

Version 2.0



Abstract

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PI Title:

Project Title: COHORT STUDY OF CANCER PATIENT CAREGIVER OUTCOMES

Abstract: *Despite recent advances in cancer detection and treatment, each year more than half a million cancer patients die from their disease. Patient's and families who are living with terminal cancer often encounter emotional distress, unmet needs, increasing physical limitations, symptomatic discomfort, and financial burdens. Despite the importance of caregivers in the care of patients with advanced cancer, there is a paucity of research describing the longitudinal outcomes of caregivers over the continuum of care from active patient illness to death, bereavement, and post bereavement. To begin to fill these important knowledge gaps, a multidisciplinary research team from Lombardi Cancer Center will use a conceptual framework of the caregiving experience to conduct a longitudinal cohort study of caregivers of terminally ill cancer patients. The primary objectives of this study are to use a conceptual model of caregiving: 1) to describe caregiver burden and health outcomes over the continuum of care and 2) to address methodological issues associated with longitudinal research in this setting. We will conduct phased research to achieve these goals. In the first phase of the project, we will conduct six focus groups with individuals who are either active caregivers or bereaved. In the second phase of the project, we will use these data to conduct a longitudinal cohort study. The cohort will consist of nearly 300 caregivers of advanced gastrointestinal, lung, and breast cancer patients. Caregivers will be interviewed at enrollment, 2 and 4 months post-enrollment, and 3, 6, and 13 months post-bereavement. The results of this project will serve as a framework for the development of future interventions to improve the quality of care for cancer patients and their families. In addition, approaches developed in this project should be broadly portable to studying the caregiver experience in caring for*

patients with other types of chronic and terminal illnesses.

Thesaurus Terms:

*cancer rehabilitation /care, caregiver, coping, terminal patient care
bereavement, health care quality, longitudinal human study
behavioral /social science research tag, clinical research, human subject*

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