



Closing the Caregiving Gap: Considerations for Pancreatic and Periampullary Cancer Caregivers

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Pancreatic cancer continues to have the poorest 5-year relative survival rate of all cancers, and the prevalence is steadily increasing.¹ In fact, by 2030, pancreatic cancer will be the *second* leading cause of all cancer-related deaths.² These statistics reflect the overall poor prognosis for these patients, as pancreatic cancer is often difficult to both detect and treat.³ As a result, patients report a high degree of symptom burden from pain, fatigue, gastrointestinal and appetite issues, and emotional distress that significantly impairs their overall functioning and quality of life.⁴ Yet, because cancer does not exist in a vacuum, the burden of pancreatic cancer and its treatment often fall onto the shoulders of those who are, essentially, unpaid extensions of the medical team: family and friend caregivers.

Despite caregivers' heavy involvement in care, very little is known about their practical and emotional needs. In fact, three recent systematic reviews collectively identified only 12 studies in the past 15 years that report on the experience of pancreatic cancer caregivers.⁵⁻⁷ In the article that accompanies this editorial, a prospective, cross-sectional tri-institutional study by Fong et al⁸ expands this evidence base by evaluating the sociodemographic characteristics, mental health symptoms, common responsibilities, and greatest challenges of caregivers of patients with pancreatic and periampullary cancers (N = 240). Investigators comprehensively used both quantitative and qualitative methods at 1 month postsurgical resection, a time with known impacts to patient quality of life.⁹

In line with other cancer caregiving literature,⁵ the sample comprised mostly White (84%), college-educated (55%), female (71%), spousal (59%) caregivers. These caregivers identified the time immediately postoperation/postdischarge as the most stressful period of their caregiving experience (47%). Specifically, during this time, caregivers reported difficulties with managing daily, practical concerns, including housework and the diet of the person they were caring for. Exploratory qualitative findings suggested that caregivers felt unprepared for their roles and perceived a lack of appropriate medical knowledge to effectively manage the patients' symptoms. Examining psychological well-being, the investigators found that 18% and 24% of their sample met the clinical cutoff for depression and anxiety, respectively. Although a majority of the sample stated they had friends and family members who served as both emotional and practical supports, only approximately 3% stated they participated in a caregiver support group. Similarly, only 11%-12% used respite care or a paid caregiver for additional assistance.

The results of the study of Fong et al⁸ highlight the nuanced challenges of this subgroup of caregivers. These caregivers have trouble managing the patients' gastrointestinal symptoms/diet, navigating the health care system, communicating with providers, juggling multiple responsibilities, and maintaining their own well-being.^{5,7} They report a range of emotions, including shock at the time of diagnosis, anger as they were suddenly forced into their role, guilt for the inability to manage symptoms, and feeling alone and invisible to the medical team.^{5,7} While distress was lower in this sample, extant research suggests that caregivers' psychological distress may be even higher at different points of the disease trajectory, as an estimated 33% of caregivers reported clinical levels of anxiety, and up to 32% reported clinical levels of depression.⁵ Some even reported symptoms that were greater than that of the patients they were caring for,^{6,7} a pattern of distress that has been observed in caregivers of patients with gastrointestinal cancers¹⁰ and primary brain tumors.¹¹⁻¹³ Despite caregivers' high need for psychological support, the results of Fong et al⁸ mirror a general trend in cancer caregiving, which finds a significant gap between caregivers' need/interest in supportive care and their actual use

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of these services—likely because of the myriad systemic hurdles.¹⁴⁻¹⁶ It is clear that this is a caregiver population with many supportive care needs and high emotional burden.

The age composition of the sample in the study of Fong et al⁸ highlights the growing trend of young adult caregivers: 26% of the study's sample were the adult child of the patient, and 22% had at least one child of their own younger than 18 years. These young adult caregivers must integrate their career with other care responsibilities and are at a much greater risk of financial toxicity than older adult caregivers.¹⁷⁻¹⁹ In fact, a study by Engebretson et al²⁰ found that almost half of pancreatic cancer caregivers had to quit their job to care for their loved one. There were similar indications from the qualitative portion of Fong et al⁸ such that caregivers struggled with understanding billing and preparing financially for the level of care required. With this, tailoring support to consider the distinct needs of different at-risk caregivers across the disease trajectory and across multiple domains of functioning is ideal—not only for the well-being of the caregiver but also for the well-being of the patient.

Nevertheless, much remains unknown about this group of caregivers, and there is an opportunity to build on the formative work conducted by Fong et al.⁸ First, in addition to describing the rates of depressive and anxious symptoms, we must understand which caregivers are most at risk for poor mental health outcomes by examining intrapersonal patient and caregiver sociodemographic and socio-cultural factors that are most closely related to mood symptoms. For example, evidence suggests that lower education, patients' quality of life, patients' prognostic awareness, chronic comorbidities, and bereavement are factors that place pancreatic cancer caregivers at a greater risk for depressive symptoms, although confirmatory studies are needed.^{5,7,10} Next, further work should explore the dyadic effect of patient-caregiver emotional distress, given the known interdependence of distress in advanced cancer populations.²¹⁻²³ In addition, given that the needs of these pancreatic and periampullary cancer caregivers likely evolve over time and as the patients' disease progresses, we should strive to assess their needs longitudinally—beyond the 1-month postoperation follow-up and including when the caregiver is bereaved. Finally, pancreatic cancer is more prevalent in African American patients; however, most caregivers in pancreatic studies to date have been White.²⁴ It is critical that future research examines the care needs of minoritized, at-risk caregivers (eg, racial/ethnic minority, LGBTQIA+ caregivers), who may experience a double vulnerability because of institutionalized racism and face additional hurdles to receiving support.²⁵ A deeper exploration into these topics is a necessary step toward the development of comprehensive, tailored interventions for pancreatic cancer caregivers, given no study to date has examined the efficacy of any intervention developed specifically for this group.

Beyond empirical recommendations, the results from the study of Fong et al⁸ and studies of caregivers more broadly highlight the significant need for clinical intervention.²⁶ Recently published guidelines from ASCO strongly recommend that all patients and caregivers receive information about anxiety and depression, including referrals to appropriate resources.²⁷ Moreover, ASCO has identified cognitive behavioral therapy as the front-line treatment for patient distress in cancer, offering a roadmap for how we might begin to support caregivers.²⁷ Nevertheless, comprehensive care for the caregiver should be *multimodal* such that it also addresses the educational, practical, and emotional needs of this group. Moreover, interventions should be *tailored* to the unique needs of pancreatic and periampullary cancer caregivers (eg, providing better training to manage the patient's diet and medications after surgery) and easily accessible (eg, smartphone-based interventions) to increase engagement.²⁶ Finally, because the needs of these caregivers likely change over the course of the disease, clinical intervention should span the trajectory of care and adapt at each time point, as has been performed in other caregiving interventions.²⁸

Recommendations for clinical intervention will only be possible with policy changes supporting caregivers. Currently, few policies exist that directly affect caregivers. The Caregiver Advise Record and Enable (CARE) Act mandates that hospitals document caregiver information and provide medical education on the patient's discharge; however, the CARE Act is not routinely implemented across the United States because of, in part, challenges related to the documentation of this information.²⁹ The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act—which set the foundation for the National Family Caregiving Strategy—has potential to meaningfully change how caregivers are supported.³⁰ Current recommendations seek to increase formal assessments, supportive/respice care, and financial/employment security. Nevertheless, it will take time before these recommendations become the lived experience of cancer caregivers in the United States. There is more that could be performed to optimize support for cancer caregivers at the health care systems level now. As has been advocated by other experts in the field,³¹ a medical record specific for the caregiver can expedite clinical communication, distress screening, and appropriate referrals to supportive care interventions, including billable services. Interestingly, Fong et al⁸ found that most caregivers who had access to MyChart/Patient Gateway (91%) used the patient's log-in information instead of their own, reiterating the need for better documentation options and billing infrastructure for the sustainable care of caregivers.

Given the increasing incidence³² and high morbidity and mortality of pancreatic and periampullary cancer, it is critical that the supportive care needs of these caregivers are better understood through developments at the research, clinical, and policy levels. The comprehensive

assessment by Fong et al⁸ highlights the greatest needs of these caregivers and, in doing so, sets the foundation for the development of tailored interventions in behavioral

and supportive oncology care. It is time that we, collectively, take care of the people caring for our patients beyond hospital and clinic walls.

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