Comprehensive psychosocial care of cancer patients: Screening for distress in family members

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ABSTRACT
Family members have multiple roles when caring for someone diagnosed with cancer. The burden associated with these roles can result in family members experiencing elevated levels of emotional distress including depression, anxiety, and physical complaints. For comprehensive psychosocial care to be all inclusive, the well-being and distress levels of family members must also be addressed. To date, little is known about the specific sources of distress for family members.

The purpose of this research study was to fill this gap. Specifically, the researchers developed a unique screening tool to identify sources contributing to family members’ emotional distress. The study was conducted in three phases: 1) a comprehensive literature review was done to elicit a first set of items, 2) two separate focus groups of health care professionals and family members were held to obtain their feedback on possible items that would comprise the tool and, 3) a sample of family members was invited to speak to the relevancy of the proposed items. Results from these analyses led to a tool comprising 46 items. Family member responses on these items suggested that they are often confronted with unique sources of distress including those related to self-care, patient care, and relational.

Cancer affects the entire family. While emotional distress experienced by cancer patients is widely studied (Graves et al., 2007; McLean & Jones, 2007; Sellick & Edwardson, 2006; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001), the distress of the family members is often overlooked. Yet, the rates of distress experienced by family members of oncology patients have been shown to be elevated. For instance, using the Distress Thermometer, a team of researchers reported that 29.2% and 18% of family members of oncology patients experienced moderate and high levels of distress respectively (Zwahlen, Hagenbuch, Carley, Recklitis, & Buchi, 2008). Additionally, research suggests that family members’ distress tends to increase during specific time points across the disease trajectory (Murray et al., 2010). Finally, a patient’s overall coping is said to be positively related to the well-being of the family members (Northouse, 2012). Based on the population of family members seen in our psychosocial oncology program, we argue that comprehensive patient care must also take into account addressing the needs of family members who are directly involved in the cancer experience of their loved one. At present, all new patients and family members who are seen by a clinician in the program are invited to complete the Canadian Problem Checklist (CPC) (Cancer Journey Action Group, 2009) to help identify the sources of their distress. While the CPC was not specifically designed for family members, we were using it to obtain some information on what they identified as sources of distress for them. Family members had noted and provided us with feedback that they felt the tool was not entirely applicable to them. They felt that not all of their sources of distress were identified, or they felt the sources of distress listed were very patient-specific. In order to address this concern, we recognized that the development of a screening tool for these family members was a necessary first step in the provision of optimal care to these family members.

The purpose of the present study was to develop a screening tool designed to identify the distress level of family members with a list of their specific concerns. The study was completed in three phases. First, a comprehensive literature review was conducted on sources contributing to emotional distress in family members. Second, separate focus groups of health care professionals in oncology and family members of cancer patients were conducted. Goals of these focus groups were to: 1) review the preliminary items generated from the literature review, 2) solicit suggestions of additional or removal of items and, 3) provide feedback on the Family...
Member Problem Checklist (FMPC). These focus groups were audio-taped and transcribed. The content of these groups were coded and relevant themes were extracted. Finally, a sample of N=106 family members recruited from oncology clinics were asked to rate the relevancy of the FMPC items to their overall experience.

The screening tool resulted in 46 items (see Figure 1). The results of this research indicated that, like cancer patients, family members reported sources of distress related to practical (e.g., transportation/parking), emotional (e.g., anxiety/worry), social/family (e.g., lack of support), informational (e.g., about prognosis) and spiritual domains (e.g., faith). However, family members also reported unique sources of distress relevant to them including those related to relational (e.g., relationship with the patient), self-care (e.g., managing one’s own time) and patient-care (e.g., managing patient’s symptoms).

The study also asked participants to respond to qualitative questions pertaining to their experience in completing the screening items. Many felt strongly that the new “checklist covers most concerns a family member might have” and that it was “clear” and “easy to read.” The average time of completion was 7.6 minutes and a range of time needed to complete the FMPC, from 30 seconds to 20 minutes was noted by reading their qualitative responses. These responses on the qualitative questions suggested that the FMPC was easy for them to complete and they found to be a meaningful tool for them.

Family members are often considered the “hidden patient” in oncology settings. They are often required to deliver different types of care to patients, without any former training and recognition, and are expected to be continuously supportive during the patient’s illness. As a result, family members can become easily overwhelmed, anxious and/or depressed. The development of this clinical tool specifically designed to screen for the sources of distress experienced by family members is the first step towards a more comprehensive assessment of their distress and, likely, that of the patient. This assessment/screening places nurses, and all health care professionals, in a stronger position to provide optimal support and appropriate family interventions in the future.

REFERENCES


Figure 1

Family Member Problem Checklist:
Please check all of the following items that have been a concern or problem for you in the past week, including today

Practical
☐ Finances
☐ Legal Issues
☐ Transportation/Parking
☐ Household duties
☐ Taking care of others
☐ Work/Studies
☐ Managing my own time

Information
☐ About the disease
☐ About the treatment
☐ About prognosis
☐ About supportive resources

Communication
☐ Acting as a spokesperson
☐ Difficulty talking about certain topics

Emotional
☐ Sadness
☐ Anger/frustration
☐ Anxiety/worry
☐ Guilt
☐ Feeling overwhelmed
☐ Helplessness
☐ Shock
☐ Resentment

Family Member Problem Checklist: Practical
Mehra & Hamel, 2015

Social
☐ Feeling alone
☐ Lack of support
☐ Expectations from others

Relational
☐ Change in social roles
☐ Relationship with patient
☐ Relationship with health care team
☐ Family dynamics

Spiritual
☐ Faith
☐ Meaning and purpose
☐ Hope
☐ Death/Dying

Self-Care
☐ Sleep
☐ Appetite
☐ Concentration/Memory
☐ Fatigue/Weakness
☐ Intimacy/Sexuality
☐ My own physical health problems
☐ My own mental health problems
☐ Finding time for myself
☐ Coping

Patient Care
☐ Managing patient symptoms
☐ Managing patient medications
☐ Organising patient appointments
☐ Caring for the patient at home
☐ Self-confidence as a caregiver

[Table of items such as "Managing my own time" and "Feeling overwhelmed" with corresponding codes]