Original Article

A Pilot Study of the Experience of Family Caregivers of Patients With Advanced Pancreatic Cancer Using a Mixed Methods Approach

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Abstract

Context. Pancreatic cancer presents a wide spectrum of significant symptomatology. The high symptom burden, coupled with a rapidly fatal diagnosis, limits preparation or time for adjustment for both patients and their family caregivers. From the initial diagnosis and throughout the illness experience, the physical and emotional demands of caregiving can predispose caregivers themselves to illness and a greater risk of mortality. Understanding the negative and positive aspects of caregiving for patients with advanced pancreatic cancer will inform interventions that promote positive caregiver outcomes and support caregivers in their role.

Objectives. To provide feasibility data for a larger, mixed methods, longitudinal study focused on the experience of family caregivers of patients with advanced pancreatic cancer and preliminary qualitative data to substantiate the significance of studying this caregiver population.

Methods. This was a mixed methods study guided by the Stress Process Model. Eight family caregivers of patients with advanced pancreatic cancer from oncology practices of a university-affiliated medical center were surveyed.

Results. The pilot results supported the ability to recruit and retain participants and informed recruitment and data collection procedures. The qualitative results provided preliminary insights into caregiver experiences during the diagnosis and treatment phases. Key findings that substantiated the significance of studying these caregivers included the caregiving context of the history of sentinel symptoms, the crisis of diagnosis, the violation of assumptions about life and health, recognition of the circle of association, and contextual factors, as well as primary and secondary stressors, coping strategies, resources, discoveries, gains and growth, associated changes/transitions, and unmet caregiver needs.

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Conclusion. Findings indicated caregivers' willingness to participate in research, highlighted the negative and positive aspects of the caregiver experience, and reinforced the significance of the future study and the need to develop interventions to support family caregivers in their roles.

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Key Words
Family caregivers, advanced pancreatic cancer, qualitative research, mixed methods

Introduction

Pancreatic cancer is the fourth leading cause of cancer deaths in the U.S.,[1] and 80% of patients present with advanced stage (i.e., III, IV) disease.[2,3] Limited treatment options and resistance of the disease to chemotherapy result in a 95% mortality rate within one year of diagnosis and an estimated survival rate of only 4%.[2] The high symptom burden, coupled with a rapidly fatal diagnosis, does not allow preparation or time for adjustment for either patients or their family caregivers. During this compressed time frame, caregivers experience uncertainty, anger, depression, anxiety, exhaustion, and anticipatory grief[4] and also may worry about their own genetic risk and that of other family members.[2]

Family caregivers provide a broad range of assistance to patients, which involves time and logistics, physical care, emotional burden, and financial costs that often lead caregivers to neglect their own needs.[5] Throughout the illness experience, the physical demands of caregiving can predispose caregivers themselves to medical illness and a greater risk of mortality.[6] Emotionally, caregivers often become demoralized and exhausted[4] and may need to be treated for psychiatric problems.[7] Family caregivers often abandon their own activities, which create stress on themselves, and the family as a unit.[8] However, some researchers suggest a focus on the benefits of the caregiving experience and possible gains, which may act as a buffer against overwhelming burden and traumatic grief,[9] and may motivate caregivers to maintain their roles.[10—12]

Despite numerous studies focusing on caregivers in general and caregiving in the context of cancer,[5,7,8,10,11,13—26] there is a dearth of literature regarding the experience of family caregivers of patients with advanced pancreatic cancer. Petrin et al.[27] highlighted the distress of first-degree relatives of patients with pancreatic cancer, who articulated the stress they experience because of competing responsibilities, unfamiliar physical care demands, and the disruption of usual daily activities. In a longitudinal study that included patients with advanced pancreatic cancer and their family caregivers, Sherman et al.[28,29] found that caregivers themselves had significant physical and emotional symptoms and lower quality of life as the patient's illness progressed.

Because there is ample evidence that family caregivers are neglected by the health care system and remain an at-risk and vulnerable population,[6] a future mixed methods longitudinal study is planned to inform the development of interventions aimed at reducing negative consequences and promoting positive aspects of caregiving across the illness trajectory.[30,31] The knowledge gained based on caregivers of patients with advanced pancreatic cancer may be applicable to caregivers of patients with other solid tumors; Salpeter et al.[32] report the similarities in illness trajectories when these tumors are in the advanced stages.

Here, we report the results of a pilot study designed to 1) examine the feasibility of a larger, mixed methods, longitudinal study of family caregivers of patients with advanced pancreatic cancer, specifically the initial recruitment and retention of participants, ease of administration of selected instruments, evaluation of interview questions, and data collection procedures and 2) provide preliminary qualitative data obtained during the diagnosis/treatment phases to gain insights into the caregiver experience and further substantiate the significance of research for this specific caregiver population.