

# Pilot study of an interdisciplinary supportive care planning intervention in pancreatic cancer

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## Abstract

**Purpose** A diagnosis of pancreatic cancer is often associated with higher symptom burden, lower functional status, and worse quality of life (QOL). To date, few interventions have focused on the unique QOL needs of patients with pancreatic cancer. The purpose of this pilot study is to determine the feasibility of an interdisciplinary supportive care planning intervention in patients with pancreatic cancer during disease-focused treatments.

**Methods** Patients enrolled in this prospective, pre- and post-intervention pilot study received a supportive care intervention that included the following three components: comprehensive QOL assessment, case presentation at interdisciplinary care meetings, and two nurse-administered educational sessions on QOL concerns. Patients completed outcome measures that included the FACT-Hep, FACIT-Sp-12, and self-report of finances and out-of-pocket costs since diagnosis. Measures were completed at baseline prior to receiving the intervention, and follow-up occurred at 1 and 2 months post-intervention.

**Results** A total of 10 patients were enrolled during a 4-month period who provided informed consent, received the intervention, and completed the study (58 % accrual). Examination of pre- and post-intervention QOL outcomes revealed changes across the three evaluation time points that were not statistically significant. Patients were highly satisfied with the intervention, with 80 % reporting that the intervention was “excellent.” Discussions during the interdisciplinary care meetings and educational sessions were largely focused on physical and psychosocial needs.

**Conclusions** An interdisciplinary supportive care planning intervention was potentially feasible and acceptable for pancreatic cancer patients in an ambulatory care setting.

**Keywords** Pancreatic cancer · Quality of life · Supportive care · Symptoms

## Introduction

In the USA, pancreatic cancer will affect an estimated 53,000 individuals in 2016 [1]. While improvements in cancer treatments overall have been made over the past decades, mortality rates remain relatively constant for pancreatic cancer, and it remains the fourth leading cause of cancer death [1]. While incidence rates declined for many cancers, the incidence rate for pancreatic cancer increased between 1999 and 2008 [2]. Pancreatic cancer patients are burdened with a significant number of debilitating symptoms as a direct or indirect result of disease, treatments, and co-morbidities. Incidence of specific symptoms such as pain and depression is higher with pancreatic cancer [3–5]. In addition, psychological distress is also found to be higher in pancreatic cancer patients when compared with other malignancies [6–8]. Long-term post-operative morbidity such as pancreatic exocrine and endocrine

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insufficiency can have a major impact on overall quality of life (QOL) [9–12]. Multimodality treatments with the addition of pre- and post-operative radiotherapy and/or chemotherapy often contribute to worsening of treatment-related toxicities [13]. Hence, maintaining pancreatic cancer patients on standard multimodality and disease-focused treatments is often challenging, and this potentially limits the benefits that patients can derive from their cancer treatments.

Pancreatic cancer patients are particularly vulnerable and have many unique QOL needs while receiving disease-focused treatments. In a sample of 16,095 cancer survivors, surveillance of QOL revealed that pancreatic cancer survivors reported the worst scores for physical and psychological well-being compared to survivors of other malignancies and individuals without cancer [14]. An interdisciplinary approach to symptom management and psychosocial support is of primary importance for maintaining the QOL of pancreatic cancer patients. This approach has the potential to optimize the utilization of existing supportive care services for the delivery of quality management of symptoms and psychosocial needs. Furthermore, interventions that are tailored to the needs of each individual patient can aid in recognizing and fulfilling personal goals and maintaining QOL. Despite widespread efforts in other cancer populations, few interventions are designed to address the specific QOL needs of pancreatic cancer patients. The purpose of this prospective, pre- and post-intervention pilot study was to assess the feasibility of an interdisciplinary supportive care planning intervention for patients with pancreatic cancer for application in a future larger scale multisite study.

## Methods

### Study and intervention design

The design of the intervention was based on a previous National Cancer Institute (NCI)-funded Program Project grant, which tested the efficacy of interdisciplinary care coordination and patient education in lung cancer [15]. The intervention consisted of two key components. The first component included a nurse-completed comprehensive QOL assessment organized in physical, psychological, social, and spiritual well-being domains. The QOL assessment was derived from the baseline patient-reported outcome measures, and the nurse completed a care plan to summarize findings from the assessment. Guided by the care plan, the nurse presented each patient during bi-weekly interdisciplinary team meetings, which was attended by oncologists, representatives from supportive care services (pain specialists, palliative medicine, social work, chaplaincy, rehabilitation, and nutrition), and the research team. Following the presentation of each case, the interdisciplinary care team made care coordination and

recommendations tailored to each patient's needs, and referrals to supportive care services were initiated as indicated. To reduce burden, providers were invited to attend the interdisciplinary care meetings in person or via telephone conference call lines.

The second component of the intervention involved educating patients on QOL concerns and included two nurse-administered education sessions. Content for the patient education sessions was also organized around the four QOL domains and consisted of common disease- and treatment-related concerns for pancreatic cancer patients (Table 1). The first session focused on physical and emotional well-being and the second on social and spiritual well-being. Patients received a manual that contained written information on all content. Content delivery was tailored to each patient's individual needs and priorities. At the beginning of each session, patients were presented with a list of the education content and asked to identify three priority topics for discussion, which ones if any should be omitted, and in what order the three chosen topics should be covered. To reduce potential patient burden for participation, we allowed for flexibility in the method of session administration as chosen by patients based on their preferences and availability, which included face-to-face sessions or phone sessions.

### Sample and setting

Patients with confirmed diagnosis of pancreatic cancer, who were English-speaking and within 6 months of initial diagnosis, were eligible for participation in the study. We included patients regardless of disease stage or resectability in order to determine feasibility of the intervention across the cancer

**Table 1** Patient education session content

Session 1: physical and emotional well-being	
	Pain/neuropathy
	Constipation/diarrhea
	Fatigue
	Appetite and weight loss
	Nausea/vomiting
	Sleep disturbance
	Anxiety and depression
Session 2: social and spiritual well-being	
	Family needs
	Communication
	Sexuality
	Social support
	Advanced healthcare planning
	Financial burden
	Meaning of illness
	Religious/spiritual support

continuum trajectory. Eligible patients were recruited from the medical and surgical oncology ambulatory clinics of one NCI-designated Comprehensive Cancer Center located in Southern California. Study procedures and protocol were approved by the institutional review board. All participating patients provided voluntary informed consent prior to enrollment.

### Study procedures

Patients completed baseline evaluation using self-reported outcome measures following informed consent. A comprehensive QOL assessment using baseline data was undertaken for each patient, and each case was presented to the interdisciplinary team during bi-weekly team meetings. Patients received education on common physical, emotional, social, and spiritual well-being concerns. Post-intervention outcome evaluations were repeated at 1 and 2 months following study enrollment. Collectively, the time taken to complete all patient-reported outcome measures ranged from 40 to 45 min.

### Patient-reported outcome measures

The *Functional Assessment of Cancer Therapy-Hepatobiliary* (FACT-Hep) was used to assess QOL and symptoms. The FACT-Hep is a 45-item measure with items rated on 5-point Likert scale, where higher scores reflect better QOL and fewer symptoms. Items are divided into the physical, social/family, emotional, and functional well-being domains, with an additional subscale that assesses disease-specific symptoms. Reliability coefficients of 0.72 to 0.94 have been reported [16]. Retest reliability ranged from 0.81 to 0.79 [17–19]. Spiritual well-being was assessed using the *Functional Assessment of Chronic Illness Therapy-Spirituality* (FACIT-Sp-12). The FACIT-Sp-12 assesses sense of meaning, peace, and faith in illness. Data from a validation study demonstrates good internal consistency, reliability, and a significant relation with QOL of cancer patients [20, 21]. Healthcare utilization was assessed through patient self-report of use of cancer-related services, hospital admission, and outpatient visits outside of the cancer center setting [22]. Financial burden and out-of-pocket costs were assessed through self-report of patients' finances since diagnosis and out-of-pocket medical costs. Patients also completed a survey on satisfaction with the intervention at completion of the study. In addition, we obtained basic patient sociodemographic characteristics at baseline and clinical/disease characteristics (disease stage, time since diagnosis, treatments received) through electronic medical record (EMR) audits following completion of the study.

**Table 2** Sociodemographic, clinical, and health status characteristics (N = 10)

	Number	Percent
Gender		
Male	5	50
Female	5	50
Age		
Median (range)	65.8 (48–80)	
Race/ethnicity		
Hispanic/Latino	5	50
White	4	40
Asian	1	10
Education		
Less than high school	1	10
High school/vocational school	3	30
College	4	40
Graduate/professional school	2	20
Marital status		
Married	7	70
Widowed	2	20
Divorced	1	10
Annual household income		
15,000 to 30,000	4	40
30,001 to 50,000	1	10
50,001 to 75,000	3	30
Greater than 75,000	2	20
Employment status		
Full time	2	20
Part time	2	20
Retired	4	40
Medical leave	2	20
Co-morbidities <sup>a</sup>		
Cardiovascular	5	50
Arthritis	2	20
Respiratory	1	10
Endocrine/diabetes	1	10
None	2	20
Disease stage		
III	4	40
IV	6	60
Time since diagnosis		
<3 months	9	90
3–6 months	1	10
Treatments received <sup>b</sup>		
Surgery	3	30
Chemotherapy	9	90
Radiation	1	10
Social support (range = 0–100; higher score = more support)		
Median	75.0	
Instrumental activities of daily living (IADLs)		
Frequency and percentage with at least one impairment		

**Table 2** (continued)

	Number	Percent
Baseline (pre-intervention)	9	90
1 month (post-intervention)	7	70
2 months (post-intervention)	9	90

<sup>a</sup> Subjects can select more than one answer

<sup>b</sup> Subjects may have received multimodality treatment

### Statistical analysis

Data from Cardiff teleforms were scanned into a relational database and audited for accuracy prior to analysis. Descriptive statistics were used to summarize patient demographics, clinical information, delivery of interventions, patient-reported outcomes, and data abstracted from patient medical charts. Data was summarized using means for normally distributed continuous data, medians for non-normally distributed continuous data, and proportions and percentages for categorical data. Established instruments were scored according to standard instructions, and appropriate descriptive statistics were computed. The Kruskal-Wallis test was used to test differences in scores at the three different time points (baseline, month 1, and month 2).

### Results

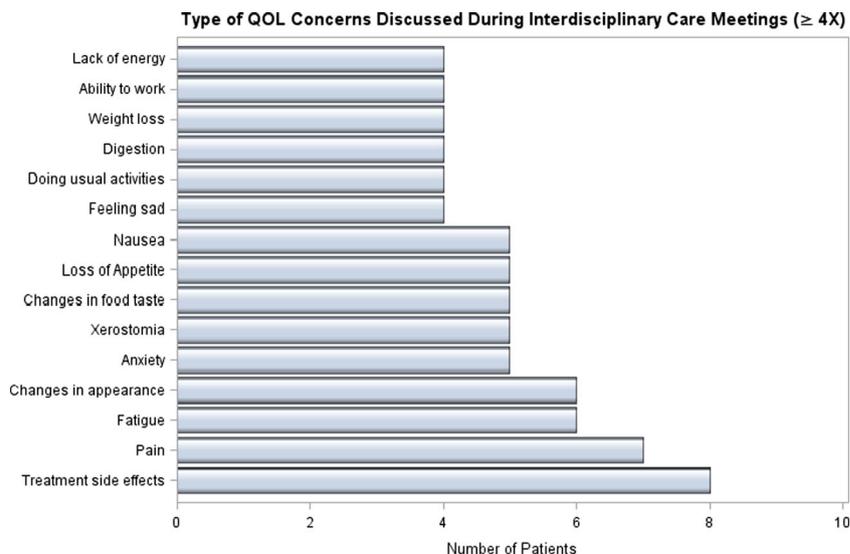
A total of 19 eligible patients were invited to participate in the study over a 4-month period (approximately 4–5 per month). Of this total, 11 patients agreed to participate and provided written informed consent, representing approximately 58 % of all eligible patients over 4 months. The most common reason for declining participation was patient self-report of being too

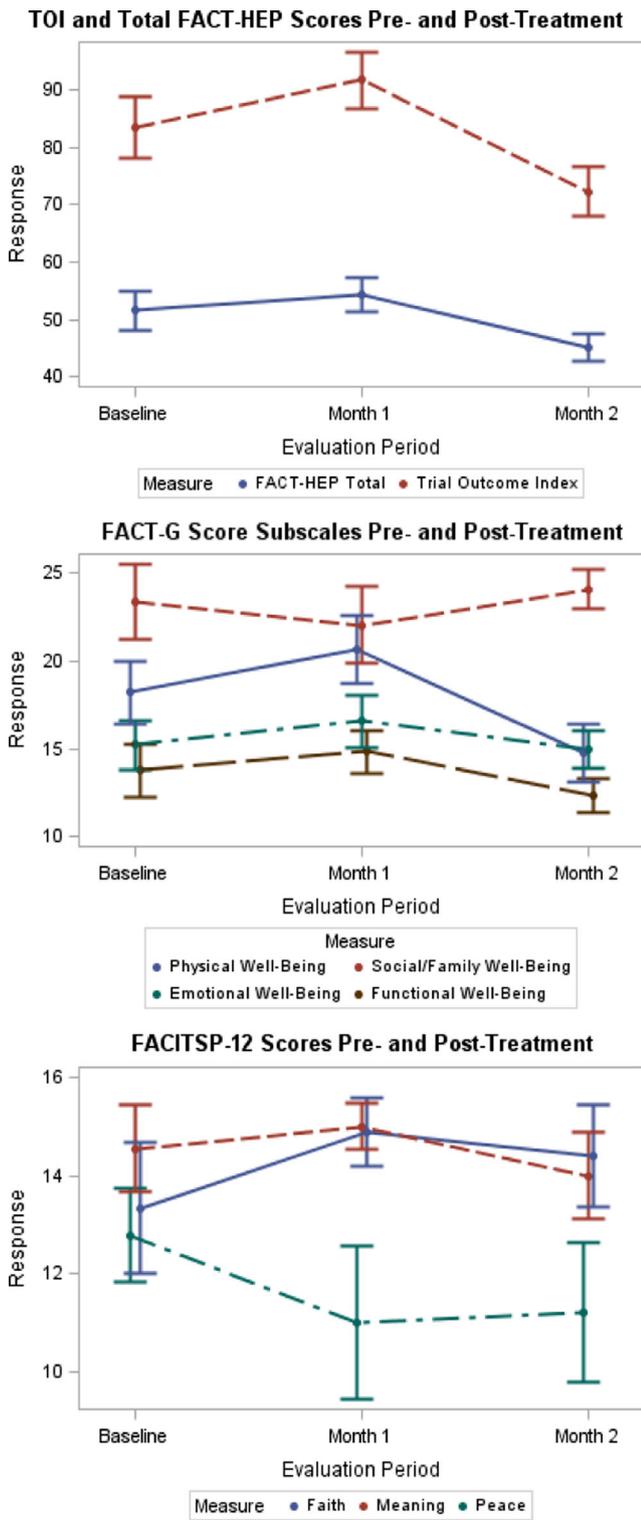
ill (78 %) and being too overwhelmed (22 %). One consented patient voluntarily discontinued study participation due to disease progression. We were able to retain the remaining 10 patients at both 1 and 2 months following enrollment. Patients' mean age was 65, and more than half were ethnic minorities (60 %) and were married (70 %). The majority of patients were diagnosed with stage IV disease (60 %), were within 3 months since initial diagnosis (90 %), and were treated with chemotherapy (90 %) and surgery (30 %). Overall, patients reported high levels of social support, but all patients reported at least one functional impairment for instrumental activities of daily living (IADLs) at all three evaluation time points (Table 2).

Data from the care plans were qualitatively analyzed to describe key elements of QOL that were discussed during the interdisciplinary care meetings (Fig. 1). Physical and psychosocial concerns were common, with pain, fatigue, and overall treatment side effects being the most frequently discussed during the interdisciplinary care meetings. Common psychosocial concerns included anxiety, changes in appearance, feeling sad, and the ability to work and undertake usual activities. For patient education sessions, the mean length of time for the physical/psychological well-being session was 44.2 and 32.6 for the social/spiritual well-being session. Pain/neuropathy (40 %), constipation (20 %), and lack of appetite/weight loss (20 %) were the three most commonly selected topics for discussion during the physical/emotional well-being session. Social support (40 %), advance care planning (40 %), and family needs (20 %) were the most commonly selected topics for the social/spiritual well-being session.

Overall, we detected changes in QOL outcomes across the 2-month study time frame, but these differences were not statistically significant (Fig. 2, Table 3). For healthcare utilization, supportive care referrals to social work, pain/palliative care team, and nutrition were most common throughout the

**Fig. 1** Quality of life concerns discussed during interdisciplinary care meetings (four or more times)





**Fig. 2** Patient-reported outcomes: quality of life pre- and post-intervention—mean scores ± one standard error plotted within each measure. For all measures, higher scores indicate better quality of life

study (Table 4). Unscheduled outpatient encounters were at 30 %, and these encounters were for symptom management purposes. For financial concerns, 70 % of patients reported

**Table 3** Pre- and post-intervention scores for quality of life and symptoms<sup>a</sup>

	Mean (SD)	Median	<i>p</i> value <sup>b</sup>
Physical well-being subscale (range = 0–28)			
Baseline	18.2 (5.4)	20.0	0.09
Month 1	20.7 (5.1)	23.0	
Month 2	14.8 (5.3)	14.0	
Social/family well-being subscale (range = 0–28)			
Baseline	23.4 (6.4)	26.0	0.60
Month 1	22.1 (5.8)	22.0	
Month 2	24.1 (3.6)	24.2	
Emotional well-being subscale (range = 0–24)			
Baseline	15.2 (4.2)	16.0	0.40
Month 1	16.6 (3.9)	18.0	
Month 2	15.0 (3.3)	16.0	
Functional well-being subscale (range = 0–28)			
Baseline	13.8 (4.6)	14.0	0.30
Month 1	14.9 (3.2)	14.0	
Month 2	12.4 (3.1)	13.0	
Symptoms subscale (range = 0–72)			
Baseline	51.6 (10.1)	52.0	0.08
Month 1	54.3 (7.6)	54.0	
Month 2	45.1 (7.8)	44.5	
Total FACT-Hep (range = 0–180)			
Baseline	122.2 (21.2)	124.0	0.09
Month 1	130.2 (15.7)	133.5	
Month 2	111.4 (15.6)	107.8	
Faith subscale (range = 0–16)			
Baseline	13.3 (4.0)	16.0	0.70
Month 1	14.9 (2.1)	16.0	
Month 2	14.4 (3.2)	16.0	
Meaning subscale (range = 0–16)			
Baseline	14.6 (2.7)	16.0	0.70
Month 1	15.0 (1.4)	16.0	
Month 2	14.0 (2.8)	15.0	
Peace subscale (range = 0–16)			
Baseline	12.8 (2.9)	14.0	0.70
Month 1	11.0 (4.7)	12.0	
Month 2	11.2 (4.5)	12.5	
Total spiritual well-being (FACIT-Sp-12) (range = 0–48)			
Baseline	40.7 (9.1)	44.0	0.80
Month 1	40.9 (5.5)	39.0	
Month 2	39.6 (7.8)	43.5	

<sup>a</sup> For all scores, higher scores are representative of better quality of life

<sup>b</sup> *p* Values from Kruskal-Wallis test to detect differences over results from three time points

decreases in household income level since diagnosis, with out-of-pocket cost increases for doctor bills, medical supplies, prescription, and over-the-counter medications. Satisfaction with the intervention was high, with 70 % of patients rating the overall intervention as “excellent” and 30 % as “very good.” Eighty percent of patients thought the time spent for

**Table 4** System and process-related outcomes (*N* (%))

*Healthcare utilization—supportive care referrals	
Social work	6 (60)
Pain/palliative care services	3 (30)
Nutrition	3 (30)
Psychology/psychiatry	1 (10)
Child life specialist	1 (10)
Financial counselor	1 (10)
Unscheduled outpatient encounters	
Yes	3 (30)
Source of unscheduled encounters ( <i>N</i> = 3)	
Evaluation and Treatment Center (ETC)	2 (66.6)
Nursing Triage Call Center	1 (33.3)
Reason for unscheduled encounters ( <i>N</i> = 3)	
Symptom management	3 (100)
Finance and out-of-pocket costs <sup>a</sup>	
Has there been a decrease in your household income level since your diagnosis?	7 (70)
Since your diagnosis, have you or your family spent out-of-pocket costs on:	
Doctor bills	3 (30)
Medical supplies	3 (30)
Prescription medicine	8 (80)
Over the counter medicine	8 (80)
Since your diagnosis, have you had to do the following?	
File for unemployment	3 (30)
Makes changes to your lifestyle	3 (30)
Other sacrifices (i.e., vacations)	5 (50)
Use up your savings	3 (30)
Satisfaction with intervention	
Overall rating of intervention	
Very good	3 (30)
Excellent	7 (70)
Was the amount of information in the education manual:	
The right amount	3 (30)
Too much	7 (70)
Was the time spent in the education sessions:	
The right amount	8 (80)
Too long	2 (20)

<sup>a</sup> Patients who answered yes

the education sessions was the “right amount,” but 70 % thought written content in the educational manual was “too much.”

## Discussion

In this study, we aimed to pilot test an interdisciplinary supportive care planning intervention for pancreatic cancer patients that is delivered concurrently with disease-directed, multimodality therapies. We found that the intervention, which incorporated comprehensive QOL assessment, interdisciplinary care

planning, and patient education, had potential feasibility for this cancer population. Although enrollment was slightly over 50 % for available patients within the relatively short time frame of 4 months, we were able to retain 90 % of patients who provided informed consent through the 2-month study period. We were able to complete interdisciplinary care meetings for all patients within the 4-month enrollment time frame. Our previous experience of testing the same intervention in lung cancer patients was successful, with 272 patients enrolled and 139 interdisciplinary care meetings conducted over a 3-year intervention group enrollment period. In the lung cancer study, 90 % of the 272 patients enrolled completed all educational sessions [15].

We observed changes in QOL outcomes in patients over the 2-month study period, although these changes were not statistically significant. In our previous study in lung cancer, intervention group patients reported statistically significant improvements in overall QOL scores, QOL subscale scores (physical, emotional, functional well-being), and symptom scores at 3 months post-intervention, compared to the usual care group patients. Based on this previous experience, we anticipate that the same intervention administered in pancreatic cancer patients will have similar benefits and impact on QOL, physical well-being, and symptoms. A large, randomized trial would provide evidence on whether significant, clinically meaningful differences in QOL-related outcomes are associated with the intervention.

This pilot study has several important limitations that warrant further discussion. First, a major limitation of this pilot study is the small sample size, and this most likely contributed to our findings. In addition, we did not perform power calculations to statistically derive the sample size. Therefore, study findings should be interpreted with caution. The sample size was derived to be realistic and practical for the study time frame of 9 months, and our intent was to determine whether the three key components of the interdisciplinary care intervention can be feasibly administered with pancreatic cancer patients and providers during active treatment. Second, our sample population was relatively heterogeneous in the stage of disease and type of treatments received. We elected to include all patients regardless of the stage of disease or type of treatments based on our experience in the lung cancer study. In that study, we found that early-stage patients (stages I–III) derived more significant benefits from the intervention [15]. The standard for locally advanced/borderline resectable pancreatic cancer often involves the use of multimodality regimens, including chemotherapy, radiation, and surgery. This population is equally in need of supportive care and quality symptom management, as side effects from systemic treatments, localized treatments with radiation, and invasive surgical procedures can result in significant symptom burden.

Several important lessons should be noted from our pilot experience. First, although the majority of key care team members were able to attend the interdisciplinary care meetings, the generalizability of the in-person approach may be limiting, as not all providers were able to attend at all times. The in-person approach may be challenging to translate into routine, busy clinic settings for providers. To address this important issue, we made available the option for providers to dial in and participate via a conference call line. Other strategies to reduce provider burden may include the incorporation of mobile, smartphone, or tablet application-based technology to conduct care meetings. Second, although patients were overall satisfied with the intervention, they found that the written content in the educational manual was too much. Written content from the educational manual was delivered

in a tailored fashion as patients selected the topics discussed during the educational sessions, but all patients received the complete written manual. We attempted to decrease burden by condensing all written content for each topic to one page. Based on this finding, the amount of written content given to patients should also be tailored to their preference. Third, for successful study implementation, close collaborations with medical and surgical oncologists were helpful for accrual and retention purposes. This was true not only for enrollment purposes but also for participation at the interdisciplinary care meetings.

In conclusion, an interdisciplinary supportive care planning intervention to address QOL concerns was potentially feasible to implement in an ambulatory care setting and acceptable in patients with pancreatic cancer during concurrent, disease-focused treatments. Several key lessons were derived during study implementation, and they will aid with the further refinement and design of a future larger randomized trial to test the efficacy of the intervention to improve QOL in patients with pancreatic cancer. For trial design, we intend to consider the following: (1) addition of attention control condition to avoid attention bias in the experimental group, (2) inclusion of other options (conference call lines, smartphone applications) for clinicians to participate in the interdisciplinary team meetings, (3) personalization of both the content and written materials delivered during the education sessions, and (4) further refinement of the written materials to reduce information overload and patient burden.

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**Compliance with ethical standards** Study procedures and protocol were approved by the institutional review board. All participating patients provided voluntary informed consent prior to enrollment.

**Conflict of interest** The authors declare that they have no competing interests.

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