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Title: Risk factors for current and future unmet supportive care needs of people with pancreatic cancer. A longitudinal study.

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Abstract

Purpose: To determine if the supportive care needs of people with pancreatic cancer change over time and identify factors associated with current and future unmet needs.

Methods: Australian pancreatic cancer patients completed a self-administered survey 0–6 months post-diagnosis (n=116) then follow-up surveys 2 (n=82) and 4 months (n=50) later. The validated survey measured 34 needs across five domains. Weighted generalised estimating equations were used to identify factors associated with having ≥ 1 current or future moderate-to-high unmet need.

Results: The overall proportion of patients reporting ≥ 1 moderate-or-high-level need did not significantly change over time (baseline=70% to 4 months=75%), although there was a non-significant reduction in needs for patients who had a complete resection (71% to 63%) and an increase in patients with locally advanced (73% to 85%) or metastatic (66% to 88%) disease. Higher levels of pain (OR 6.1, CI 2.4-15.3), anxiety (OR 3.3, CI 1.5-7.3) and depression (OR 3.2, CI 1.7-6.0) were significantly associated with current needs. People with pain (OR 4.9, CI 1.5-15.4), metastatic disease (OR 2.7, CI 0.7-10.0) or anxiety (OR 2.5, CI 0.7-8.6) had substantially higher odds of reporting needs at their next survey. The prevalence of needs was highest in the physical/daily living and psychological domains (both 53% at baseline). Pain and anxiety had respectively the strongest associations with these domains.

Conclusions: Careful and continued attention to pain control and psychological morbidity is paramount in addressing significant unmet needs, particularly for people with metastatic disease. Research on how best to coordinate this is crucial.

Key words: Pancreatic cancer, unmet supportive care needs, risk factors, longitudinal study, pain, anxiety, depression

Introduction

Pancreatic cancer is the fifth most common cause of cancer death in more developed regions of the world [1]. There is no screening test for this disease and patients are generally identified when already symptomatic, often presenting with unexplained weight loss, back or abdominal pain, or obstructive jaundice [2]. Surgical resection of the tumour is the only curative therapy, but only 15-20% of patients have tumours that are resectable [3], with most patients presenting with advanced disease or comorbidities that preclude resection.

People with pancreatic cancer have the worst survival prognosis of any cancer. Only 20% of patients survive the first year and five-year all-stage survival is 6% [4]. Even in those patients who undergo curative surgical resection, the five-year survival is only 10-25% [5]. Chemotherapy and chemo-radiation options are available for use in neo-adjuvant, adjuvant or palliative settings, but for most patients the survival benefit is minimal [2]. Thus, effective palliation of symptoms and improvements in quality of life are critically important for the majority of patients with pancreatic cancer [6].

Quality of life endpoints have become standard in the evaluation of cancer therapies in clinical trials [7] and these are of particular importance in cancers with poor prognosis and short median survival. Many studies of pancreatic cancer have compared patient outcomes following different treatments and palliative procedures at different stages, but few have specifically considered patients' supportive care needs.

Needs assessment in the context of cancer assesses the person's desire for action, information or support [8]. Quality of life can be improved through meeting people's supportive care needs [9]. However, to facilitate change in patient-reported outcomes, screening must be followed with timely provision of interventions that are based on evidence [10, 11]. Unfortunately, some patients will decline interventions offered by their health care team because they feel they are receiving informal help elsewhere or prefer to manage on their own [12]. Thus needs assessment is a sensible approach, asking patients formally if they have a desire for further assistance with unresolved concerns. The few longitudinal studies that have assessed needs have shown that unmet supportive care needs decrease over time during treatment in women with breast cancer [13, 14], following treatment in women with ovarian

cancer [15] and in groups of people with a mix of cancer types [16, 17] including those with advanced disease [17].

Our previous cross-sectional analysis found that people with newly diagnosed pancreatic cancer had very high levels of unmet supportive care needs, particularly with respect to alleviating fatigue, pain or psychological distress [18]. However, no population-based studies have considered how needs of pancreatic cancer patients may change over time and which factors are associated with having unmet needs. Thus, this work used a population-based sample to determine the changes in supportive care needs and factors associated with current and future unmet needs in people with pancreatic cancer.

Methods

Participants and procedures

Patients 18 years and over in Queensland, Australia with a suspected or confirmed diagnosis of pancreatic cancer between January 2007 and June 2011 were recruited for the Queensland Pancreatic Cancer Study (QPCS). This was a Queensland-wide, population-based case-control study with the aim to examine environmental and genetic risk factors for pancreatic cancer. [19]. The study used a rapid ascertainment approach, recruiting patients as early as possible through a state-wide network of clinicians in hospitals and private practices, often while diagnostic investigations were ongoing. Controls were randomly selected from the Australian Electoral Roll (enrolling to vote is compulsory for Australian Citizens aged 18 years or more). Participants completed a face-to-face or telephone interview during which we asked about socio-demographic and lifestyle factors, medical and occupational history and family history of cancer. Participants were also asked to donate a blood sample and to give consent for us to review their medical records. Trained research nurses subsequently reviewed the medical records of all potential cases recruited and 704 (84%) had a confirmed diagnosis of pancreatic cancer.

From July 2009 newly recruited QPCS participants with confirmed pancreatic cancer were also invited to participate in this longitudinal cohort sub-study of patient-reported outcomes. This sub-study involved completing a self-administered mail questionnaire at recruitment and follow-up questionnaires 2-monthly until the participant was lost to follow-up or 8 months after diagnosis (due to an expected >30% attrition rate at this time). Patients were excluded if

they were more than 8 months after diagnosis or if they were physically or mentally unable to complete a written questionnaire. Patients were given the information sheet, consent form, baseline questionnaire and reply-paid envelope at the end of their QPCS interview where possible or by mail soon after and all follow-up questionnaires were administered by mail.

Figure 1 outlines the flow of participant recruitment. Of the 351 eligible QPCS participants recruited after July 2009, 97 were excluded and not approached, 57 declined, 23 died shortly after receiving the questionnaire and 38 others did not return the questionnaire. The remaining 136 QPCS participants completed the baseline patient-reported outcome questionnaire (54% of those approached). A further 20 had unusable data for this analysis, leaving 116 participants contributing data.

The QPCS and patient-reported outcome sub-study were both approved by the Human Research Ethics Committees of the QIMR Berghofer Medical Research Institute and participating hospitals.

Measures

Outcome measure

The Supportive Care Needs Survey-Short Form (SCNS-SF34) 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) [20]. 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. Binary categories for any overall and domain-specific needs were classified as: 'no-to-low needs' versus 'at least one moderate-to-high need'. Summated standardised scores (ranging from 0 to 100) for any need and domain-specific needs were also derived as per the scoring manual [21]. The SCNS-SF34 is a validated measure; in a sample of patients with a wide range of cancers its five domains collectively accounted for 73% of the variance, with Cronbach's alpha for domains ranging from 0.86 to 0.96 [20].

Potential risk factor variables measured

A range of measures to evaluate risk factors consistent with a social–ecological model were assessed [22]. This model theorises that needs can be influenced by demographic

characteristics, clinical conditions, personal symptoms, social support, health care provision and community level factors.

Demographic variables: Age, sex, marital status and education level were self-reported at recruitment.

Clinical variables: Information was extracted from medical records about disease stage, whether the patient had undergone a resection of the primary tumour, comorbidities, chemotherapy type, dose and dates. Stage and resection were used to construct a disease status variable (completed resection - curative disease, locally advanced disease, metastatic disease). Dates for chemotherapy and survey completion were cross-referenced to determine if participants were receiving chemotherapy at the time they completed each questionnaire.

Self-reported physical and psychological symptoms/wellbeing: Pain was assessed by a single item within the FACT- physical wellbeing subscale [23]. Response options to 'During the last 7 days I was bothered by pain' were not at all, a little bit, somewhat, quite a bit and very much. Anxiety and depression were assessed using the Hospital Anxiety and Depression Scale (HADS) [24]. The two sub-scales, anxiety and depression, each distinguish between 'non-case' (0–7), 'sub-clinical case' (8–10), and 'clinical case' (11–21).

Self-reported support: Social support was assessed by the FACT- social/family wellbeing subscale [23]. Scores were summed across 7 items and the final scores ranged between 0 and 28, with higher scores indicating better social support.

Health care variables: Information was extracted from medical records about treatment in the public or private health system, whether the patient had a care coordinator or care plan and whether the patient had seen a palliative care specialist and, if so, the initial date first seen. Dates for palliative care and survey completion were cross-referenced to determine if participants had seen a palliative care specialist at the time they completed each questionnaire.

Remoteness of community: Postcode was used to classify participants as residing in a major city, or an inner regional, outer regional, remote or very remote area using the Accessibility/Remoteness Index of Australia [25].

Statistical methods

Not all participants completed all surveys and attrition does not occur at random, so we used a series of complex statistical analyses to account for this and to ensure that we could use all available data.

The first survey was completed a variable time after diagnosis due to the challenges of identifying patients with pancreatic cancer. Thus, we first considered the length of time after diagnosis that should contribute to the baseline measure. We compared data from the first questionnaire according to completion within 0-2 months, 3-4 months and 5-6 months after diagnosis. The proportions with moderate-to-high unmet needs was not significantly different according to the timing of first questionnaire completion, although those who completed their first questionnaire later tended to have fewer unmet needs (42/53 (79%), 29/46 (63%), 10/17 (59%), respectively; p=0.12). Baseline data came from initial questionnaires completed by patients within 6 months of diagnosis.

We had intermittent missing data for 30 (26%) participants (17 were missing the 2-month follow-up; 13 were missing the 4-month follow-up). Intermittent missing data for the 30 participants were imputed using the average response of the prior and subsequent data points. The dataset thereafter contained monotone missing only. To determine the impact of attrition (monotone missing) on representativeness [26] we plotted the proportion of patients with moderate-to-high unmet needs by time-point. To determine factors associated with attrition [26] we compared the characteristics of those who dropped out versus those who did not.

We conducted bivariable analyses, using Chi-squared tests for categorical variables and twosample t-test for continuous variables to examine associations between factors of interest and the presence of moderate-to-high unmet needs at baseline. We plotted the unadjusted relationship between time and moderate-to-high unmet needs stratified by disease status, although the sample size within each disease status subgroup was small and statistical significance could not be considered.

Finally we fitted multivariable models to examine factors associated with: (a) any; (b) physical; or (c) psychological moderate-to-high unmet needs. We examined those factors that were statistically significant (p<0.01) in the bivariable analyses as well as age and severity of

disease, which were of clinical interest. Longitudinal logistic regression models using weighted generalised estimating equations (GEEs) were used to determine factors associated with (a) current and (b) future moderate-to-high unmet needs. GEEs account for intrapersonal correlations allowing the outcome and independent variables to change over time. Thus we were able to use data from all surveys. We defined current unmet needs as those reported at the time of each survey and future unmet needs were those reported in the next survey if it was completed. Time-specific weights were calculated for each patient using two separate logistic regression models where the response variable was observed during either the 2month or the 4-month follow-up. Those with imputed data were defined as observed as they were still active in the study. Weighting was included in the GEEs to account for the unbalanced number of data points for participants who were lost to follow up. Weights were calculated as the inverse of the probability of being observed, as estimated from the logistic regressions. The probability of being observed at the first time point was defined to equal one. Factors associated with being observed during the 2-month follow-up were age and prognosis, whereas those associated with being observed during the 4-month follow-up were age and number of months post-diagnosis.

Results

Participants

On average, participants were 67 years old at diagnosis (SD=10), 60% were men, most (80%) were married or had a partner and 58% had a college education or higher (Table 1). These characteristics were proportionally similar to the cases enrolled in the QPCS [19]. Participants completed the first questionnaire on average 3 months after diagnosis, many (61%) were initially treated in the private setting, 44% had a complete resection, 31% had metastatic disease and most (83%) had chemotherapy (Table 1).

Characterizing attrition

Sixty-eight percent (n=79) of participants remained active in the study at the 2-month followup and 42% (n=49) at the 4-month follow-up. Among those who were lost to follow-up, 40% (n=27) did so because they were too sick or had died and 24% (n=16) withdrew or did not respond. Participants who were lost to follow-up on average had a lower proportion of unmet needs at baseline than those with complete data (Figure 2). Those who were too sick, had died or were excluded from follow-up because they were >8 months after diagnosis were significantly older than those who completed the study or withdrew for other reasons (Table 2). Those who ceased follow-up due to death or being too sick were significantly more likely to have non-curative disease and slightly (but not statistically) more likely to have anxiety and depression (Table 2).

Prevalence of and change in unmet needs over time

At baseline, 70% of participants reported having at least one moderate-to-high unmet need and more than half reported physical (53%) or psychological (53%) needs at moderate-tohigh levels, whereas health system/information (29%), patient care (17%) and sexuality needs (13%) were reported less frequently. Overall there were no significant changes over time in the proportions reporting moderate-to-high unmet needs (Figure 3 – unadjusted; baseline=70% to 4 months=75% and Table 3 – adjusted odds ratio 0.9 (95% confidence interval 0.3,2.1)). Furthermore, the odds of having needs in the future was not significantly different depending on whether patients were at baseline or at the 2 month follow-up (Table 3 – OR 1.2 (CI 0.5,2.7)), although there was an indication from unadjusted stratified analysis of a reduction in needs over time for patients who had a compete resection (71% to 63%) and an increase in needs over time in patients with locally advanced (73% to 85%) or metastatic disease (66% to 88%) (Figure 3).

Factors associated with having at least one current or future moderate-to-high unmet need

In bivariable analyses no significant associations were found between reporting moderate-tohigh unmet needs and age, sex, marital status, education, place of residence, initial place of treatment, having a resection, comorbidities, chemotherapy, social support, having a care coordinator or accessing palliative care (Table 1).

Variables retained in the multivariable analyses are presented in Table 3. Higher levels of pain, anxiety and depression were significantly associated with current needs. Pain was the only factor statistically significantly associated with any future needs, although people with metastatic disease and those with anxiety had substantially higher odds of having future needs. We considered factors associated with the two most prevalent needs domains and found that depression and pain were significantly associated with current physical needs, whereas pain and locally advanced disease were the main factors associated with future physical needs. Anxiety, depression and pain were associated with current psychological needs, and in addition to these factors, those patients with metastatic disease had higher odds

of future psychological needs.

Discussion

This unique study is the first to provide formal population-based longitudinal assessment of supportive care needs of patients with pancreatic cancer. The findings provide evidence for health professionals and service providers as to which types of unmet needs are prevalent and persistent and which risk factors should be considered in assessing the likelihood of ongoing needs. We show that unmet needs among pancreatic cancer patients were high at baseline and persisted over time. Physical and psychological needs were the most prevalent subcategories, with about half the participants reporting these at moderate-to-high levels. While in general, patients with non-resectable disease and higher levels of pain, anxiety and depression were at higher risk of having unmet supportive care needs, these associations varied across support domains and were dependent on whether people were currently experiencing the need or if it was a need that they reported during further follow-up. Of note, pain and anxiety had respectively the strongest associations with having unmet physical and psychological needs both in the present and in the future. The consistency of these two risk factors for unmet needs over time may suggest that they are not being adequately addressed or that they are associated with rapid disease progression and may be normal with an imminent end of life.

In the last decade, pain and distress have been positioned as the fifth and sixth vital signs in cancer care with emphasis placed on the importance of screening [27-29]. Carlson [30] concluded that screening for distress and unmet needs facilitates communication around emotional complications and, in conjunction with empirical treatment, has the potential to significantly improve quality of life. Our findings that pain and distress are extremely important in people with pancreatic cancer highlight the need to focus on these issues. People with these two risk factors should be closely monitored and receive early referral to palliative care.

Our results also indicate those with locally advanced disease are most likely to have current and future unmet physical needs. It may be that patients with locally advanced disease are not accessing palliative care where their physical needs for things like pain relief would be managed. People with metastatic pancreatic cancer were not at immediate elevated risk of having unmet psychological needs compared to those with non-metastatic disease but were at risk of having these needs in the future. This is most likely linked to their fast disease progression, development of cancer-related symptoms and increasing fear of death [31].

In contrast to other longitudinal studied that have assessed unmet needs [13-17] our study found that people with pancreatic cancer have persistently high levels of unmet needs and that there may be a trend for needs to increase over time in patients who are unable to undergo resection of their tumour (i.e. in 80% or more of people with pancreatic cancer [3]). Furthermore, our results show that it is the patients with metastatic pancreatic cancer, anxiety and pain who are at higher risk of having unmet supportive care needs in the future.

In the setting of advanced cancer, patients and their families require discussions about both the goals of their immediate care and planning for their future health care needs [32]. In addition to any patients in pain and distress, our data support timely referral of patients with non-resectable pancreatic cancer to palliative care where multidisciplinary teams can assess and manage the full range of patients' care needs across physical, psychological, social, spiritual, and information domains [33]. We previously reported that fewer than 60% of people with non-resectable pancreatic cancer accessed palliative care before our baseline survey [18]. This may in part explain the initial high levels of unmet needs. Continuing unmet needs most likely reflect worsening quality of life. A longitudinal study of quality of life showed that symptom burden significantly increased in the first 3 months post-diagnosis with metastatic pancreatic cancer [34]. The majority of advanced pancreatic cancer patients have pain at the time of diagnosis, requiring a multidisciplinary approach involving palliative care providers as well as medical and radiation oncologists to optimise pain management [35].

Our study did not detect differences in the level of unmet needs by remoteness of the patients' residential location, by initial treatment in a public or private hospital or by whether a person saw a care coordinator or accessed palliative care. However, this may be due to our modest sample size or some reverse causality. For example, people who saw a care coordinator or accessed palliative care may have had higher levels of unmet need to start with.

This study had several design limitations. The sample size was relatively small, but sophisticated statistical analyses used all available cases to identify significant effects which were both plausible and of clinical importance. Participants in this sub-study had significantly better prognosis than the larger population of people diagnosed with pancreatic cancer, among whom resection is completed for 15% and 58% are diagnosed with metastatic disease [36]. We therefore are likely to have underestimated supportive care needs, particular with increasing time as our subgroup analysis was indicative of increasing needs over time in patients with advanced disease. As participants were required to complete various other study components first, the timing of recruitment for this component was some time after diagnosis. While we did conduct analyses justifying our pooling of participants who completed their first questionnaire 0-6 months after diagnosis, we had not expected recruitment to take so long and had set the study protocol to have no further follow-up at 8 months post-diagnosis, which resulted in the exclusion of a number of patients. We also had considerable intermittent missing data and attrition due to death or incapacity. While we imputed intermittent missing data and used weighted GEEs that allowed data to be missing at random, it is possible we have further underestimated the level of unmet needs, as those who withdrew due to sickness were significantly more likely not to have had a resection, and non-curative disease was associated with substantially higher odds of future needs.

Studies of people with pancreatic cancer are difficult to undertake due to its rarity, severity and fast progression. However, the rapid progression and poor survival do mean that the effectiveness of interventions may be quickly assessed. Despite some limitations, this study makes a valuable contribution to the pancreatic cancer care literature. The longitudinal design illuminates a continuing burden of unmet needs over time. Early attention to issues of pain and anxiety may reduce current and future unmet supportive care needs in this population. Until substantial gains are made in the curative treatment of this disease, optimising supportive management is a key priority in maximising patient quality of life.

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Conflict of interest

The authors have no conflicts of interest to disclose.

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Participants with ≥1 Participants with no-to-Responders moderate-to-high low unmet needs (n=35) (n=116) unmet need (n=81) (%) (%) (%) p-value^a n n n Age (years) 67.0 (9.5) 68.0 (8.3) 66.6 (10.0) Mean (SD) 0.500 Sex 70 (60)22 (31)48 (69) Male 0.716 46 (40)13 (28) 33 (72) Female **Marital Status** 93 (80)28 (30)65 (70)0.976 Married/partner 23 (20)7 (30) 16 (70) Divorce/separated/widowed/never married Education 48 (42)15 (31)33 (69) High school or lower 0.738 67 (58)19 (28) 48 (72) College or higher Place of residence 54 (47)15 (28)39 (72)Major city 0.570 52 (45)18 (35)34 (65) Inner regional 10 (9) 2 (20) 8 (80) Outer regional Months post-diagnosis at questionnaire 1 Mean (SD) 2.9 (1.3) 3.1 (1.5) 2.8 (1.3) 0.344 Initial place of treatment 43 12 (28) 31 (37)(72) Public hospital 0.728 71 (61)22 (31)49 (69) Private hospital/specialist rooms **Disease status** 51 (44)15 (29)36 (71)Resection completed - curative disease 0.991 3 (25) 9 12 (10)(75) Resection failed - locally advanced disease 3 2 (3) 1 (33)(65)Resection failed - metastatic disease 4 10 14 (12)(29) (71)No resection - locally advanced disease 32 (28)11 (34) 21 (66) No resection - metastatic disease 4 (3) 1 (25)3 (75) No resection - because of age/comorbidities Number of comorbidities 2.2 (1.4) 2.5 (1.6) 2.0 (1.4) Mean (SD) 0.100 Had chemotherapy 17 (15)5 (29)12 (71)No 0.880 96 (83)30 (31) 66 (69) Yes 3 (3) Not stated Anxiety 67 (58)28 (42) 39 (58)Non-case 0.001 49 42 (42)7 (14)(86) Sub-clinical/clinical case Depression 61 (53)27 (44)34 (56)0.001 Non-case 55 (47) 8 (15) 47 (85) Sub-clinical/clinical case Social/family wellbeing Mean (SD) 23.6 (4.7) 24.0 (5.0) 23.4 (4.5) 0.500 Pain 77 (68) 32 (42) 45 (58)Not at all/a little bit < 0.001 36 (32)1 (3) 35 (97) Somewhat/quite a bit/very much Had a care coordinator/care plan 83 (72)27 (33)56 (67) No/not stated 0.430 32 (28)(25) 8 24 (75) Yes Accessed palliative care at baseline 65 (29) 46 (71) (56)19 0.800 No 51 (44)16 (31)35 (69)Yes

 Table 1: Baseline demographic and clinical characteristics of participants and bivariable associations with any baseline moderate-to-high unmet needs

^a P-value comparing characteristics for low-to-no needs versus moderate-to-high needs (Chi-squared test for categorical variables, t-test for continuous variables).

		Reason			
_	Completed the study n=49	Too sick or died n=27	>8 months post- diagnosis n=24	Other n=16	
	n (%)	n (%)	n (%)	n (%)	
Age (years)					
Mean (SD)	65 (9.5)	70 (8.5)	70 (6.4)	62 (11.7)	0.006
Marital Status					
Married/partner	40 (82)	20 (74)	19 (79)	14 (88)	0.729
Divorce/separated/widowed/never married	9 (18)	7 (26)	5 (21)	2 (13)	
Education					
High school or lower	22 (46)	11 (41)	10 (42)	5 (31)	0.738
College or higher	26 (54)	16 (59)	14 (58)	11 (69)	
Gender					
Male	33 (67)	14 (52)	13 (54)	10 (63)	0.484
Female	16 (33)	13 (48)	11 (46)	6 (38)	
Disease status					
Curative disease	24 (49)	4 (15)	14 (58)	9 (56)	0.001
Locally advanced/metastatic disease	25 (51)	23 (85)	10 (42)	7 (44)	
Anxiety					
Non-case	31 (63)	11 (41)	15 (63)	10 (63)	0.220
Sub-clinical/clinical case	18 (37)	16 (59)	9 (38)	6 (37)	
Depression					
Non-case	27 (55)	10 (37)	14 (58)	10 (63)	0.284
Sub-clinical/clinical case	22 (45)	17 (63)	10 (42)	6 (38)	
Pain					
Not at all/a little bit	33 (69)	14 (54)	20 (87)	10 (63)	0.165
Somewhat	6 (13)	6 (23)	3 (13)	4 (25)	
Quite a bit/very much	9 (19)	6 (23)	-	2 (13)	

¹ Associations with categorical variables were tested using chi-squared analysis and with continuous variables using ANOVA.

	Any needs				Physical needs			Psychological needs				
	Current (n=112) ^a		Future (n=75) ^{ab}		Current (n=112) ^a		Future (n=75) ^{ab}		Current (n=112) ^a		Future (n=75) ^{ab}	
	Odds ratio		Odds ratio		Odds ratio		Odds ratio		Odds ratio		Odds ratio	
	(95% confidence interval)	p- value	(95% confidence interval)	p- value	(95% confidence interval)	p- value	(95% confidence interval)	p- value	(95% confidence interval)	p- value	(95% confidence interval)	p- value
Time												
Baseline	Referent	0.909	N/A	0.725	Referent	0.433	N/A	0.706	Referent	0.501	N/A	0.799
2 mth follow-up	0.9 (0.5,1.6)		Referent		0.6 (0.3,1.3)		Referent		0.9 (0.5,1.4)		Referent	
4 mth follow-up	0.9 (0.3,2.1)		1.2 (0.5,2.7)		0.7 (0.3,1.7)		1.2 (0.6,2.4)		0.7 (0.3,1.3)		0.9 (0.5,1.7)	
Age (years)	1.0 (0.9,1.0)	0.122	1.0 (0.9,1.0)	0.402	1.0 (0.9,1.0)	0.414	1.0 (0.9,1.0)	0.835	1.0 (0.9,1.0)	0.113	1.0 (0.9,1.0)	0.274
Disease status												
Curative	Referent	0.506	Referent	0.283	Referent	0.269	Referent	0.089	Referent	0.291	Referent	0.251
Locally advanced	1.7 (0.7,4.1)		1.9 (0.6,6.6)		2.1 (0.8,5.6)		3.6 (1.1,11.4)		0.6 (0.2,1.6)		0.6 (0.2,1.9)	
Metastatic	1.5 (0.5,4.2)		2.7 (0.7,10.0)		1.0 (0.4,2.9)		1.5 (0.5,4.7)		1.5 (0.6,3.8)		2.5 (0.6,10.2)	
Anxiety												
Non-case	Referent	0.003	Referent	0.147	Referent	0.096	Referent	0.523	Referent	<0.001	Referent	0.039
Sub- clinical/clinical	3.3 (1.5,7.3)		2.5 (0.7,8.6)		2.1 (0.9,5.3)		1.5 (0.5,4.7)		4.2 (2.2,7.9)		2.4 (1.0,5.6)	
Depression:												
Non-case	Referent	<0.001	Referent	0.680	Referent	<0.001	Referent	0.504	Referent	0.015	Referent	0.043
Sub- clinical/clinical	3.2 (1.7,6.0)		1.2 (0.4,3.5)		4.9 (2.2,11.2)		1.4 (0.6,3.3)		2.0 (1.1,3.7)		2.5 (1.0,5.9)	
Pain												
None - a little bit	Referent	<0.001	Referent	0.007	Referent	<0.001	Referent	0.003	Referent	0.001	Referent	0.065
Somewhat - very much	6.1 (2.4,15.3)		4.9 (1.5,15.4)		10.6 (5.0,22.6)	4.2 (1.6,10.8)		2.8 (1.6,5.0)		2.2 (1.0, 4.9)		

Table 3. Factors from multivariable analysis associated with current and future reporting of moderate-to-high unmet needs

Contextually significant: odds ratio ≥ 2 or ≤ 0.5

^a 4 participants who had no resection because of age/comorbidities were excluded due to model instability with small cell size.
 ^b 37 participants had only baseline data and were excluded from this analysis.

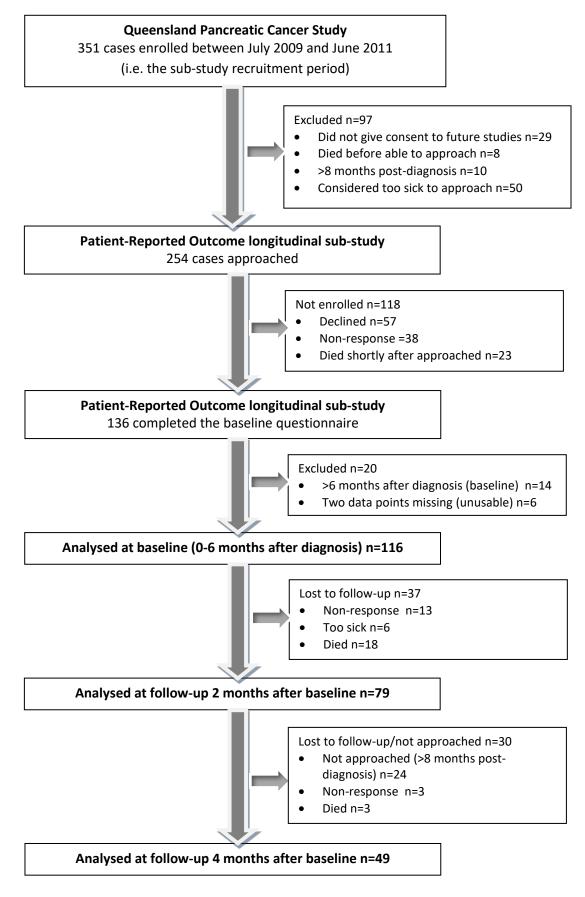


Figure 1. Flow of participant recruitment

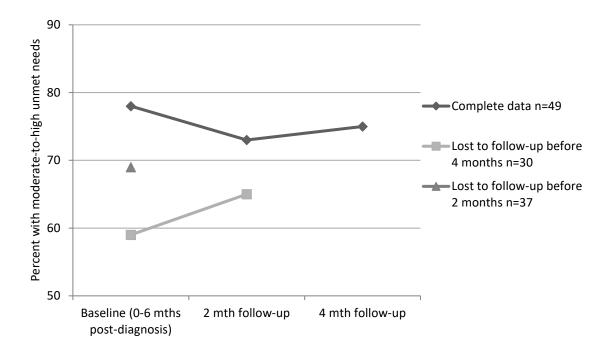


Figure 2. Percent of people experiencing moderate-to-high unmet needs by time of follow-up.

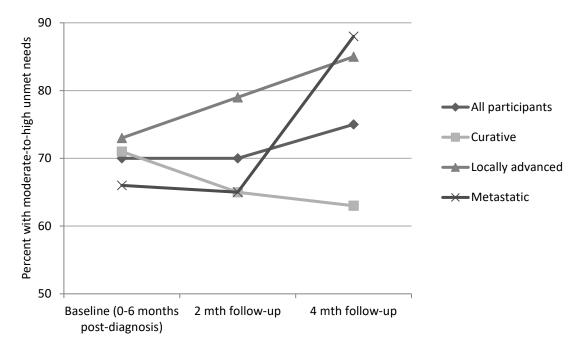


Figure 3 Percent of people experiencing moderate-to-high unmet needs by disease status