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The Physical Health of Patients with Advanced Pancreatic Cancer and the Psychological Health of their Family Caregivers When Newly Enrolled in Hospice

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Introduction

In the United States, there are approximately 50,000 new cases of pancreatic cancer annually.¹ Pancreatic cancer involves the head or body of the pancreas² and is the fourth leading cause of death in the US.³ With virtually no early detection methods and limited treatment options, pancreatic cancer often is not diagnosed until the advanced stage of disease at which time the life expectancy is 12 to 18 months.⁴ In contrast to patients with most other cancers, patients with pancreatic cancer have a high symptom burden including intractable pain, wasting, jaundice, difficulty eating, septic episodes, and numerous treatment-related side effects.⁵ The role of the family caregiver begins immediately at diagnosis and continues over the illness trajectory,⁶ with a need for information about the patient's disease and treatment options⁷ that varies at the different stages of the patient's illness.

A family caregiver is defined as any relative, partner, friend, or neighbor who has a significant personal relationship with, and provides a broad range of assistance for an individual with an acute, chronic or disabling condition,⁸ including physical care, practical assistance, and emotional support, often in the forms of nutrition, spiritual support, symptom management, housekeeping, and transportation.^{7,6} Approximately, 74% of caregivers live with their loved one or within twenty minutes from their homes and provide an average of 20 hours of care per week.⁹ Overall, an estimated 65.7 million people in the U.S. have served as family caregivers,⁹ providing extraordinary uncompensated care that is often coupled with other job or family responsibilities.

Higher levels of physical strain, emotional stress, and financial hardship have been reported in caregivers of cancer patients as compared to caregivers of elderly or diabetic patients.¹⁰ Cancer caregivers are distressed by various acute medical conditions experienced by the patient, such as surgery, chemotherapy, or radiation therapy (e.g., catheter care, or managing

patients' emesis or fatigue symptoms). In advanced pancreatic cancer, there is a compressed time frame during which family caregivers manage incredibly ill patients while simultaneously experiencing the full range of caregiving emotions and stressors.^{11, 12, 13}

Caregivers often suffer from symptoms of anger, depression, and anxiety and may become demoralized and exhausted.¹⁴ The postings of family caregivers on Johns Hopkins' pancreatic cancer website were analyzed and indicated that caregivers are quickly overwhelmed by grim statistics and discouraging information about the disease and its prognosis.¹¹ First degree relatives of patients with pancreatic cancer are distressed and struggle with establishing an early diagnosis, the rapid illness trajectory, few treatment options, and balancing their own strong feelings with patients' needs. Further, stress occurs due to competing demands, unfamiliar physical care demands, disruption of daily activities, and the management of intense physical and emotional symptoms.¹²

Patient well-being is also closely linked with caregiver well-being,^{15, 16} particularly as patient performance status and quality of life decline over time,¹⁷ and caregiver distress limits optimal care.¹⁸ For family caregivers, the cumulative effects of physical, emotional, social, and economic stress, often results in their own physical illness, exacerbation of co-morbid conditions, and a greater risk of their own mortality.⁸ The stress only increases as patients get closer to death. The caregiver and extended family are aware of the poor prognosis with this disease and that death of the patient often occurs fairly quickly with relatively little time to prepare.¹³ Despite numerous studies of caregivers and caregiving in general and within the context of cancer,^{19, 20, 21, 22, 23, 24} few investigators have studied the caregiving experience of patients with pancreatic cancer. The purpose of this study was to describe patients' most commonly occurring symptoms and level of associated patient distress, as well as the perceived social support, perceived health, and depressive symptoms of caregivers of hospice patients with advanced pancreatic cancer.

Methods

Sample

The sample consisted of 64 patients with advanced pancreatic cancer who were newly enrolled in one of two large not-for-profit hospice programs, and their primary family caregiver. This sample was accrued as part of a large clinical trial funded by NIH (5R01 NR008252). The study was approved by the Internal Review Board of the University and affiliated Medical Center. Study inclusion criteria were patients who were adults, alert and oriented, able to self-report, able to read and understand English, and had a diagnosis of advanced pancreatic cancer and related symptoms, while family caregivers were included if they were adults, able to read and understand English, were identified as the primary family caregiver, provided at least four hours of care each day, and had no cancer diagnosis themselves. Patients were excluded if they were confused, disoriented, or actively dying. Demographic data collected from patients included gender, age, ethnicity and marital status, while demographic data collected from family caregivers included gender, age, ethnicity, marital status, education level, and relationship to the patient.

Instruments - Patients

Memorial Symptom Assessment Scale—The Memorial Symptom Assessment Scale (MSAS),²⁵ a well-known and commonly used scale, was used to assess occurrence and distress caused by symptoms. The MSAS is a patient self-report scale that assesses a diverse group of symptoms common to persons with cancer. This scale provided data about occurrence of each symptom and distress associated with these symptoms. First patients endorsed the symptoms that they were experiencing from a list provided. Distress from the endorsed symptoms was measured on a 5 point summated rating scale with scores that could range from 0 (no distress) to 4 (very much distress). Validity was supported by high correlations with clinical status and quality of life. Alpha reliabilities were high (0.83-0.88).

Instruments: Caregivers

Perceived Social Support—Social support or perceptions of help received from others, was assessed using a 3-item measure from the work of Krause and Borawski-Clark.²⁶ This self-report summated rating scale has total scale scores ranging from 3 (lowest support) to 12 (highest support).²⁷ Received support scales include tangible support, such as help with transportation, emotional support, such as having others listen and show interest, and informational support, such as sharing suggestions and information. Haley and colleagues²⁸ found that several of these dimensions of social support predicted caregiver depression and life satisfaction in a hospice caregiving sample. In particular, caregivers with more social support and lower negative social interactions had lower depression and higher life satisfaction, even after controlling for patient impairment and caregiver appraisal variables in regression analyses. These results support the validity of the scale.

Self-rated Health Perceptions and Physical Functional Health—Two subscales from the Medical Outcomes Study (MOS) Short Form Health Survey (SF-12)²⁹ were used to assess caregivers' self-reported health. The MOS health measures have been widely used in health services research, including a study of the effects of HMOs on older adults,³⁰ and in a study of hospice caregiving (Haley et al., 2001). The Health Perceptions Scale (5 items) includes items assessing overall self-rated health and comparison of health to others. Self-rated health perceptions have been found to be valid indicators of physical health and important predictors of mortality in older adults. The Physical Functioning Scale (6 items) includes such items as ability to climb stairs or carry groceries. Haley and colleagues²⁸ found that, in a hospice sample, the Health Perceptions Scale was lower in spousal caregivers of dementia patients and spousal caregivers of lung cancer patients than in non-caregiving controls supporting the validity of its use with caregivers. The scales have extensive normative information, but no clinical cut points have been identified (Haley et al., 2001). Total scores can range between 12 (best) and 57 (worst).

Center for Epidemiologic Study-Depression (CES-D): The CES-D Short Form was used to assess depressive symptoms in family caregivers. The CES-D³¹ is a widely used scale that has proven useful both as a screening instrument to detect individuals at risk for depression, and to measure the *symptoms* of depression. The CES-D is widely used in research on depression, has been translated into multiple languages, and has impressive reliability, validity, sensitivity, and specificity.³² The full 20-item CES-D has been widely

used, but a shorter version has been validated for use in clinical settings and large scale survey research projects. The 10-item version of the CES-D (sometimes referred to as the “Boston short form”) has been developed to balance ease of administration and psychometric concerns. Items are scored as either present or absent, rather than rated for frequency as with the full CES-D. Irwin et al.³³ assessed psychometric characteristics of this short form CES-D. Results showed that Cronbach alpha was .92 for this short form, and test-retest reliability was .83. These indicate excellent reliability. Correlation of the short form and full CES-D was .88, suggesting that the short form is highly correlated with the lengthier and more widely validated full version. It was also determined that, using a cutoff of greater than or equal to 4 on the scale, sensitivity, specificity, and positive predictive value of the scale were 97%, 84%, and 85% respectively when compared with clinical diagnosis of depression, which indicates excellent validity for the scale.

Procedures and Data Analysis

Baseline data were used from the large NIH Clinical Trial (5R01 NR008252) with only advanced pancreatic patients included. Data were cleaned and then analyzed using the Statistical Package for the Social Sciences (SPSS) to determine means, standard deviations, frequencies, and percentages to describe the sample and report patient and caregiver issues.

Results

Sample

The sample included 64 patients with advanced pancreatic cancer who were newly admitted to home hospice care and their primary family caregivers. The mean age of patients was 72.8 years, with the number of patients nearly equally divided between males (48.4%) and females (51.6%); the majority were married (65.6%) and White (98.4%) (Table 1). The mean age for family caregivers was 68.4 years, with caregivers primarily women (68.7%), married (79.7%), White (96.9%), and the majority (70.3%) were spouses or significant others of the patient (Table 1).

Patient Scores

The symptoms reported by 50% or more of the patients with advanced pancreatic cancer were fatigue, lack of appetite, dry mouth, pain, feeling drowsy and feeling sad (Table 2). Of those symptoms, the ones causing the patients the most distress were fatigue (mean = 3.0), pain (mean = 2.6) and having no appetite (mean = 2.4).

Caregiver Scores

In measuring perceived social support, caregivers were most satisfied with emotional support but all three scores (tangible, emotional and informational support) were clustered together (mean range 3.5-3.8). As measured by the SF-12 Scale, caregivers' total mean score for perceived health was 17 (range 12 to 57). On the item from the SF-12 asking about general health, caregivers, on average, reported perceived health as fair to good (mean = 3.4), with other indicators of their perceived health being generally better (mean = 0.2-2.9) (Table 3). Caregivers' mean score on depressive symptoms, as measured by the CES-D, was low (2.8) with 32% of caregivers scoring 4 or higher.

Discussion

An important role of family caregivers is to provide practical, emotional, social, and spiritual support, as well physical care and the management of symptoms.⁸ In this study, the most common symptoms experienced by patients with advanced pancreatic cancer were fatigue, lack of appetite, dry mouth, pain, feeling drowsy, and feeling sad. That fatigue is most common is not surprising; this symptom is one of the most prevalent symptoms for all types of cancers.^{34, 35, 36, 37} Lack of appetite also is to be expected in patients with advanced cancers that affect digestive organs. Dry mouth has not been studied often, but has been reported in other cancer symptoms studies among the more common symptoms.³³ The fact that pain was fourth, affecting 72% of patients was unexpected. Patients with pancreatic cancer are known to have intractable pain,⁵ and patients in this sample were in the advanced stage of the disease; thus, they would be expected to have severe pain. It is unclear why 28% of these patients denied pain. It is possible that the pain management regimen that they were receiving was relieving their pain, so they reported no pain. However, it should be noted that in earlier studies of hospice patients with a variety of advanced cancers, as many as 20% of patients denied pain when asked how severe their pain was *at its worst*.³⁸

With regards to patient symptom distress, unlike symptom intensity, distress is believed to be related, at least in part to the meaning the patient attributes to the symptom, and this can contribute to the suffering the patient experiences as a result of the symptom.³⁹ Not only was fatigue the most commonly occurring symptom in this group of patients, it also was reported to cause the greatest symptom distress (mean = 3.0). It is an unexpected finding that in a sample where 72% have pain, that fatigue was more distressing than the pain which ranked second. However, this is consistent with earlier studies³⁴ of patients with a variety of cancers. Perhaps the patients are distressed that they feel weak and unable to participate in work, chores, and social activities because of their fatigue. It is also not surprising that patients with advanced cancer who report pain, also identify pain as a very distressing symptom that warrants a complete pain assessment and adequate pain management.^{40, 41}

Third among the distress items was having no appetite. This might have been related to the fact that these patients had already lost so many of their enjoyable activities that losing the opportunity to share meals with loved ones just seemed very distressing. It should be noted that symptom distress is believed to be related to meaning of symptoms,²⁴ and when patients are not able to eat, they may interpret this to mean that the cancer is worse and death is nearer. Distressing symptoms experienced of patients was a significant stressor for family caregivers in a recent qualitative study of pancreatic patients and caregivers.¹³ Although caregivers realized on an intellectual level, that when people are ill they have limited desire to eat, on an emotional level there is the belief that food equals love and was a caregiver's need to "will them into wellness."¹³ Caregivers often expressed guilt about "insisting" that the patient eat, but nurses can explore the caregiver's beliefs around nutrition and hydration and help them to realize that eating and drinking may increase suffering rather than relieve it. As meals are associated with connection, communication and family rituals, nurses can explore meaningful and practical ways to recognize that despite anorexia, being together and sharing even one desired food can be a time of enjoyment rather than becoming a power struggle around eating. Caregivers also expressed distress when the symptom of fatigue

slowed the patient down in performing activities of daily living or resulted in their lack of ability to participate in family events. Nurses and nursing assistants can help family caregivers to identify the time of day when the patient has the greatest level of energy and plan interactions or family visits during this time-frame. Meaningful activities can also be spaced within a day or a week to allow periods of rest. In addition, physical pain was also very distressing, not only for the patient but for the caregiver, who was often unsure how to relieve their loved one's pain. As patients are newly enrolled in hospice, there is an opportunity for all members of the interdisciplinary team to relieve the physical, emotional, and spiritual pain associated with advanced disease. Comprehensive assessments can identify the multidimensional aspects of pain and its associated symptoms. All team members have the ability to identify pain and symptoms, and to develop interdisciplinary plans of care to effectively manage the symptoms through pharmacological, non-pharmacological, and complementary therapies. For example, pain may be relieved by medications prescribed and administered by physicians and nurses, or by energy work such as healing touch therapy. Pain may also be relieved by the reduction of fear and anxiety through the emotional support offered by social workers, chaplains, music therapists, or volunteers. Given the reciprocal suffering of patients and their family caregivers, relief of patient's suffering provides need support and relief for their family caregivers.

The value of support of patients and family newly enrolled in hospice is reflected in the results of this study. Although family caregivers in this sample were caring for patients with advanced pancreatic cancer who had multiple distressing symptoms, and in spite of that, and their average age (68.4 years), family caregivers reported strong perceived social support, very good self-perceived health, and low levels of depressive symptoms. This finding is not consistent with the literature which indicates that finding help can be a difficult task as there may be lack of contribution and cooperation by other family members, leading to exacerbation of family resentments and conflicts.^{42, 8, 9} The fact that caregivers in this sample did not feel that their personal resources were exhausted when these data were collected may be related to several things. First, because pancreatic cancers often cause death fairly quickly compared to some other cancers, respondents might have been caregivers for a relatively short time. Second, because all of these caregivers were providing care as part of the hospice interdisciplinary team, they might have felt more supported than caregivers in other settings. Finally, the admission to the hospice was new for these caregivers, and during the admission period, hospice workers are more frequently in the home, sometime multiple times a day, while needs are assessed and the plan of care is being developed. This might have provided much needed reassurance to caregivers. However, outside of hospice settings, few health care organizations have any focus beyond the patients, leaving caregivers to cope on their own.

Conclusion and Implications

Advanced pancreatic cancer is a fatal disease with significant symptoms and associated distress for patients, as well as for their family caregivers within the context of an acute care setting.¹³ The results of this study of patients with advanced pancreatic cancer indicate that fatigue, lack of appetite, dry mouth, and pain continue to be high incidence symptoms across the illness trajectory to the end of life. With the recognition of a limited life expectancy, yet

hope for aggressive pain and symptom management and holistic care, the patients in this study decided to enroll in hospice. The distress associated with fatigue, pain, and lack of appetite requires the expertise of interprofessional teams, who can address the physical, emotional, social, and spiritual needs of patients, helping them to make meaning to their illness, and promoting the best quality of life possible even as death approaches. Further research regarding the effectiveness of hospice care on the assessment and management of intractable symptoms experienced by patients with advanced pancreatic cancer is important, and has implications, not only for the relief of suffering and quality hospice care, but for palliative care, which may offered “upstream” in the illness trajectory within the acute care or community settings or which may be continued to the end of life when patients decline hospice enrollment. Understanding the experience of this patient population with an aggressive solid tumor, such as pancreatic cancer, also has implications for other advanced solid tumors with similar cancer trajectories, such as colorectal, esophageal, non-small cell lung, glioblastoma, advanced melanoma, and advanced bladder and renal cell.⁴³

Given that palliative care and hospice care focus not only on the needs of patients, but their family caregivers, as the unit of care,⁴⁴ this study considered the psychological health of family caregivers of patients with advanced pancreatic cancer who were newly enrolled in hospice. This is an understudied family caregiver population. When examined in acute care settings, these family caregivers reported a very compressed illness trajectory during which time they struggled with the full range of caregiver emotions and stressors. They expressed true appreciation that research was being conducted which focused on their experience and needs as family caregivers.^{12, 13} Upon admission to hospice, further research would be of value to explore whether caregivers experience and perception of social support, and the validation of their roles as family caregivers, are related to caregiver's perceived health and low depressive symptoms. Even though caregivers may continue in home hospice as primary family caregivers, there is an entire team of professionals to manage symptoms and provide emotional, practical, and spiritual support to both patients and their caregivers. Often, particularly in the acute care or community settings, family caregivers are perceived to be members of the health care team, rather than a person, who is themselves “at risk” and “vulnerable” within the context of an advanced illness experience.

Family caregivers have a right to their own support and assessment of their needs, with their experience evaluated “not as a proxy response for patients but as an outcome itself.”⁴⁵ Often, health professionals do not intervene in ways that take caregiver well-being into account, and resources are limited, fragmented, and discontinuous.²² Health risks and serious illness of caregivers may increase their utilization of health care resources, contribute to escalating health care costs, and place caregivers at greater risk for life-threatening illness.⁸

Hermanns and Mastel-Smith⁴⁶ describe the caregiving experience and suggest that an individualized approach is needed to insure optimal health outcomes for not only patients with advanced illness but their family caregivers. Quality palliative and hospice can make a significant difference in the lives of patients with advanced pancreatic cancer and their family caregivers. It is important that healthcare professionals in all settings recognize and

address the physical, emotional, social, and spiritual needs and transitions experienced by caregivers as patients move into the end of life and caregivers move into bereavement.^{21, 47}

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Table 1
Frequencies and Percentages of Demographic Variables of Patients with Advanced
Pancreatic Cancer (N = 64) and Their Caregivers (N = 64)

Variable	Frequency	Percent
<i>Patient Gender</i>		
Males	31	48.4
Females	33	51.6
<i>Patient Marital Status</i>		
Married	42	65.6
Not married*	22	34.4
<i>Patient Race/Ethnicity</i>		
White, non-Hispanic	63	98.4
Black non-Hispanic	1	1.6
<i>Caregiver Gender</i>		
Female	44	68.7
Male	20	31.3
<i>Caregiver Ethnicity</i>		
White, non-Hispanic	62	96.9
Black, non-Hispanic	1	1.6
Hispanic	1	1.6
<i>Caregiver Marital Status</i>		
Married	51	79.7
Not married*	13	20.3
<i>Caregiver Relationship to patient</i>		
Spouse/significant other	45	70.3
Mother/father/daughter/son/sister	10	15.7
Other/friend	9	14.1

* Not married includes divorced, widowed, never married

Table 2
Symptoms Reported by Patients with Advanced Pancreatic Cancer with Mean Distress Scores (N = 64)

Symptom	SYMPTOM OCCURRENCE		SYMPTOM DISTRESS	
	Frequency	Percent	Mean	SD
Fatigue	53	83	3.0	1.2
No appetite	48	75	2.4	1.3
Dry mouth	47	73	1.9	1.4
Pain	46	72	2.6	1.1
Feeling Drowsy	44	69	1.5	1.3
Feeling sad	32	50	2.3	1.2

Table 3
Means and Standard Deviations (SD) of Family Caregivers on Perceived Social Support, Perceived Health, and Depression (N = 64)

Variable	Mean	SD
<i>Perceived Social Support</i>		
Satisfied with tangible support	3.5	0.9
Satisfied with emotional support	3.8	0.4
Satisfied with informational support	3.6	0.6
<i>Perceived Health (SF-12)</i>		
General Health	3.4	1.0
Feel calm and peaceful	2.9	1.2
Do not feel full of energy	2.8	1.3
Feel downhearted and blue	1.8	1.2
Health limits climbing stairs	1.5	0.8
Health limits moderate Activities	1.5	0.7
Pain interferes with activities	0.8	1.1
Physical or Emotional health interfered with social activities	1.2	1.3
Limited Activities due to Physical problems	0.3	0.5
Accomplishing less due to <i>physical</i> problems	0.3	0.5
Accomplished less due to <i>emotional</i> problems	0.4	0.5
Health caused you to do work less carefully	0.2	0.4
<i>Depressive Symptoms (CES-D)</i>	2.8	1.9
TOTAL	17.0	3.1