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Cancer Patients and Families

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DESCRIPTION OF PSYCHOSOCIAL ONCOLOGY STRESSORS

Many consider cancer to be a death sentence (Moser et al., 2014). Yet, incidence and mortality rates for most cancers have been declining while five-year survival rates have been increasing (National Cancer Institute [NCI], 2017). Symptoms, treatments, side effects, and survivorship can vary depending on cancer site and severity (e.g., late-stage lung cancer). Outside of the physical concerns that cancer patients and their families encounter, the disease can also lead to clinically significant emotional distress (Carlson et al., 2019). NCI's Physician Data Query (see https://www.cancer.gov/publications/pdq) provides summarizations of information related to cancer, including best practices of screening, prevention, caregiver issues, and approaches to treatment. In addition, the American Society of Clinical Oncology (see https://www.cancer.net/) website provides similar helpful information. Both are linked here as a way for counselors to gain a basic sense of what cancer can entail for patients and their families. However, psychosocial aspects of cancer may be of particular importance to counselors.

Psychosocial aspects of cancer depend largely on the cancer site (e.g., breast or colorectal), stage of the disease (e.g., early or advanced disease), and other contextual factors (e.g., presence of other chronic illnesses), but the psychosocial issues of cancer can be similar among different types of cancer. For the patient, concerns around mortality (e.g., their own death and its effects on family) may become a focus (Vrinten et al., 2017). Cancer-related distress can also be a concern for patients (Carlson et al., 2019). Distress can be seen as increased depressive symptoms, increased anxiety symptoms, increased stress, and lower quality of life (QoL) in cancer patients (Artherholt & Fann, 2012). Depression was an issue for 20.7% of those with cancer, with 38.2% having any mood disorder (Mitchell et al., 2011). Approximately 18 to 20% of adult cancer survivors experienced symptoms of anxiety, with many having post-traumatic stress symptoms as well (Yi & Syrjala, 2017). Further, the stress of dealing with cancer can have a biological impact on the development of cancer itself, creating a cyclical problem (Soung & Kim, 2015). Many cancer treatments cause chronic physiological stress, some treatments are known to cause cognitive dysfunction (Hermelink et al., 2017), and some surgical treatments can have side effects that disturb QoL and psychosocial wellness (e.g., radical prostatectomy for prostate cancer and impotence or incontinence; Carrier, Edwards, & Harden, 2018).

Families of cancer patients can encounter fear of losing a loved one, complicated grief, and caregiver burden (Bevans & Sternberg, 2012; Guldin, Vedsted, Zachariae, Olesen, & Jensen, 2012). They may also become caregivers of patients, which can provide both negative and positive experiences (Li & Loke, 2013). Clinical work with these family members may focus on the stresses of caregiving and seeing a loved one suffer. For example, Tan, Molassiotis, Lloyd-Williams, and Yorke (2018) indicated that the psychosocial impact felt by the patient has an effect on the caregiving experience. In all, it is important to understand how cancer affects patients, caregivers, and families at a psychosocial level.

Resources:

American Cancer Society website:
https://www.cancer.org/treatment/treatments-and-side-effects/emotional-side-effects/distress.html
Institute of Medicine and their Cancer Care for the Whole Patient assessment:
https://www.nap.edu/catalog/11993/cancer-care-for-the-whole-patient-meeting-psychosocial-health-needs

NCI's Physician Data Query: https://www.cancer.gov/publications/pdq
American Society of Clinical Oncology: https://www.cancer.net/

IDENTIFICATION/ASSESSMENT STRATEGIES

Cancer-related psychosocial distress screeners and caregiver burden measures are ways of measuring the burden of cancer on patients and their families. Use of QoL instruments is common in the medical field, but not in the counseling field (Peterson, Lomas, Neukrug, & Bonner, 2014). QoL instruments measure overall physical, social, emotional, functioning, and other areas of potential concern while some also assess cancer-related symptoms. Professional counselors can use general distress and QoL instruments to measure psychosocial concerns.

Psychosocial Screen for Cancer (PSSCAN)

The PSSCAN (Linden et al., 2009) is a 21-item instrument that assesses psychosocial distress in cancer patients with two main subscales: anxiety and depression. In addition to the two main subscales, the PSSCAN also contains items related to social support, spirituality, and information about cancer. The PSSCAN can provide specific information about the patient by assessing psychosocial distress in more depth than most QoL measures allow. The PSSCAN also inquires about the number of days in the past month in which physical health, mood, and functional ability were an issue for the patient. The subclinical score for both the anxiety and depression subscales are between 8 and 10, with 11 and greater indicating a clinical disorder. Mean scores for those with cancer in outpatient settings are 8.2 (anxiety or depression), while inpatient setting averages are 10.9 (anxiety) and 9.8 (depression). Linden and colleagues (2009) conducted validation work and Vodermaier, Linden, and Siu (2009) conducted a review of reliability, both of which indicated strong psychometrics for the instrument. With the accumulation of support items in the PSSCAN, strengths may also be helpful for clinical conversations.

Resources:
For more information on this instrument, visit
https://hqlo.biomedcentral.com/articles/10.1186/1477-7525-7-16 and
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1215503/#!po=81.2500
for access to the screening tool (referred to as the PSCAN in this article).

Functional Assessment of Cancer Therapy (FACT) Scales

The Functional Assessment of Chronic Illness Therapy (FACIT) group focuses most of their work on measuring QoL related to cancer (Cella et al., 1993). However, the original Functional Assessment of Cancer Therapy (FACT) scale has grown to have many subscales designed to assess for specific cancers, cancer symptoms, cancer treatments, and non-cancer specific measures. The FACT scales measure four domains related to QoL: physical well-being, social/family well-being, emotional well-being, and functional well-being. Other versions of the FACT have been developed with questions specific to treatment, cancer site, and symptoms (e.g., the FACT for breast cancer contains items pertaining to symptoms of breast cancer and treatment). The FACT scales allow counselors to capture an overall snapshot of the state of well-being for cancer patients, especially as it relates to their experience with cancer at the time of administration. The FACIT group has also developed an analogous scale for those without cancer, which could be given to family members or caregivers.

Most versions of the FACT scales will contain the original 27-item FACT (i.e., FACT-G) scale answered on a 5-point Likert-type response format. Luckett and colleagues (2011) found that the FACT-G performs as well as other well-known cancer-based QoL measures, with the majority of published studies on reliability and validity information showing strong support for the scale. The original author of the FACT-G suggests distribution-based and anchor-based cutoff scores. Thus, there are no established cutoff scores, and professional counselors should use responses to facilitate discussion regarding clients' current QoL. Each version includes scoring and interpretation materials available upon registration with the site.
Resources:

For more information on this instrument, visit: http://www.facit.org/

Caregiver Burden Scale

The Caregiver Burden Scale (Macera, Eaker, Jannarone, Davis, & Stoskopf, 1993) can provide a short and practical understanding of caregiver duties and associated stress, which can yield material for therapeutic discussion. The Caregiver Burden Scale consists of three response categories with two options each (i.e., patient needs assistance [Yes/No], do you provide assistance [Yes/No], and does it add to your stress level [Yes/No]), with 15 items focused on areas in which the caregiver provides assistance (e.g., transportation, cooking, bathing, and eating). Further, the scale allows the client to express why they answered the way they did in a short response area that can help guide clinical concerns with a counselor. The measure breaks down into three different measured domains: patient needs, caregiver tasks, and caregiver burden, with scores ranging from 0-15. The total scale scores displayed an internal consistency of $\alpha = .87$ with the standardization sample and evidence of construct validity through a small to moderate correlation with a measure of depression.

Resources:

Caregiver Burden Scale: http://www.midss.org/content/caregiver-burden-scale

Burden Scale for Family Caregivers

A second measure, the Burden Scale for Family Caregivers, has both standard (Gräsel, Chiu, & Oliver, 2003) and short forms (Graessel, Berth, Lichte, & Grau, 2014) and provides more emotion-focused items, rather than task-based items (e.g., *From time to time I wish I could "run away" from the situation I am in* or *I am still capable of feeling really joyful*). This measure can provide more emotional-context for burden, rather than task-based-context that the Caregiver Burden Scale (Macera et al., 1993) provides. The Burden Sacle for Family Caregivers (Gräsel et al., 2003) accounts for social, wellbeing, life satisfaction, health, financial, and anger-related issues. The full version is 28 items, and the short version is 10 items, both of which measure burden as a unidimensional concept, with a four-point Likert-type response format. The long version had acceptable score reliability and validity, as summarized in the manual linked below. The long version lists two sets of cutoff scores based on their norms: burden for care-receivers with dementia and burden for care-receivers without dementia. For care-receivers with dementia, a score of 0-35 (0-41 without dementia) indicates no to mild burden and no risk of psychosomatic symptoms, a score of 36-45 (42-55 without dementia) indicates moderate burden and increased risk of psychosomatic symptoms, and a score of 46-84 (56-84 without dementia) indicates severe to very severe burden and very high risk of psychosomatic symptoms. Cutoff scores are not provided for the short version, but it has demonstrated strong psychometric evidence in its development and is available in 20 different languages. Although the norms are based partially on individuals providing care for those with dementia, the scale is designed to measure any type of caregiving.

Resources:

Burden Scale for Family Caregivers – Short version:

http://www.virtualhospice.ca/Assets/BSFC-s_english_s%20(Caregiver%20Burden%20Scale-Short%20Version)_20170306133440.pdf

INTERVENTION STRATEGIES

The treatment of cancer patients involves everyone in the cancer care team. In an ideal situation, oncologists, nurses, professional counselors, and other helping professionals work in an interdisciplinary team to provide comprehensive patient care. The interventions suggested below address communication within and between medical care workers, peer support, and individually-focused counseling.

Increasing Quality of Communication with Medical Professionals

Increasing the ability to communicate concerns with medical professionals can be one area of intervention to increase outcomes of cancer care, especially as communication with medical professionals can be stressful for patients (Arora et al., 2002). Diefenbach and colleagues (2009) reviewed some options of communication in cancer care, highlighting the PACE system (Cegala, Street, & Clinch, 2007) as a way of *Presenting* important information about the patient's emotional state, *Asking* questions of medical professionals, *Checking* for understanding, and *Expressing* concerns. Originally developed as a patient education tool, counselors can use the PACE system in individual or group settings to help provide guidance in communication between cancer patients and their medical professionals. Professional counselors can discuss these skills with cancer patients and their families as a way of understanding how to gather information with medical professionals about effects on clients' physical, mental, and emotional states. Professional counselors can help clients practice these skills before and after meetings with medical professionals. In addition, family members can help assist patients with the PACE system if they are too overwhelmed with information being presented. Further, counselors can process unanswered questions or concerns and help patients with those concerns as well. Cegala and colleagues found that this communication style led to physicians providing more information when questioned, as well as physicians volunteering more information outside of questions asked by patients using the PACE system. Although researchers have not investigated the psychosocial outcomes of this communication intervention, previous studies have found that a lack of information can have a negative influence on QoL for patients (e.g., Arora et al.).

Peer Support

Overall, peer support programs for those with cancer tend to be beneficial (e.g., decreased feelings of anxiousness, decreased feelings of emotional burden with family, and increased positive outlook for the disease; Campbell, Phaneuf, & Deane, 2004; Hoey, Ieropoli, White, & Jefford, 2008). Peer support programs for cancer patients allow them to discuss experiences of the disease, treatment, and how others have dealt with cancer. Although peer support programs can be helpful, they tend to have low participation (Boyes et al., 2018). Boyes and colleagues found that a majority of their sample of cancer patients wanted to participate in a peer support group specifically for similar treatments or same types of cancers, but few wanted to meet online.

One-to-one or support group formats, usually in person, are the typical ways that peer support programs are designed. These meetings and groups can occur in person at a variety of locations, including oncologists' offices, medical centers, community centers, on the telephone, and online. Further, sponsorship for meetings can come from different cancer organizations (e.g., American Cancer Society) or local cancer patients. Counselors interested in working with or starting a peer support group should be specific in the type of group (e.g., cancer site or treatment), and work with local cancer patients to design a group that would be beneficial to patients locally (Boyes et al., 2018). A listing of different peer support and support groups can be found at the University of California San Francisco website to help counselors either refer cancer patients or to better verse themselves in the different aspects of support available.

Resource:
UCSF website: https://psc.ucsf.edu/peer-support-and-support-groups

CALM Therapy

For patients and the families dealing with advanced or metastatic disease, researchers in Canada have developed a therapy called Managing Cancer and Living Meaningfully (CALM; Hales, Lo, & Rodin, 2015). This is a manualized, evidence-based treatment that was designed to include patients and primary caregivers (referred to together as clients from this point). CALM consists of six individual sessions over 3-6 months in which primary caregivers can attend one or as many sessions as the patient feels is appropriate. CALM supports a strong therapeutic relationship in which the counselor and clients can delve into larger subjects of meaning, death, life, and fear. CALM addresses four interrelated domains: symptom management and communication with healthcare providers, changes in self and relations with close others, sense of meaning and purpose, and the future and mortality. Within the first domain, the counselor and client focus on understanding the disease and experiences with symptoms while also investigating experiences and work with other healthcare providers and issues in medical decision making. Within the second domain, they focus on self-concept, caregiving and care receiving, and supporting children and other family members. Conversations in these areas focus on the developing and re-orienting of clients' experiences as the disease can damage self-concept and their relationships with others. Work in the third domain focuses on developing and investigating life narratives, personal meaning of the disease, and priorities and goals while living with advanced disease. The existential portion of CALM is most present here, as the renegotiation of purpose and meaning in life can seem insurmountable for the client(s). Finally, in the fourth domain, the counselor and client(s) address anticipatory fears around death, balance of living and dying, and advance care planning. These sessions address the realities of advanced and metastatic disease while ensuring the patient has a chance to explore and confront fears and concerns. There is little empirical evidence to support CALM, but some research was completed and other research is currently being conducted (Scheffold et al., 2015). In a randomized controlled trial for CALM, Rodin and colleagues (2018) found that those who participated in CALM, as opposed to usual care had less severe depressive symptoms than those at usual care at three ($d = 0.23$, $p = .04$) and six month ($d = 0.29$, $p = .02$) follow-up. Counselors can find further information on CALM therapy and training opportunities on their website.

Resources:
CALM http://gippec.org/projects/cancer-and-living-meaningfully-calm.html
The International Psycho-Oncology Society (IPOS): https://ipos.wildapricot.org/
The American Psychosocial Oncology Society: https://apos-society.org/

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