ACA Practice Briefs

Counseling Individuals Living with Chronic Illness

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DESCRIPTION OF CHRONIC ILLNESS

Definitions

Chronic disease and chronic illness are terms that are often used interchangeably, but actually convey different meanings. Chronic disease is a term used to broadly define chronic conditions which: (a) last at least a year or more, (b) limit daily activities, and (c) require ongoing care (CDC, 2018). Common chronic diseases include cancers, diabetes, HIV, epilepsy, lupus, arthritis, alzheimer's disease, heart disease, and depression. Chronic illness (CI), on the other hand, refers to the personal experiences of living with the pain, symptoms, disturbances, and distress that typically accompanies life with a chronic disease (Bernell & Howard, 2016; Martin, 2007). CI affects individuals across the lifespan, including an estimated six in ten adults in the United States (CDC, 2018), making this significant health concern a likely factor in the lives of many clients seeking mental health services. Further, as advances in medical treatment result in a number of once life-threatening illnesses being instead considered chronic (e.g., HIV, many cancers, numerous pediatric diseases), clients with CI must place further emphasis on illness management. Professional counselors can play an important role in assisting clients in managing CIs, as well as the associated mental health symptoms.

Chronic Illness and Mental Health

In addition to the physical symptoms that often affect individuals living with CI, people often complain of emotional symptoms such as mood disorders, physical or emotional fatigue, decreased self-image, loss of control (e.g., depending on others for personal care), anxiety, fear of the future, shifts in family roles, stress, pain of affecting loved ones, and depression (Cleveland Clinic, 2016). In addition, individuals living with chronic illness are more likely to miss work or school, report lower quality of life, have greater anxiety and distress (Mullins et al., 2017), and experience increased suicidal ideation (Greydanus, Patel, & Pratt, 2010).

Although it is common and expected to experience a range of mental health concerns after receiving a related chronic illness diagnosis, clinicians should be careful not to dismiss these symptoms as a normal part of living with CI. Treatment for mental health concerns, such as depression, are particularly important for those living with CI, as emotional symptoms can exacerbate physical health symptoms, leading to more severe CI symptoms (NIH, 2015). Further, the reverse is also true: individuals living with depression are more at risk for developing physical illnesses. At the same time, clients living with CI can also experience personal growth (i.e., posttraumatic growth or PTG) following a diagnosis or the stress of CI (Zeligman, Varney, Grad, & Huffstead, 2017), suggesting a strengths-based approach is appropriate with these clients.

Resources:

Centers for Disease Control and Prevention. (2018). *About chronic illness*.
    Retrieved from https://www.cdc.gov/chronicdisease/about/index.htm

Cleveland Clinic. (2016). *Chronic illness.* Retrieved from
https://my.clevelandclinic.org/health/articles/4062-chronic-illness

National Institutes of Health (NIH). (2015). *Chronic illness and mental health: Recognizing and treating depression.* Retrieved from https://www.nimh.nih.gov/health/publications/chronic-illness-mental-health/nih-15-mh-8015_151898.pdf

IDENTIFICATION/ASSESSMENT STRATEGIES

When working with clients living with CI, it is important to ensure they are receiving appropropriate medical care from a physician. Due to the noted overlap in mental health concerns and chronic illness, it is important to further assess for common comorbid disorders. Additionally, many screening instruments include items asking about somatic symptoms. Since clients living with CI may be experiencing similar symptoms (e.g., not sleeping well, fatigue, work challenges), helping professionals will need to be intentional in separating out CI symptoms, as not to inflate scores of depression. Ideally, counselors must also be careful to use instruments that have been used with clients living with CI, and have demonstrated sound psychometric properties with this population.

Center for Epidemiologic Studies - Depression Scale Revised (CESD-R)

The Center for Epidemiologic Studies - Depression Scale Revised (CESD-R; Eaton, Muntaner, Smith, Tien, & Ybarra, 2004) is widely used to measure symptoms associated with depression, and takes approximately 5-10 minutes for clients to complete. The instrument consists of 20 items, and can be used longitudinally to monitor changes in clients over time. Individuals are considered meeting criteria for major depressive episodes if they are experiencing the items associated with anhedonia (questions 8 and 10), dysphoria (questions 2, 4 and 6), and an additional four symptom group "nearly every day" for the past two weeks (i.e., answering these questions with a score of 3). Other symptom groups reflected on the instrument include appetite (questions 1 and 18), sleep (questions 5, 11, and 19), thinking/concentration (questions 3 and 20), guilt/worthlessness (questions 9 and 17), tired/fatigue (items 7 and 16), movement/agitation (questions 12 and 13), and suicidal ideation (questions 14 and 15). Individuals with a total score less than 16 likely show no clinical significance. Concurrent and construct validity (Eaton et al., 2004), and score reliability were demonstrated with clients living with CI (Blake Mortimer et al., 2005). For example, the scale shows a strong correlation (r = 0.74) with the State-Trait Inventory for Cognitive and Somatic Anxiety (STICSA; Grös, Antony, Simms, & McCabe, 2007) (Van Dam & Earleywine, 2011).

Resources:
To view this instrument, visit https://cesd-r.com/wp-content/uploads/2018/04/cesdrscale.pdf

Illness Intrusiveness Rating Scale (IIRS)

The Illness Intrusiveness Rating Scale (IIRS; Devins, 2010) is a self-report meaure that allows clients to rate the degree to which their illness- and treatment-related factors disrupt their overall quality of life. The scale consists of 13 items, which measure intrusiveness over the following domains: health, diet, work, active and passive recreation, financial, relationship with partner, sex life, family and other social relations, self-expression/self-improvement, religious expression, and community/civic involvement. Scores range from 13 (representing minimum intrusiveness) to 91 (representing extreme intrusiveness). An Illness Intrusiveness Scale - Parent version (IIS-P) also exists for working with parents whose quality of life is being affected by their childs' chronic illness and treatment. The parent version was directly adapted from the original rating scale, only modified to change *your illness* to your *child's illness*.

Resources:
Instrument https://www.selfmanagementresource.com/docs/pdfs/English_-_illnessintrusiveness.pdf

INTERVENTION STRATEGIES

Knowing that people living with CI are more susceptible to mental health concerns, and vice versa, professional counselors have the opportunity to provide meaningful support and intervention for clients living with CI. Further, given the potential psychological distress (e.g., depression, anxiety, increased substance use) that clients living with CI may be experiencing, clinical intervention has the potential to increase quality of life in these clients.

Resources:
For how school counselors can intervene with students living with chronic illness read:
> Hamlet, H. S., Gergar, P. G., & Schaefer, B. A. (2011). Students living with chronic illness: The school counselor's role. *Professional School Counseling*, 14, 202-210.

Social Support

Social support is an integral part of health care for individuals living with CI. The support of others has the potential to bring emotional and physical health beneifts (Fukkink, 2011; Goldsmith & Albrect, 2011), making it of particular importance for those facing chronic health conditions. Adolescents living with CI may also experience less peer contact, and increased social anxiety, especially if forced to miss work or school due to their health, making social support and connection even more relevant (Lewis, Klineberg, Towns, Moore, & Steinbeck, 2016). Offering peer support groups to clients living with CI allow clients to explore feelings associated with their diagnosis or treatments, while also allowing connection with others who are going through a similar experience. This connection with peers experiencing similar health challenges helps to combat potential feelings of isolation often reported by clients living with CI (Salas, Casassus, Rowlands, Pimm, & Flanagan, 2018). Working with clients living with CI in a group setting, where they can connect with others with similar experiences, can further allow clients to integrate their CI into their identity (Lehardy & Fowers, 2018). Specific group elements that can help in increasing support and belonging include: noting common themes, providing ice-breakers for members, providing refreshments so members can mingle informally, and providing clients with explicit invitations (Salas et al., 2018). Finally, it is important to note that support can also exist in online communities such as online support or social media groups (Partridge, Gallagher, Freeman, & Gallagher, 2018).

Resources:
For online support for clients, visit https://reachout.life/
For additional information on models of care management, visit
> http://www.smpcp.com.au/Portals/13/Documents/DH%20Fact%20sheet%20on%20different%20
> types%20of%20self%20managment%20approaches.pdf

Cognitive-Behavioral Therapy

Cognitive-behavioral therapy (CBT) is an evidence-based approach to working with a number of mental health concerns. CBT is used in working with clients with CI, whether as traditional CBT, third-wave CBT (e.g., acceptance commitment therapy), or mindfulness-based interventions (Petricone-Westwood et al., 2018). Religiously-integrated cognitive behavioral therapy (RCBT) was also shown effective in working with clients living with CI (Pearce et al., 2016). In using CBT, counselors are able to restructure irrational beliefs related to their illness (Roessler, 2004), while also providing psychoeducation, and self-management skills (Haemmelmann & McCain, 2013). Consistent with the goals of CBT, counselors can also challenge their clients' irrational beliefs stemming from feelings of shame or decreased self-worth due to their illness, and combat these beliefs with contradictory evidence.

Resources:
For additional information on this topic, visit: https://beckinstitute.org/depression-chronic-illness/

For additional reading: Safren, S., Gonzalez, J., & Soroudi, N. (2007). *Coping with chronic illness: A cognitive-behavioral therapy approach for adherence and depression*. New York, NY: Oxford University Press.

Illness Intrusiveness Model

The illness intrusiveness model emerged from the idea that illness-induced interference increases personal distress, and compromises one's overall well-being. The model posits that "when there is a decrease in positively reinforcing outcomes from valued activities and limited personal control to obtain positive outcomes and avoid negative ones, significant adaptive changes and coping demands occur" (Haemmelmann & McClain, 2013, p. 107). Professional counselors can assess client levels of CI intrusiveness by exploring five areas of client illness: (a) treatment requirements, (b) psychological factors, (c) personal control, (d) social factors, and (e) life outcomes (Devins, 2010). Professional counselors can further use the IIRS as a way to gather additional information on how their clients' CI is impacting their lives. Results from these assessment approaches can allow professional counselors to better understand with which areas (e.g., coping, self-efficacy) their clients with CI struggle, and then potentially include these areas in treatment plans. Furthermore, empirical support identified illness intrusiveness as a predictor of depression and loss of control (Roessler, 2004), providing further insight into clinical interventions for these clients.

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