

Cancer Patients and Families

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

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., *I feel like I am doing too much for my loved one* or *I am a caregiver for someone who is not able to take care of themselves*). 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 Scale 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 from F

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 *P*eer important information about the patient's emotional state, *A*ssess questions of medical professionals, *C*heck for understanding, and *E*xpress 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

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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