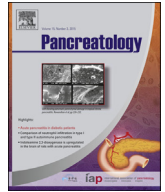




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Original article

Pancreatic cancer: Patient and caregiver perceptions on diagnosis, psychological impact, and importance of support[☆]Anitra Engebretson^{a,*}, Lynn Matrisian^a, Cara Thompson^b^a Pancreatic Cancer Action Network, Manhattan Beach, CA, USA^b Celgene Corporation, Summit, NJ, USA

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ABSTRACT

Background/Objectives: Pancreatic cancer (PC) can have an enormous psychological toll on those affected by it. This study evaluated patient and caregiver perceptions about diagnosis and daily life with PC.**Methods:** The Pancreatic Cancer Action Network (PanCAN) administered a 25-min online survey (funded by Celgene) between July 30 and September 18, 2013 to patients with PC and caregivers whose loved ones were alive or had died within the past 6 months.**Results:** There were 397 respondents (all in the US) including 184 patients (81 with metastatic disease) and 213 caregivers (145 with loved ones with metastatic disease); 80% of patients reported having a primary caregiver. Over 90% reported symptoms before diagnosis, the most common of which being acute abdominal pain, pain radiating into the back, and fatigue. Gastroenterologists were the diagnosing physician in 36.3% of cases. The mean duration from symptom onset to diagnosis was 2.4 months. The most common action taken by diagnosing physicians was referral to another physician (57.7%). No treatments were offered for 9% of patients with nonmetastatic disease and 17% of patients with metastatic disease. The most commonly reported caregiver roles were providing support on treatment days and talking to physicians. A greater percentage of caregivers than patients recognized the various roles played by caregivers. Patients aware of the PanCAN Patient and Liaison Services (PALS) program reported fewer negative emotions than PALS-unaware patients.**Conclusions:** This study provides insights into the issues patients and caregivers in the US face and the importance of support services for both.

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Introduction

Pancreatic cancer has one of the worst prognoses of any cancer type, with a 5-year overall survival rate for patients with any stage of disease of just 7% [1]. In 2015, an estimated 48,960 patients will be diagnosed with pancreatic cancer [2]. Pancreatic cancer often develops without any obvious early symptoms [2]; the symptoms that may occur include weight loss, abdominal discomfort, glucose intolerance, jaundice, nausea, and vomiting [2]. Furthermore, the

symptom profile is dependent on the location of the primary tumor (pancreatic head, body, or tail) [3]. There is no reliable tool for early diagnosis [2], and confirmatory diagnosis is usually based on imaging tests, such as computed tomography (CT) scan, magnetic resonance imaging (MRI), ultrasound (US), or positron emission tomography [4,5].

Unfortunately, at least partially because of the lack of obvious symptoms, over half of patients will be diagnosed with disease that has already metastasized [1]. The remaining patients will be diagnosed with resectable disease (i.e., surgery is possible) or locally advanced disease that is characterized by a lack of metastatic lesions but is inoperable due to involvement of the tumor with important arteries or veins [1].

Diagnosis of pancreatic cancer is often made by a gastroenterologist due to symptoms such as abdominal discomfort, nausea, and vomiting [6]. Once a diagnosis is made, a patient may be referred to a medical oncologist, radiation oncologist, or surgeon

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[7]. Because prognosis is highly dependent on disease stage [1], and because active treatments can significantly improve clinical outcomes [8–18], the lengths of time from symptom onset to diagnosis and from diagnosis to treatment are critical. The unfavorable prognosis that accompanies a pancreatic cancer diagnosis leads to a substantial emotional burden for many patients, which speaks to the importance of support from friends and family [19,20]. Caregivers provide many levels of support for patients with cancer, including emotional support, as well as more practical functions, such as contributing to treatment decisions, accompanying patients to receive treatments, taking notes during medical appointments, and relaying information from medical appointments to friends and family. Little information is available on patient and caregiver perceptions of pancreatic cancer diagnosis and its impact.

The Pancreatic Cancer Action Network distributed a survey on a wide range of topics to patients with pancreatic cancer and caregivers of patients with pancreatic cancer. The focus of this study was to analyze the results of the survey for information on patient and caregiver perceptions about diagnosis, psychological impact of disease, and the importance of support services.

Methods

The Pancreatic Cancer Action Network prepared a 25-min survey funded by Celgene Corporation. The survey included 70 questions that could be self-administered online (Supplemental Appendix 1). The survey was distributed to patients with pancreatic cancer and caregivers of patients with pancreatic cancer who were either still alive or had died within the past 6 months. The caregivers were not necessarily associated with the patients who completed the survey. The designation of caregiver was self-identified and excluded those who received pay for their services. The survey was promoted to the constituency of the Pancreatic Cancer Action Network through email communications and social media channels and was accessed through the organization's website. Participants were required to be ≥ 18 years of age. Surveys were completed between July 30, 2013 and September 18, 2013. All data were tested for statistical significance by appropriate z or t test at a confidence level of 95%, and the results are reported on an unweighted basis.

Respondents

A total of 397 respondents in the US completed the survey (Table 1). This included 184 patients and 213 caregivers. At the time of the survey, 111 of the 213 caregivers were currently caring for a patient, and 102 caregivers had cared for a patient who had died

within the past 6 months. Metastatic disease was diagnosed in fewer patients who completed the survey themselves than patients whose caregivers completed the survey (44% vs 68%). Most of the respondents were female and white. Of the patients who completed the survey, most (79.9%) reported that they had a primary caregiver, usually a spouse or significant other (77.6%). Most patients and caregivers were married at the time of the survey (75.0% and 67.1%, respectively), although not necessarily to each other. More patients than caregivers reported having children ≥ 18 years of age (70.7% vs 46.0%; $P < 0.05$), and more caregivers than patients reported having no children (30.0% vs 14.1%; $P < 0.05$). A large proportion of respondents reported living in a suburban (58.9%) or rural (24.2%) area, and 56.7% of respondents reported having graduated university or college.

Results

Personal and family history

Most respondents reported not having any personal history of cancer or family histories of pancreatitis or pancreatic cancer. However, 11.3% of respondents did report a previous cancer diagnosis for the patient, most commonly prostate ($n = 9$), skin ($n = 7$), and breast cancer ($n = 4$). A family history of pancreatic cancer was reported by 14.4% of respondents, and a family history of pancreatitis was reported by 5.5% of respondents.

Symptoms and diagnosis

The 3 most common symptoms of disease prior to diagnosis were reported to be acute abdominal pain (45.9%), pain radiating into the back (45.4%), and fatigue (43.7%). More survey participants with/caring for a patient with metastatic disease than those with/caring for a patient with nonmetastatic disease reported acute abdominal pain (51.6% vs 37.7%; $P < 0.05$) and pain radiating into the back (49.8% vs 39.1%; $P < 0.05$). Jaundice was more often reported by patients or caregivers of patients with nonmetastatic disease (41.1% vs 27.0%; $P < 0.05$). Only 31 of 397 respondents (7.8%) reported that the patient did not experience any symptoms. Respondents who indicated that diagnosis was made ≥ 3 months after symptom onset reported significantly higher incidences of the following symptoms than those diagnosed < 1 month after symptom onset: pain radiating into the back (54.1% vs 37.6%), acute abdominal pain (52.0% vs 33.8%), indigestion (45.9% vs 22.6%), nausea (34.7% vs 22.6%), malaise (33.7% vs 18.8), heartburn (32.7% vs 21.1%), bloating (31.6% vs 15.8%), diarrhea (25.5% vs 13.5), and depression (27.6% vs 7.5%; $P < 0.05$ for each comparison). For patients who did not experience symptoms, most diagnoses were made from US, CT scan, or MRI for an unrelated reason (35.5%).

When symptoms were present, the first doctor most commonly seen was a family practice or general physician (60.9%), emergency room physician (15.6%), internist (10.1%), or gastroenterologist (7.7%). The reported average time duration from symptom onset to diagnosis was 2.4 months, and only 36.3% of patients were diagnosed within 1 month of symptom onset. According to the survey respondents, patients for whom a diagnosis was made < 1 month after symptom onset were more likely to have seen an emergency room physician first (22.6%) than those whose diagnosis occurred 1–2 months (11.9%; $P < 0.05$) or ≥ 3 months (11.2%; $P < 0.05$) from symptom onset.

Respondents most commonly reported that the doctor who made the diagnosis was a gastroenterologist, a medical oncologist, a family practice or general physician, or an oncologic surgeon (Fig. 1). However, these trends were somewhat different for metastatic and nonmetastatic disease: gastroenterologists made the

Table 1
Respondents.

Characteristic	Patients	Caregivers	All
n	184	213	397
Patient had metastatic disease, n (%)	81 (44)	145 (68)	226 (57)
Average age, years	55.1	46.8	50.6
Sex, n (%)			
Female	127 (69)	190 (89)	317 (80)
Male	57 (31)	23 (11)	80 (20)
Race, n (%)			
White/Caucasian	170 (92)	186 (87)	356 (90)
Hispanic/Latin American	2 (1)	12 (6)	14 (4)
African American/black Caribbean	3 (2)	7 (3)	10 (3)
Indian (Indian subcontinent)	2 (1)	0	2 (<1)
Asian Pacific Islander	4 (2)	1 (<1)	5 (1)
American Indian/Alaskan native	0	2 (<1)	2 (<1)
Other	1 (<1)	3 (1)	4 (1)
Prefer not to answer	2 (1)	2 (<1)	4 (1)

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