

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

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References:

1. National Alliance for Caregiving. *Caregiving in the U.S.*: AARP Public Policy Institute; 2015.
2. Rumpold T, Schur S, Amering M, Kirchheiner K, Masel EK, Watzke H, Schrank B. 2016. Informal caregivers of advanced stage cancer patients: Every second is at risk for psychiatric morbidity. *Support Care Cancer*. 2016 May; 24(5):1975-1982. doi: 10.1007/s00520-015-2987-z. Epub 2015 Oct 17. PMID: 26476628
3. Karabekiroğlu A, Demir EY, Aker S, Kocamanoğlu B, Karabulut GS. Predictors of depression and anxiety among caregivers of hospitalized advanced cancer patients. *Singapore Med J*. 2018 Jun 7. doi: 10.11622/smedj.2018066. [Epub ahead of print] PMID: 29876580
4. Clark MM, Atherton PJ, Lapid MI, Rausch SM, Frost MH, Cheville AL, et al. Caregivers of patients with cancer fatigue: A high level of symptom burden. *American Journal of Hospice and Palliative Medicine*. 2014; 31(2):121-125. doi: 10.1177/1049909113479153. PubMed PMID: 23434836; PubMed Central PMCID: PMC4392763
5. Mystakidou K, Parpa E, Panagiotou I, Tsilika E, Galanos A, Gouliamos A. Caregivers' anxiety and self-efficacy in palliative care. *European Journal of Cancer Care* 2013; 22(2):188-195. doi: 10.1111/ecc.12012. PubMed PMID: 22989256
6. Borges EL, Franceschini J, Costa LH, Fernandes AL, Jamnik S, Santoro IL. Family caregiver burden: the burden of caring for lung cancer patients according to the cancer stage and patient quality of life. *J Bras Pneumol*. 2017 Jan-Feb; 43(1):18-23. doi: 10.1590/S1806-37562016000000177. Epub 2017 Jan 23. English, Portuguese. PMID: 28125154
7. Al-Daken LI, Ahmad MM. Predictors of burden and quality of sleep among family caregivers of patients with cancer. *Support Care Cancer*. 2018 Nov; 26(11):3967-3973. doi: 10.1007/s00520-018-4287-x. Epub 2018 May 26. PMID: 29804204
8. Lee KC, Hsieh YL, Lin PC, Lin YP. Sleep pattern and predictors of sleep disturbance among family caregivers of terminal ill patients with cancer in Taiwan: a longitudinal

- study. *Am J Hosp Palliat Care*. 2018 Aug; 35(8):1109-1117. doi: 10.1177/1049909118755453. Epub 2018 Feb 1. PMID: 29390869
9. Antony L, George LS, Jose TT. Stress, coping and lived experiences among caregivers of cancer patients on palliative care: a mixed method research. *Indian J Palliat Care*. 2018 Jul-Sep; 24(3):313-319. doi: 10.4103/IJPC.IJPC_178_17. PMID: 30111945
 10. Righi L, Bruhn RF, De Cicco R, Kanda JL, Matos LL. Quality of life impairment in patients with head and neck cancer and their caregivers, *Braz J Otorhinolaryngol*. 2016 Nov - Dec; 82(6):680-686. doi: 10.1016/j.bjorl.2015.12.012. Epub 2016 Apr 11. PMID: 27133907
 11. Lee YH, Liao YC, Liao WY, Shun SC, Liu YC, Chan JC, Yu CJ, Yang PC, Lai YH. Anxiety, depression and related factors in family caregivers of newly diagnosed lung cancer patients before treatment. *Psychooncology*. 2013 Nov; 22(11):2617-23. doi: 10.1002/pon.3328. Epub 2013 Jul 28. PMID: 23893960
 12. Li G, Yuan H, Zhang W. The effects of mindfulness-based stress reduction for family caregivers: Systematic review. *Arch Psychiatr Nurs*. 2016; 30(2):292-299. doi: 10.1016/j.apnu.2015.08.014. PubMed PMID: 26992885.
 13. Birnie K, Garland SN, Carlson LE. Psychological benefits for cancer patients and their partners participating in mindfulness-based stress reduction (MBSR). *Psychooncology*. 2010; 19(9):1004-1009. doi: 10.1002/pon.1651. PubMed PMID: 19918956.
 14. van den Hurk DG, Schellekens MP, Molema J, Prins J, Speckens AE, van der Drift MA. Feasibility and acceptability of mindfulness-based stress reduction (MBSR) in patients with lung cancer and their partners: A mixed-method pilot study. Paper presented at: IPOS 15th World Congress of Psycho-Oncology 2013; Rotterdam, the Netherlands.
 15. Schellekens MPJ, van der Hurk DGM, Prins JB, Donders ART, Molema J, Dekhuijzen R, et al. Mindfulness-based stress reduction added to care as usual for lung cancer patients and/or their partners: A multi-center randomized controlled trial. *Psychooncology*. 2017:1-9. doi: 10.1002/pon.4430. PubMed PMID: 28337821.
 16. Lengacher CA, Kip KE, Barta M, Post-White J, Jacobsen PB, Groer M, et al. A pilot study evaluating the effect of mindfulness-based stress reduction on psychological status, physical status, salivary cortisol, and interleukin-6 among advanced-stage cancer patients and their caregivers. *J Holist Nurs*. 2012; 30(3):170-185. doi: 10.1177/0898010111435949. PubMed PMID: 22442202.
 17. Mikolasek M, Berg J, Witt CM, Barth J. Effectiveness of mindfulness- and relaxation-based eHealth interventions for patients with medical conditions: A systematic review and synthesis. *International Journal of Behavioral Medicine*. 2017:1-16. doi: 10.1007/s12529-017-9679-7. PubMed PMID: 28752414.
 18. Carpenter KM, Stoner SA, Schmitz K, McGregor BA, Doorenbos AZ. An online stress management workbook for breast cancer. *J Behav Med*. 2014;37(3):458-468. doi: 10.1007/s10865-012-9481-6. PubMed PMID:23212928; PubMed PMCID: PMC3622129.
 19. Beatty L, Koczwara B, Wade T. Evaluating the efficacy of a self-guided web-based CBT intervention for reducing cancer-distress: A Randomized controlled trial. *Support Care Cancer*. 2015;25(3):1043-1051. doi:10.1007/s00520-015-2867-6. PubMed PMID: 26248651.

20. Haines J, Spadaro KC, Choi J, Hoffman LA, Blazeck AM. Reducing stress and anxiety in caregivers of lung transplant patients: Benefits of mindfulness meditation. *International Journal of Organ Transplantation Medicine*. 2014;5(2):50. PubMed PMID: 25013679; PubMed Central PMCID: PMC4089339.
21. Lengacher C, Reich RR, Ramesar S, Alinat, CB, Moscoso M, Cousin L, et al. Feasibility of the mobile mindfulness-based stress reduction for breast cancer (mMBSR(BC)) program for symptom improvement among breast cancer survivors. *Psychooncology* 2018 doi: 10.1002/pon.4491. PubMed PMID: 28665541.

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,¹ 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.^{2,3}

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,⁴ along with anxiety, and depression² caregiver burden,^{5, 6} and sleep disturbances⁷ that often affected care as sleep disturbances increased.⁸ Cancer caregivers report higher levels of stress leading to negative coping⁹ and increased anxiety and depression leading to reduced QOL.¹⁰⁻¹¹

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.^{12, 13, 14, 15, 16} Within a systematic review¹² among 21 cancer patient/caregiver dyads in an 8-week MBSR program, improvements were found in mood disturbance, stress and mindfulness.¹³ Similarly, 19 lung cancer patients and 16 caregivers, showed decreases in caregiver burden due to MBSR.¹⁴ 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.¹⁵ 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.¹⁶ A systematic review of mindfulness and relaxation-based eHealth interventions¹⁷ found only 2 studies among cancer patients resulting in improvements in general health and psychological well-being.¹⁸¹⁹ Additionally, a 4-week single group study among caregivers of lung transplant patients testing an MBSR DVD resulted in improvements in stress and anxiety.²⁰ 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.²¹

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.