Patients With Advanced-Stage Cancer: Caregivers Perspective on Patient Symptoms, Treatment Sessions, and Coping

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Session Title:
Family Caregivers: Presence, Perspectives, Challenges, and Health

Keywords:
alternative therapy, cancer and caregivers

References:


**Abstract Summary:**
Attendees will learn about perspectives on patient symptoms, difficulties during treatment, and coping needs in caregivers of advanced stage cancer survivors (ASCS). Strategies for interventions to support these caregivers will be discussed.

**Content Outline:**
I. Introduction
With an increase in numbers of advanced stage cancer survivors, cancer caregivers face multiple challenges that place their own quality of life and place them at health risk when caring for patients with advanced-stage cancer. Caregivers find they are at risk for multiple problems, and at greater risk for developing depression and anxiety, affecting caregiver QOL.

II. Body
A. Caregivers report their perspectives on patient symptoms, difficulties during treatment, and coping needs.
B. Caregivers provide feedback on the design of Mobile Mindfulness Based Stress Reduction for Caregivers to address important factors and needed outcomes.

III. Conclusions
A. Obtaining caregiver perspectives on patient symptoms, difficulties experienced during patient treatments, and areas to improve coping are important considerations to inform the design of effective, self-management interventions. Obtaining caregiver feedback on intervention outcomes indicate mMBSR-(C) is an important self-management intervention to effectively address needs of caregivers of ASCS.

**Topic Selection:**
Family Caregivers: Presence, Perspectives, Challenges, and Health (25439)

**Abstract Text:**

**Purpose:** To describe perspectives on patient symptoms, difficulties during treatment, and coping needs in caregivers of patients with advanced-stage cancer to inform the design of an effective, self-management alternative therapy mobile intervention for caregivers.
Methods: Focus group interviews among caregivers (CG) and a review of the literature specific to cancer caregivers and alternative mindfulness interventions were completed. Focus groups included English speaking caregivers of advanced stage breast, lung, and colon patients 18 years and older, with caregivers providing care at least 5 hours per week. Caregivers were recruited from a NCI Cancer Center in the Southeast. Focus group interviews were conducted by research assistants and included caregiver self-report responses to interview questions. Literature reviews were conducted on caregivers of patients with cancer and advanced-stage cancer; mindfulness and mindfulness based stress reduction interventions for cancer caregivers; web-based mobile interventions for cancer caregivers; and mindfulness and relaxation-based eHealth interventions for cancer caregivers.

Results: Evidence from focus group questions among 7 CG of ASCS (2 lung, 3 breast and 2 colon) related to symptoms of the patient found to be most bothersome included: 1) pain; 2) poor sleep quality; 3) fatigue; 4) exhaustion; 5) anxiety; 6) unexpected symptoms; and 7) unexplained symptoms. Difficulties experienced by the CG during patient treatment sessions included: 1) feeling overwhelmed; 2) depression; 3) anxiety of the unknown; 4) diarrhea; 5) frustration; 6) unpreparedness; 7) the need to advocate for best care; 8) guilt from missed symptoms or side effects noted by others; 9) the physical act of feeding someone; 10) figuring out what and how to prepare food to be less painful; and 11) ineptitude of physicians. Areas to improve coping for caregivers included: 1) aggravation from constant schedule changes; 2) easily overwhelmed; 3) added stress from surgical body disfigurement; 4) burden of caregiving responsibility; 5) burden of keeping friends and family informed; 6) maintaining hope; 7) frustration from process issues at pharmacy and infusion center; 8) routine disruption; 9) staying informed by providers; and 10) debilitating lack of energy. In summary feedback from focus group interviews suggest quality of life, depression, anxiety, pain, stress, fatigue, and sleep are the most important factors to address in an effective intervention for caregivers. A review of literature supports these outcomes, showing caregivers report high levels of fatigue leading to high symptom burden, along with anxiety, and depression caregiver burden and sleep disturbances that often affected care as sleep disturbances increased. Cancer caregivers report higher levels of stress leading to negative coping and increased anxiety and depression leaning to reduced QOL.

Additional feedback from CG interviews on participation in a mobile Mindfulness Based Stress Reduction (MBSR) program for caregivers mMBSR-(C) indicated the intervention may benefit the CG and result in the following outcomes: 1) less stress, 2) lower anxiety, 3) less dwelling/ruminating on the circumstances, 4) sense of well-being, 5) more...
present, 6) ability to process circumstances, and 7) improved overall health. A review of literature related to mindfulness based stress reduction interventions for caregivers of cancer patients is limited. Within a systematic review among 21 cancer patient/caregiver dyads in an 8-week MBSR program, improvements were found in mood disturbance, stress and mindfulness. Similarly, 19 lung cancer patients and 16 caregivers, showed decreases in caregiver burden due to MBSR. Additionally, an RCT among 62 lung cancer patients and 44 partners, randomized to MBSR or Usual Care, resulted in less distress, and improvements in quality of life, mindfulness skills, self-compassion, and rumination among the MBSR patients, however no differences were found between groups among partners. Our team tested a MBSR(C) program among advanced stage patients and caregivers resulting in improvements in stress and anxiety; caregivers showed trends in caregiver QOL and psychological status; with both patient and caregivers showing decreases in salivary cortisol and IL-6 levels. A systematic review of mindfulness and relaxation-based eHealth interventions found only 2 studies among cancer patients resulting in improvements in general health and psychological well-being. Additionally, a 4-week single group study among caregivers of lung transplant patients testing an MBSR DVD resulted in improvements in stress and anxiety. Our preliminary study revealed that our mobile mMBSR(BC) program for early stage breast cancer survivors (BCS) produced significant improvements in depression, state anxiety, stress, fear of recurrence, sleep quality, fatigue and QOL.

**Conclusion:**
Caregiver perspectives on patient symptoms, difficulties experienced during patient treatments, and areas to improve coping, are essential to inform the design of effective, self-management alternative therapy interventions for CG of ASCS. Caregivers agreed that the outcomes they need addressed should be considered in the design of a mobile mMBSR-(C) program that would be more accessible than a traditional time consuming program.