieved from https://www.basw.co.uk/system/files/resources/basw_code_of_ethics_-_2021.pdf
2. Bjorgvinsdottir, K., & Halldorsdottir, S. (2014). Silent, invisible and unacknowledged: experiences of young caregivers of single parents diagnosed with multiple sclerosis. *Scandinavian Journal of Caring Sciences*, 28(1), 38-48. doi:10.1111/scs.12030
3. British Medical Association. (2021). Physician-assisted dying legislation around the world. Retrieved from <https://www.bma.org.uk/media/4402/bma-where-is-pad-permitted-internationally-aug-2021.pdf>
4. Centers for Disease Control and Prevention. (2020). National Diabetes Statistics Report, 2020: Estimates of diabetes and its burden in the United States. Retrieved from <https://www.cdc.gov/diabetes/data/statistics-report/index.html>
5. Coughlin, M. B., & Sethares, K. A. (2017). Chronic sorrow in parents of children with a chronic illness of disability: An integrative literature review. *Journal of Pediatric Nursing*, 37, 108-116.
6. Corless, I. B. (2014). The pot calling the kettle black: depression in chronic disease. *Illness, Crisis, & Loss*, 22(1), 29-42. doi:10.2190/IL22.1.d
7. Fennell, P.A., Dorr, N., & George, S.S. (2021). Elements of suffering in myalgic encephalomyelitis/chronic fatigue syndrome: The experience of loss, grief, stigma, and trauma in the severely and very severely affected. *Healthcare*, 9(5), 553. doi:10.3390/healthcare9050553
8. Ghesquiere, A., Marti Haidar, Y. M., & Shear, M. K. (2011). Risks for complicated grief in family caregivers. *Journal of Social Work in End-of-Life Care & Palliative Care*, 7(2-3), 216-240. doi:10.1080/15524256.2011.593158
9. Hall, A., & Powell, J. (2013, April 25). Chronic sorrow: Grief and loss for families facing chronic illness or disability of their child. *Health Care Reform: Navigating through Changes*. Presented at the SSWLHC-Utah Chapter Annual Conference.
10. Heron, M. (2021, July). Deaths: Leading causes for 2019. *National Vital Statistics Reports*, 70(9). doi:10.15620/cdc107021
11. International Federation of Social Workers (IFSW). (2018). Global social work statement of ethical principles. Retrieved from <http://ifsw.org/policies/statement-of-ethical-principles/>
12. Lenger, M.K., Neergaard, M.A., Guldin, M.B., & Nielsen, M.K. (2020). Poor physical and mental health predicts prolonged grief disorder: A prospective, population-based cohort study on caregivers of patients at the end of life. *Palliative Medicine*, 34(10), 1416-1424. doi:10.1177/0269216320948007
13. National Association of Social Workers. (2015). Standards and indicators for cultural competence in social work practice. Retrieved from <http://www.socialworkers.org/practice/standards/PRA-BRO-253150-CC-Standards.pdf>
14. National Association of Social Workers. (2021). Code of ethics of the National Association of Social Workers. Retrieved from <https://www.socialworkers.org/About/Ethics/Code-of-Ethics/Code-of-Ethics-English>
15. Paun, O., & Farran, C. J. (2011). Chronic grief management for dementia caregivers in transition: Intervention development and implementation. *Journal of Gerontological Nursing*, 37(12), 28-35. doi:10.3928/00989134-20111103-04
16. Roehr, B. (2021). Assisted dying around the world. *BMJ*, 374, n2200. doi:10.1136/bmj.n2200
17. Rolland, J. S. (2012). Families, health, and illness. S. Gehlert & T. Browne (Eds.), *Handbook of Health Social Work*. Hoboken, NJ: John Wiley & Sons, Inc.
18. Schuelke, T., Crawford, C., Kentor, R., Eppelheimer, H., Chipriano, C., Springmeyer, K., & Hill, M. (2021). Current grief support in pediatric palliative care. *Children*, 8(4), 278. doi:10.3390/children8040278
19. U.S. CDC. (2021). Asthma. Retrieved from <https://www.cdc.gov/nchs/fastats/asthma.htm>
20. WHO. (2020). The top 10 causes of death. Retrieved from <https://www.who.int/news-room/fact-sheets/detail/the-top-10-causes-of-death>