

A tsunami of unmet needs: pancreatic and ampullary cancer patients' supportive care needs and use of community and allied health services

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Abstract

Objective: People diagnosed with pancreatic cancer have the worst survival prognosis of any cancer. No previous research has documented the supportive care needs of this population. Our objective was to describe people's needs and use of support services and to examine whether these differed according to whether or not patients had undergone surgical resection.

Methods: Queensland pancreatic or ampullary cancer patients ($n = 136$, 54% of those eligible) completed a survey, which assessed 34 needs across five domains (Supportive Care Needs Survey-Short Form) and use of health services. Differences by resection were compared with Chi-squared tests.

Results: Overall, 96% of participants reported having some needs. More than half reported moderate-to-high unmet physical (54%) or psychological (52%) needs, whereas health system/information (32%), patient care (21%) and sexuality needs (16%) were described less frequently. The three most frequently reported moderate-to-high needs included 'not being able to do things they used to do' (41%), 'concerns about the worries of those close' (37%) and 'uncertainty about the future' (30%). Patients with non-resectable disease reported greater individual information needs, but their needs were otherwise similar to patients with resectable disease. Self-reported use of support was low; only 35% accessed information, 28%, 18% and 15% consulted a dietician, complementary medicine practitioner or mental health practitioner, respectively. Palliative care access was greater (59% vs 27%) among those with non-resectable disease.

Conclusion: Very high levels of needs were reported by people with pancreatic or ampullary cancer. Future work needs to elucidate why uptake of appropriate supportive care is low and which services are required.

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Introduction

Pancreatic cancer is the fifth leading cause of cancer death in more developed regions of the world [1]. People diagnosed with pancreatic cancer have the worst survival prognosis of any cancer; 1-year survival is 20% and 5-year survival is 6% [2]. Pancreatic and ampullary cancer have the same clinical presentation and are sometimes impossible to differentiate both clinically and on investigation. Ampullary cancers are treated similarly to pancreatic cancers, accounting for

16–50% of pancreaticoduodenectomies. The difficulty in differentiation and similarity in treatment means that they are often grouped [3]. From this point forward when referring to pancreatic cancer, this will include ampullary cancer.

The poor prognosis of pancreatic cancer is due to late presentation combined with aggressive tumour biology, complex surgery and no effective systemic treatments. The majority of patients (>60%) present with advanced disease and less than one quarter have tumours that are amenable to resection [4]. Patients who have curative

resection have low survival of 10–25% at 5 years [5]. Chemotherapy and radiotherapy options are available, but for most patients, the survival benefit is small, with 5-year survival of only 20–25% following radical resection and adjuvant therapy [6]. Therefore, a fundamental aspect of management for most patients will be supportive care and palliation of symptoms such as jaundice, cholangitis, diabetes, malabsorption, weight loss, nausea, vomiting, pain and depression [5].

Multimodality supportive management including medical, allied health and palliative interventions should be initiated early and aggressively for all patients with pancreatic cancer [7–9]. This should happen regardless of whether they are progressing along a palliative or curative pathway [10] to facilitate adjustment to diagnosis, prognosis and treatment [9]. However, among patients with pancreatic cancer, there is no quantitative research on the extent of supportive care needs or use of support services.

One qualitative study of 12 pancreatic cancer patients and 23 caregivers identified supportive care themes including management of gastrointestinal symptoms and complex dietary issues [11], with participants reporting insufficient information and dietician support. A case report highlighted the need for early referral to supportive/palliative care to achieve optimal symptom control [12].

With the dearth of information about specific issues affecting the population of people with pancreatic cancer and uptake of support services, we conducted a population-based study with the aim to determine the prevalence of unmet supportive care needs and whether these were different in those who did and did not have surgical resection. Resection was chosen for stratification as it is the only potentially curative treatment. We hypothesised that differences in needs could arise because of the difficult surgery with high comorbidity or because of psychological differences relating to having versus not having a curative procedure. We also quantified the types of support services and providers that patients were accessing.

Methods

Participants and procedures

Given the high early mortality associated with pancreatic cancer, the study used a rapid ascertainment approach, recruiting patients as early as possible through a statewide network of clinicians in hospitals and private practices, often when diagnostic investigations were ongoing. Patients aged 18 years or over with a suspected or confirmed diagnosis of primary pancreatic cancer between January 2007 and June 2011 were recruited for the Queensland Pancreatic Cancer Study (QPCS), a Queensland-wide, population-based case-control study [13]. Trained research nurses reviewed the medical records of all people recruited, and 704 (84%) had a confirmed diagnosis of pancreatic cancer.

A small number of patients with ampullary cancer were also enrolled.

From July 2009, newly recruited QPCS participants were also invited to participate in a patient-reported outcomes substudy, which involved completing a self-administered questionnaire. Patients were given the information sheet, consent form, questionnaire and reply-paid envelope at the end of their QPCS interview where possible, or by mail soon after. Those who had not returned the questionnaire and consent form were followed-up by telephone after 10 and 17 days.

Of the 351 QPCS participants with pancreatic or ampullary cancer recruited after July 2009, twenty-nine did not consent to being approached to participate in future studies, 8 died before they were able to be invited to participate, 10 were beyond the protocol timeframe of <10 months post-diagnosis and 50 were considered too unwell to approach by the research nurse.

Of the 254 patients who were approached, 57 declined, 23 died shortly after receiving the questionnaire, 5 were lost to follow-up and 33 consented but did not return the questionnaire. The remaining 136 QPCS participants completed the patient-reported outcomes questionnaire (54% of those approached), 13 of whom had ampullary cancer and were included as their exclusion did not alter the findings. Characteristics of participants were compared with those of the QPCS sample.

The QPCS and patient-reported outcomes substudy were approved by the Human Research Ethics Committees of the QIMR Berghofer Medical Research Institute and participating hospitals. Participants provided written informed consent prior to participation.

Measures

Age, sex, marital status and education level were self-reported at recruitment into QPCS. Clinical information about cancer site, disease stage, surgery (resectable or non-resectable disease and bypass procedure), chemotherapy and palliative care consultation dates were extracted from medical records as part of the QPCS.

The Supportive Care Needs Survey-Short Form was used to assess needs across five domains: psychological (10 items), physical/daily living (5 items), health system/information (11 items), patient care/support (5 items) and sexuality (3 items) [14]. This tool asks participants to rate their need for help with each item over the past month on a 5-point scale where 1 = not applicable (no need), 2 = satisfied (need was met), 3 = low unmet need, 4 = moderate unmet need and 5 = high unmet need. As per the tool's manual [15], the total scores for each domain were standardized (range of 0 to 100, where higher scores indicate higher levels of need) to allow direct comparison across need domains. Furthermore, two dichotomous need domain scores were classified: (a) no need versus any

met-to-unmet domain-specific need and (b) no-to-low need versus moderate-to-high domain-specific need. The Supportive Care Needs Survey-Short Form is a validated measure; its five domains collectively accounted for 73% of the total variance, with Cronbach's alpha for domains ranging from 0.86 to 0.96 [14,15].

Service use was assessed using a tick box list, which enabled participants to indicate whether they had accessed any of the following services: cancer helpline, tele-based cancer counselling, peer support, community-based support groups, internet-based support groups, information sheets, internet information, education programme, chaplain, relaxation/meditation class, exercise physiologist, dietician, physiotherapist, social worker, psychologist, psychiatrist, mental health team, respite care, community health nurse, pain specialist and complementary medicine practitioner.

Statistical methods

Descriptive statistics were used to assess the level of supportive care needs and service use. Chi-squared tests, *t*-tests and Wilcoxon–Mann–Whitney tests were used to examine differences in the proportions of people reporting (a) any needs and (b) moderate-to-high needs between people who did and did not have a surgical resection.

Results

Participant characteristics

The mean age of participants was 66 years, 60% was men, 79% had a partner and 74% had higher education (Table 1). These characteristics were proportionally the same as those cases enrolled in the QPCS [13] and were similar within the groups who had or did not have a resection, with the exception of age where those who had a resection were significantly younger on average.

At the time of completing the questionnaire, median time after diagnosis was 3 months, 47% had late-stage (stages III–IV) disease and 82% received chemotherapy (Table 1). Over half of the patients (56%) did not have a completed surgical resection either because they were not considered operable on the basis of staging investigations (39%), their age and/or comorbidities (5%) or because the resection was aborted because of the discovery of inoperable locally advanced disease (9%) or metastases (3%). One quarter of those with non-resectable disease had a bypass procedure to re-route the flow of bile, avoiding the pancreas, thus alleviating pain, problems with digestion, jaundice and other symptoms that occur when the bile duct is blocked. This was a relatively well sample. In comparison, most pancreatic cancer patients treated in Queensland and New South Wales have late-stage disease (67%), 10% receives adjuvant

chemotherapy and 85% does not have a completed surgical resection [16].

Prevalence of needs within domains

The median (*M*) standardised score was highest for physical/daily living needs (*M*=35; interquartile range [IQR] 15–60), followed by psychological, health system/information and patient care (*M*=25 for each; IQR respectively 8–53, 18–35 and 10–30) and lowest for sexuality needs (*M*=8; IQR 0–25). Overall, 96% of participants reported having some needs, both met and unmet, and 69% reported these to be at moderate-to-high unmet levels. More than 80% reported at least one met or unmet need in four of the five need domains, and more than half reported a moderate-to-high unmet physical/daily living (54%) or psychological (52%) need. Furthermore, 32% and 21% of participants reported having a moderate-to-high unmet need for help with health system/information needs and patient care needs, respectively. Fewer reported moderate-to-high level sexuality needs (16%). There were no statistically significant differences in needs between patients following a palliative or surgical resection pathway.

Most prevalent 'moderate-to-high' unmet need items

The prevalences of moderate-to-high unmet need for individual items are shown in Table 2. The individual physical and psychological need items did not vary by whether the patient's disease was resectable. However, patients with non-resectable disease were significantly more likely to report some health system/information needs (Table 2).

Use of community and allied health services

Table 3 shows the self-reported use of support services and palliative care as indicated in medical records. The most frequently used services (information and education) and providers (dietitians, complementary medicine practitioners and psychological practitioners) did not differ by resection. However, consultation with a physiotherapist or exercise physiologist was higher among participants who had a resection, whereas participants with non-resectable disease were more likely to have accessed respite care (Table 3). Furthermore, palliative care access was significantly greater (59% vs 27%) among those who did not have a resection (Table 3).

Psychological need for help and corresponding self-reported consultation with psychological health professionals

Overall, 90% (*n*=121) of patients reported at least one psychological need. Of these, 3% (*n*=4) reported having all psychological needs satisfied, 76% (*n*=92) reported having at least one of their psychological needs satisfied,

Table 1. Characteristics of participants with pancreatic or ampullary cancer by resection status

| | Overall (n = 136) | | Resection/curative disease (n = 60) | | No resection/palliative disease (n = 76) | | p-value ^a |
|---|----------------------|----|--|-----|---|----|----------------------|
| | n | % | n | % | n | % | |
| Age (years), mean (SD) | 66 (10) | | 62 (10) | | 69 (10) | | 0.001 |
| Gender | | | | | | | |
| Male | 82 | 60 | 37 | 62 | 45 | 59 | 0.771 |
| Female | 54 | 40 | 23 | 38 | 31 | 41 | |
| Marital status | | | | | | | |
| Married/defacto | 107 | 79 | 50 | 83 | 57 | 75 | 0.528 |
| Divorced/separated | 9 | 7 | 2 | 3 | 7 | 9 | |
| Widowed | 13 | 10 | 5 | 8 | 8 | 11 | |
| Never married and no current partner | 7 | 5 | 3 | 5 | 4 | 5 | |
| Education | | | | | | | |
| 11th grade or less | 35 | 26 | 13 | 22 | 22 | 29 | 0.557 |
| 12th grade or high school graduate | 21 | 16 | 11 | 18 | 10 | 13 | |
| Diploma/trade certificate | 56 | 41 | 28 | 47 | 28 | 37 | |
| University degree | 23 | 17 | 8 | 13 | 15 | 20 | |
| Months after diagnosis, median (range) | 3 (0–9) | | 3 (1–8) | | 3 (1–9) | | 0.074 |
| Months after diagnosis | | | | | | | |
| 0–3 | 83 | 61 | 32 | 53 | 51 | 67 | 0.225 |
| 4–6 | 42 | 31 | 23 | 38 | 19 | 25 | |
| 7–9 | 11 | 8 | 5 | 8 | 6 | 8 | |
| Cancer type | | | | | | | |
| Pancreatic cancer | 123 | 90 | 49 | 82 | 74 | 97 | 0.002 |
| Ampullary cancer | 13 | 10 | 11 | 18 | 2 | 3 | |
| Disease stage | | | | | | | |
| I | 14 | 11 | 8 | 14 | 6 | 8 | <0.001 |
| II | 55 | 43 | 48 | 86 | 7 | 10 | |
| III | 16 | 13 | 0 | 0 | 16 | 23 | |
| IV | 43 | 34 | 0 | 0 | 42 | 59 | |
| Months after resection ^b , median (range) | N/A | | 2 (1–7) | | N/A | | N/A |
| Surgical resection | | | | | | | |
| Resection completed—curative disease | 60 | 44 | 60 | 100 | 0 | 0 | N/A |
| Resection failed—locally advanced disease | 12 | 9 | 0 | 0 | 12 | 16 | |
| Resection failed - metastatic disease | 4 | 3 | 0 | 0 | 4 | 5 | |
| No resection—locally advanced disease | 15 | 11 | 0 | 0 | 15 | 20 | |
| No resection—metastatic disease | 38 | 28 | 0 | 0 | 38 | 50 | |
| Resection not attempted because of age and/or comorbidities | 7 | 5 | 0 | 0 | 7 | 9 | |
| Bypass procedure | | | | | | | |
| During failed resection | 14 | 10 | 0 | 0 | 14 | 18 | |
| Instead of resection | 5 | 4 | 0 | 0 | 5 | 7 | <0.001 |
| No bypass | 117 | 86 | 60 | 100 | 57 | 75 | |
| Chemotherapy | | | | | | | |
| No | 20 | 15 | 4 | 7 | 16 | 21 | 0.051 |
| Currently on chemotherapy | 106 | 78 | 50 | 83 | 56 | 74 | |
| Had past chemotherapy | 5 | 4 | 2 | 3 | 3 | 4 | |
| Unknown | 5 | 4 | 4 | 7 | 1 | 1 | |

SD, standard deviation; N/A, Not applicable.

^aP-value (Chi-squared test for categorical variables, t-test for means and Wilcoxon–Mann–Whitney for medians) for difference between groups with or without resection.

^bAll questionnaires were completed after surgical resection.

while only 16% ($n = 19$) consulted a psychologist, psychiatrist, social worker or telephone counsellor (Figure 1).

Discussion

This population-based study shows that the levels of supportive care needs of people with pancreatic cancer are high, spanning multiple support domains and are

generally similar between people with or without non-resectable disease. Over two-thirds of the participants reported at least one moderate-to-high level unmet need, the 10 most prevalent of these were in the physical and psychological domains. The recommendations are for early and intensive initiation of supportive management for this patient cohort [10]. Our results suggest that this is not occurring sufficiently, either due to lack of

Table 2. Top 20 moderate-to-high unmet supportive care needs reported by pancreatic or ampullary cancer patients

| Rank ^a | Items | Overall | Resection/ curative disease | No resection/ palliative disease | Domain |
|-------------------|---|----------------|--------------------------------|-------------------------------------|---------------------------|
| | | (n = 136) % | (n = 60) % | (n = 76) % | |
| 1 | Not being able to do things they used to do | 41 | 42 | 39 | Physical/daily living |
| 2 | Concerns about the worries of those close | 37 | 32 | 41 | Psychological |
| 3 | Uncertainty about the future | 30 | 27 | 33 | Psychological |
| 4 | Lack of energy/tiredness | 28 | 25 | 31 | Physical/daily living |
| 4 | Work around the home | 28 | 27 | 30 | Physical/daily living |
| 6 | Fear about the cancer spreading | 26 | 28 | 24 | Psychological |
| 6 | Pain | 26 | 20 | 30 | Physical/daily living |
| 8 | Worry that the results of treatment are beyond your control | 23 | 19 | 27 | Psychological |
| 9 | Learning to feel in control of your situation | 21 | 22 | 21 | Psychological |
| 9 | Keeping a positive outlook | 21 | 23 | 19 | Psychological |
| 11 | Feeling unwell most of the time | 20 | 18 | 21 | Physical/daily living |
| 12 | Being informed about things you can do to help yourself to get well | 19 | 14 | 23 | Health system/information |
| 13 | Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up | 17 | 14 | 21 | Health system/information |
| 13 | Anxiety | 17 | 17 | 17 | Psychological |
| 15 | Being given information (written, diagrams and drawings) about aspects of managing your illness and side-effects at home | 16 | 9* | 22* | Health system/information |
| 15 | Being given explanations of those tests for which you would like explanations | 16 | 8* | 22* | Health system/information |
| 15 | Having access to professional counselling (IE psychologist, social worker, counsellor and nurse specialist) if you, family or friends need it | 16 | 14 | 18 | Health system/information |
| 18 | Being informed about cancer, which is under control or diminishing (that is, remission) | 15 | 8 | 20 | Health system/information |
| 18 | Feeling down or depressed | 15 | 17 | 14 | Psychological |
| 20 | Being informed about your test results as soon as feasible | 14 | 5* | 22* | Health system/information |

^aRanking based on overall proportion.

*Statistically significant difference ($p < 0.05$, chi-squared) between groups with or without resection.

Table 3. Pancreatic or ampullary cancer patients' use of allied health and community support services

| Self-reported use up until the time of the survey | Overall | Resection/curative disease | No resection/palliative disease |
|---|----------------|----------------------------|---------------------------------|
| | (n = 136) % | (n = 60) % | (n = 76) % |
| Information/education support (cancer helpline, information sheet, internet information and education programme/workshop) | 35 | 35 | 34 |
| Dietician | 28 | 35 | 22 |
| Complementary medical practitioner/relaxation/meditation class | 18 | 18 | 17 |
| Psychological support (psychiatrist, psychologist, social worker and telephone-based cancer counsellor) | 15 | 18 | 12 |
| Peer support or community-based or internet-based support group | 14 | 12 | 16 |
| Community health nurse | 12 | 10 | 13 |
| Pain specialist | 7 | 3 | 9 |
| Chaplain | 7 | 3 | 9 |
| Physiotherapist/exercise physiologist | 4 | 10* | 0* |
| Respite care | 4 | 0* | 7* |
| Palliative care ^a | 45 | 27* | 59* |

^aMedical records indicate use before the time of the survey.

*Statistically significant difference ($p < 0.05$, chi-squared) between groups with or without resection.

awareness and referral or the provided services being inadequate to meet the range of needs or available services not being taken up by patients at sufficient rates.

Our study found that four out of the five need domains had median scores of ≥ 25 , while other studies using the same measures report fewer domains reaching this high level of need. A study of patients with solid tumours or

haematological cancer reported two domains having scores of ≥ 25 (physical/daily living and health system/information needs) [17], and studies of ovarian [18], breast [19] and similar aged colorectal cancer patients [20] found only one need domain of ≥ 25 (psychological, health system/information and physical/daily living needs, respectively). The lower levels of needs in these other

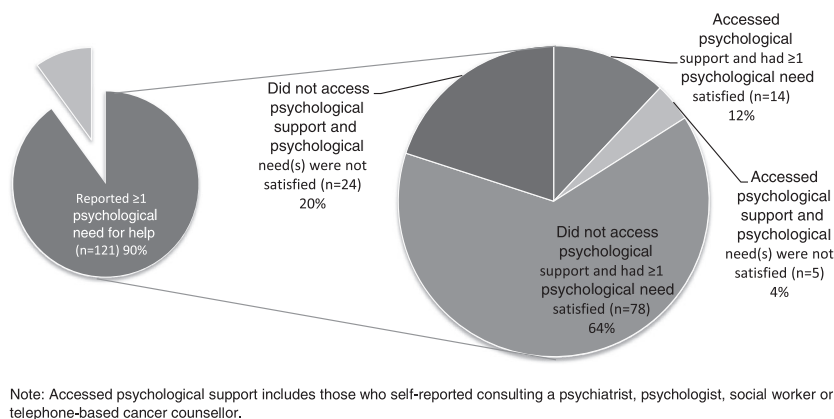


Figure 1. Psychological need burden and specialist consultation and satisfaction with care among pancreatic or ampullary cancer patients ($n = 136$)

patient groups are not unexpected given their overall better prognosis.

The domain with the greatest need reported by participants was physical/daily living needs. Needing help with lack of energy/tiredness, pain, feeling unwell and work around the home was unmet at moderate-to-high levels. With fatigue and pain significantly impairing quality of life, meeting these needs must be a priority [21]. Fatigue has been successfully managed with exercise in some cancer groups with early-stage disease [22,23], although this has not been investigated in patients with pancreatic cancer. Pain relief should involve a three-step 'ladder' including prompt oral administration of non-opioids (aspirin and paracetamol) followed by mild opioids (codeine) and then strong opioids (morphine) [24]. Celiac plexus neurolysis has achieved partial or complete pain relief in 70–90% of patients with pancreatic cancer [25]. While this and another study of patients with newly diagnosed pancreatic cancer [26] found that one quarter to one-third of patients have inadequate pain relief, it is uncertain from our data if this was due to inadequate diagnosis of pain, limited referral to services or inadequacy of pain control measures. This merits further research

In people with pancreatic cancer, the contribution of pain to psychological distress has been recognised [26]. In this study, along with high levels of physical need, almost all participants reported having a psychological need that was currently unmet by services, half at moderate-to-high levels. Clinical practice guidelines [27] demonstrate strong evidence that end of life psychological interventions can improve mood, coping, sense of personal control and physical and functional adjustment. Psychosocial support programmes for pancreatic cancer sufferers should address the priority unmet needs identified in this study, around family anxieties, uncertainty about the future and sense of personal control and positive adjustment. Our study, however, indicated that little psychological help was accessed, and interestingly, about two-thirds of people with some psychological needs had at least one, but not

all, of their psychological needs satisfied without accessing professional support. These people may have utilised informal support from family and friends. Still, innovative, acceptable and convenient ways to provide evidenced-based psychological support deserve investigation.

Our study also found that two-thirds of people with pancreatic cancer do not recall being provided with information about their cancer; in particular, needs around managing illness and side-effects at home and explanations about tests were unmet in many patients with non-resectable disease. Universal information about medical treatments, side-effects, assistance for family members and addressing practical concerns was to be the base model of care applied in a community setting in Queensland Australia [28]. Our study suggests that current provision is not meeting the end of life needs of this vulnerable population. How to improve the current information packages specific to pancreatic cancer may be a potential research topic.

Integrated oncology–palliative care is one model of service delivery where palliative care teams assess and manage the full range of patients' and families' care needs across physical, psychological, social, spiritual and information domains [29]. Early use of palliative care has been shown to lengthen survival [30], minimise physical and emotional symptoms and cost [29] and also minimise caregiver burden [31,32]. While there were no differences in physical and emotional needs for patients who had or had not undergone resection, our results showed that palliative care was largely reserved for people with advanced disease and, even then, only 59% of patients with advanced disease accessed palliative care services. One key barrier to early referral is the perception that palliative care refers only to the end of life. Clinicians may feel that referral would destroy a patient's and a family's hope [33] and some patients may refuse referral because of stigma and/or denial [34]. Using the term 'supportive care' rather than 'palliative care' might assuage some concerns [35]. Bruera and Hui further propose a theoretical framework

that uses the analogy of a car to facilitate discussion around setting goals of care and early access to supportive/palliative care [12].

Although this is the largest population-based study of people with pancreatic cancer to date, it does have limitations. Firstly, the analysis was cross-sectional and included patients with wide variation in the time from diagnosis to questionnaire completion so it was not possible to determine temporal associations between access to services and supportive care needs. Secondly, our sample had a higher proportion of people with resectable disease than would be expected in the overall population [4]. It is therefore likely that we have underestimated the level of unmet need in this patient group. Thirdly, the measure of supportive care needs was validated for patients with a mixture of prognoses, thus, there may be other important needs specific to palliation that are not identified here.

In conclusion, this study has provided new information about the types and levels of supportive care needs specific to people with pancreatic cancer and about the health services that are being accessed. While rapid universal care of a range of support needs for this patient group is clearly necessary, the stark reality is that the current system is leaving many patients with unmet needs. Whether this is due to lack of needs assessment before management or lack of support service awareness remains unknown. Type of management (resectable versus non-resectable) did not alter the high levels of unmet physical and psychological needs. However, we found that people with non-resectable disease require clearer and more timely doctor-patient communication about their test results and

how to manage their disease at home. Further research that explores how to better match available symptom management, psychological, education and specialist palliative care to all pancreatic cancer patients with high needs is paramount.

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Conflict of interest

The authors have no conflicts of interest to disclose.

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