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Association between pancreatic cancer patients' perception of their care coordination and patient-reported and survival outcomes

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ABSTRACT

Objective: People with pancreatic cancer have poor survival, and management is challenging. Pancreatic cancer patients' perceptions of their care coordination and its association with their outcomes have not been well-studied. Our objective was to determine if perception of care coordination is associated with patient-reported outcomes or survival.

Methods: People with pancreatic cancer who were 1–8 months postdiagnosis (52 with completed resection and 58 with no resection) completed a patient-reported questionnaire that assessed their perceptions of care coordination, quality of life, anxiety, and depression using validated instruments. Mean scores for 15 care-coordination items were calculated and then ranked from highest (best experience) to lowest (worst experience). Associations between care-coordination scores (including communication and navigation domains) and patient-reported outcomes and survival were investigated using general linear regression and Cox regression, respectively. All analyses were stratified by whether or not the tumor had been resected.

Results: In both groups, the highest-ranked care-coordination items were: knowing who was responsible for coordinating care, health professionals being informed about their history, and waiting times. The worst-ranked items related to: how often patients were asked about visits with other health professionals and how well they and their family were coping, knowing the

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symptoms they should monitor, having sufficient emotional help from staff, and access to additional specialist services. For people who had a resection, better communication and navigation scores were significantly associated with higher quality of life and less anxiety and depression. However, these associations were not statistically significant for those with no resection. Perception of cancer care coordination was not associated with survival in either group.

Significance of results: Our results suggest that, while many core clinical aspects of care are perceived to be done well for pancreatic cancer patients, improvements in emotional support, referral to specialist services, and self-management education may improve patient-reported outcomes.

KEYWORDS: Pancreatic cancer, Care coordination, Quality of life, Anxiety, Depression

INTRODUCTION

Pancreatic cancer is the fifth most common cause of death from cancer in the developed world (International Agency for Research on Cancer and World Health Organization, 2012). Surgical resection of the tumor currently offers the only curative treatment option, but it is only possible for about 15% of people with pancreatic cancer (Burmeister et al., 2015). The remainder present with metastatic or locally advanced disease, or with comorbidities that preclude curative resection. People with pancreatic cancer can experience a wide range of symptoms—such as pain, jaundice, diabetes, malabsorption, weight loss, nausea, vomiting, anxiety, and depression—and require strong and efficient support.

For patients potentially eligible for surgical resection, a recent statement by the Australian Gastro-Intestinal Trials Group indicated the necessity for multidisciplinary team management (Gandy et al., 2016). Arguably, people with advanced pancreatic cancer also require a multidisciplinary approach involving palliative care providers, nutritionists, psycho-oncologists, and medical and radiation oncologists to optimize symptom management and end-of-life care (Torgerson & Wiebe, 2013). However, compared with allied health, nursing, and palliative care specialists, our earlier work showed that surgeons and gastroenterologists thought it less important that multidisciplinary team meetings include palliative care specialists or allied health professionals and also that it was less important that symptom management be discussed (Burmeister et al., 2016*c*). Such perspectives are inconsistent with the European Partnership for Action Against Cancer guidelines, which emphasize the need for a multidisciplinary team to coordinate cancer care at all stages and to address supportive care and psychosocial needs (Borras et al., 2014). The guidelines also emphasize the need for coordination across different disciplines to achieve continuity of care.

People with pancreatic cancer are at risk of receiving poorly organized and fragmented care due to the rarity and complex nature of the disease and its management. We have shown that provision of optimal care, defined using a quality score that included 18 items, is associated with increased survival (Burmeister et al., 2016*a*). However, given the poor prognosis of most patients, maintenance of quality of life through effective palliation of symptoms and management of distress are arguably as important as survival (Schmier et al., 1999).

Coordination of care has been identified as a critical element of person-centered care (Institute of Medicine, 2013), which involves organizing services around the needs and preferences of the individual, emphasizing the primacy of measures based on the person's own experience (Young et al., 2011). People with cancer are ideally placed to rate the adequacy of cancer care coordination, as they are present at every encounter with health services. Previous studies assessing the care coordination of people with pancreatic cancer extracted data from medical records and lacked the ability to assess quality-of-care communication and responsiveness to the full range of supportive care needs (Buanes, 2014; Burmeister et al., 2016*a*). Therefore, the aim of our present study was to document the perception of care coordination among patients with pancreatic cancer and to assess if better perceived care coordination was associated with such patient-reported outcomes as overall quality of life, disease-specific symptoms, anxiety, and depression, as well as with survival.

METHODS

Participants and Procedures

Adults in Queensland with a suspected or confirmed diagnosis of pancreatic cancer between January of 2007 and June of 2011 were recruited into the Queensland Pancreatic Cancer Study (QPCS), a population-based case-control study that aimed to examine environmental and genetic risk factors for pancreatic cancer (Tran et al., 2013). A total of 704

(84%) had a confirmed diagnosis of pancreatic cancer. The study used a rapid ascertainment approach, recruiting people as early as possible, often while diagnostic investigations were ongoing, through a statewide network of clinicians in hospitals and private practices. We asked participants about sociodemographic and lifestyle factors, medical and occupational history, and family history of cancer via a face-to-face or telephone interview. Trained research nurses reviewed the records of all the potential cases recruited.

QPCS participants newly recruited after June of 2009 with confirmed pancreatic cancer were invited to participate in a longitudinal patient-reported outcome substudy. This involved completing a self-administered questionnaire at recruitment and follow-up questionnaires every 2 months until 8 months after diagnosis. The 8-month timepoint was selected due to an expected >30% attrition rate as a consequence of progressive disease or death at that time. People were excluded if they were physically or mentally unable to complete a written questionnaire.

Of the 351 eligible QPCS participants recruited after June of 2009, 97 were excluded by the research nurses because they were too sick to approach, 57 declined, 23 died shortly after receiving the questionnaire, and 38 others did not return the questionnaire. The remaining 136 QPCS participants completed at least one patient-reported outcome questionnaire (54% of those approached). While the cancer care-coordination questions were included at all the study timepoints, some participants did not complete all sections of the questionnaires. In total, 110 participants completed at least one questionnaire about their cancer care coordination. If more than one questionnaire was completed by a participant, only the most recent data were utilized for this analysis to capture their perception of care coordination over as much of the disease course as possible.

The human research ethics committee of the QIMR Berghofer Medical Research Institute and those of the participating hospitals approved both the QPCS and the patient-reported outcome substudy.

Measures

Cancer care coordination was assessed using an early version of the cancer care-coordination questionnaire developed by Young and colleagues (2011). This tool assesses overall care coordination and two domains: communication and navigation. The version used in the present study included all items available at the time: 10 of 13 of the communication items and 5 of 7 of the navigation items from the final version. Participants were asked about their experience of aspects of their care and given five response options that ranged from "strongly disagree" or "never" to "strongly agree" or "always," resulting in scores ranging from 15 to 75 for overall care coordination, 10 to 50 for communication, and 5 to 25 for navigation, where higher scores indicated better care coordination. The items included in this study had acceptable reliability (values of Cronbach's alpha of 0.84, 0.82, and 0.70, respectively), similar to that reported from reliability studies of the final version (Cronbach's $\alpha = 0.88$, 0.87, and 0.73, respectively) (Young et al., 2011).

Quality of life and disease-specific symptoms were measured using the 45-item Functional Assessment of Cancer Therapy–Hepatobiliary (FACT–Hep) questionnaire for people with hepatobiliary cancers, including liver, bile duct, and pancreas (Cella et al., 2013). The FACT–Hep is a multidimensional instrument that includes four general subscales (physical, social, emotional, and functional well-being), as well as a subscale specific to treatment of hepatobiliary cancers. Overall quality of life scores ranged from 0 to 180 and were derived from combining all five subscales. Higher scores indicated better quality of life. The value of Cronbach's α in the present study for the FACT–Hep was 0.93, indicating excellent internal validity.

Anxiety and depression were assessed using the 14-item Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). Its two subscales distinguish between anxiety and depression (the values of Cronbach's α are 0.88 and 0.85, respectively, in the present study, indicating good internal reliability of the subscales). Scores on both subscales ranged between 0 and 21, with higher scores indicating higher levels of anxiety or depression. Within each subscale, scoring cutpoints distinguish between "normal" (0–7), "subclinical" (8–10), and "clinical" (11–21) levels.

Demographic variables—including age, sex, marital status, and education level—were self-reported at recruitment. Postal code was used to classify participants as residing in a major city, or in an inner regional, outer regional, remote, or very remote area using the Accessibility/Remoteness Index of Australia (Department of Health and Aged Care & National Key Centre for Social Applications of Geographic Information Systems, 2001).

The clinical information extracted from medical records included: date of diagnosis, initial place of treatment, whether the person had undergone a resection of the primary tumor, disease stage, chemotherapy dates, whether the person had a care coordinator or care plan, whether they received referral to a psychologist or social worker at initial treatment, and date of palliative care referral, if received. Dates for chemotherapy, palliative care referral, and survey completion were cross-referenced to determine if participants had received chemotherapy or palliative care referrals at the time they completed each questionnaire. We also calculated an objective quality-of-care score for each participant, as described previously (Burmeister et al., 2016*a*; 2016*c*). In short, for each participant we calculated their potential quality-of-care score by identifying which of the 18 clinical items applied to their specific clinical situation and summing the mean scores of importance (range = 0–10) obtained from a Delphi survey for these items. We then summed the mean score for those items where the care was delivered for each participant. The delivered care score was divided by the potential score to calculate a proportional quality-of-care score that ranged between 0 and 1 for each participant. Date and cause of death were captured from the medical records if the person died within 12 months of diagnosis. To update survival information, we reviewed death information held by the Cancer Registry in February of 2014.

Statistical Methods

All analyses were stratified by whether or not participants had undergone a resection of their primary tumor due to the significant differences with respect to treatment and prognosis between the two groups. To rank the 15 care-coordination items in order of how well they were rated by participants, we calculated the mean score for each item. In this sample, the overall care-coordination score and communication subscale were approximately normally distributed, while the navigation subscale was not, but the skewness was not sufficient to rule out linear regression analysis. We assessed associations between personal and clinical factors and the care-coordination score using the two-sample *t*-test and analysis of variance. Small cell sizes in some categories affected statistical power, so we considered differences in mean scores between categories of 3 or more to be clinically meaningful (using the greater than one-third standard deviation rule [Sloan et al., 2005]) and $p < 0.1$ to be statistically significant. Associations between care-coordination scores and continuous patient-reported outcomes and survival were investigated using general linear regression and Cox regression, respectively. The results from bivariate analysis and causal diagrams were used to guide the selection of covariates for the multivariable models. Potential confounders that substantially changed the estimated coefficient of interest in at least one regression model were included in the final regression models for all outcomes of interest.

RESULTS

Participants

On average, participants were 66 years old at diagnosis (range = 29–89). More than half (59%) were men, most (81%) were married or had a partner, 60% had a technical college or university education, and about half (49%) lived in a major city (Table 1). These characteristics were proportionally similar to the cases enrolled in the QPCS (Tran et al., 2013). The median time after diagnosis at the time of completing the final questionnaire was 7 months (range = 1–8), and 70% were at least 6 months postdiagnosis. Many participants (65%) were initially treated in a private setting, 47% had a tumor resection, 27% had metastatic disease, and most (78%) had received chemotherapy (Table 1).

Table 1. *Participant characteristics (N = 110)*

	n	%
Age, years		
<60	33	30
60–69	36	33
70+	41	37
Sex		
Male	65	59
Female	45	41
Marital status		
Married/partner	89	81
Divorced/separated/widowed/never married	21	19
Education		
High school or lower	44	40
Diploma/trade/university	65	60
Place of residence		
Major city	54	49
Inner regional	46	42
Outer regional	10	9
Months postdiagnosis [a]		
1–2	12	11
3–5	21	19
6–8	77	70
Initial place of treatment [a]		
Public hospital	38	35
Private hospital/specialist rooms	70	65
Disease status [a]		
Resection completed, curative disease	54	47
No resection, locally advanced disease	21	19
No resection, metastatic disease	30	27
No resection, because of age/comorbidities	7	6
Had chemotherapy [a]		
No	24	22
Yes	86	78

[a] Data from medical records.
Not all frequencies sum to 110 due to some missing data.

Best- and Worst-Ranked Care Coordination Items

Overall, the mean total cancer care-coordination score was 56.8 (7.9 *SD*), and mean scores for the communication and navigation domains were 35.4 (5.9 *SD*) and 21.4 (3.3 *SD*), respectively. In general, items from the navigation domain ranked higher than items from the communication domain (Table 2). There were no significant differences between those who had a resection and those who did not for any of the 15 care-coordination items. In both participant groups, the highest-ranked care items related to knowing who was responsible for coordinating assessments and treatment, feeling that health professionals were fully informed about their history, and waiting times for appointments or treatment. The lowest-ranked care items related to how often people were asked about how visits with other health professionals were going and how well they and their family were coping, knowing the warning signs and symptoms that they should monitor, having sufficient help from staff with the emotional impact of their disease, and having access to additional services needed (e.g., counseling, cancer support groups, and nutritional advice).

Factors Associated with Care Coordination Scores

Among participants who had a resection, those who had not received chemotherapy reported poorer care coordination (Table 3). Among participants who had not undergone resection, clinically

Table 2. *Care coordination items, ranked from best (1) to worst (15) based on mean score*

Rank [a]	Items	Overall ($n = 110$) Mean (*SD*)	Resection completed ($n = 52$) Mean (*SD*)	No resection ($n = 58$) Mean (*SD*)	Domain
1	How often did you have to wait too long to get the first available appointment for a test or treatment?	4.5 (0.8)	4.5 (0.8)	4.6 (0.7)	Navigation
2	How often were you confused about the roles of the different health professionals involved in your care?	4.4 (0.9)	4.4 (0.9)	4.4 (0.9)	Navigation
3	How often did you feel that health professionals looking after you were not fully informed about your history and progress?	4.4 (0.9)	4.4 (0.9)	4.4 (0.9)	Navigation
4	I always knew the reason why I was having a test or treatment.	4.1 (0.8)	4.2 (0.8)	4.0 (0.8)	Communication
5	How often were you unsure who to call out of business hours if you had a problem?	4.1 (1.2)	4.1 (1.2)	4.0 (1.1)	Navigation
6	How often was it difficult to meet the costs associated with your healthcare?	4.0 (1.2)	3.9 (1.3)	4.1 (1.2)	Navigation
7	I had a good understanding of the things I was responsible for to help my treatment plan run smoothly.	3.9 (0.7)	4.0 (0.7)	3.8 (0.8)	Communication
8	I had sufficient help from staff with practical arrangements.	3.9 (0.7)	4.0 (0.7)	3.8 (0.8)	Communication
9	I knew whether chemotherapy and/or radiotherapy were suitable for me.	3.9 (1.0)	4.0 (1.0)	3.8 (1.0)	Communication
10	I always knew what tests, treatments, and follow-up were planned for me.	3.8 (1.0)	4.0 (0.9)	3.7 (1.0)	Communication
11	I had access to all the additional services (e.g., counseling, cancer support groups, nutritional advice) that I needed.	3.6 (1.0)	3.7 (1.0)	3.6 (1.0)	Communication
12	I had sufficient help from staff in dealing with the emotional impact of my cancer.	3.5 (1.1)	3.5 (1.1)	3.5 (1.1)	Communication
13	I knew the warning signs and symptoms I should watch for to monitor my health.	3.4 (1.1)	3.5 (1.2)	3.3 (1.0)	Communication
14	How often were you asked how well you and your family were coping?	3.1 (1.2)	3.1 (1.2)	3.2 (1.2)	Communication
15	How often were you asked how your visits with other health professionals were going?	2.1 (1.2)	2.3 (1.3)	2.0 (1.1)	Communication

[a] Ranking based on overall position.

Table 3. *Factors associated with care-coordination scores, stratified by whether or not the participants had undergone resection of their tumor*

	Resection completed ($n = 52$)			No resection ($n = 58$)		
	Overall cancer care coordination (15 worst to 75 best)			Overall cancer care coordination (15 worst to 75 best)		
	n	Mean (*SD*)	*p* value[b]	*n*	Mean (*SD*)	*p* value[b]
Age, years						
<60	19	56.1 (9.0)	0.482	14	55.0 (8.1)	0.090*
60–69	21	59.2 (7.7)		15	53.0 (8.0)	
70+	12	57.5 (8.0)		29	58.1 (6.9)	
Sex						
Male	32	57.3 (9.2)	0.660	33	56.1 (8.5)	0.948
Female	20	58.3 (6.5)		25	56.0 (6.5)	
Marital status						
Married/partner	43	57.8 (8.4)	0.760	46	55.1 (8.0)	0.066*
Divorced/separated/widowed/never married	9	56.9 (8.0)		12	60.0 (5.1)	
Education						
High school or lower	18	57.0 (9.3)	0.654	26	55.0 (9.1)	0.383
Diploma/trade/university	34	58.0 (7.7)		31	56.8 (6.5)	
Place of residence						
Major city	28	56.4 (8.0)	0.246	26	57.0 (6.6)	0.417
Regional	24	59.1 (8.5)		32	55.3 (8.4)	
Months postdiagnosis[a]						
1–5	12	58.8 (7.6)	0.592	21	53.6 (7.3)	0.073*
6–8	40	57.3 (8.5)		37	57.4 (7.6)	
Initial place of treatment[a]						
Public hospital	14	56.3 (10.1)	0.515	24	55.3 (8.0)	0.600
Private hospital/specialist rooms	37	58.1 (7.6)		33	56.4 (7.6)	
Had chemotherapy[a]						
No	8	53.2 (10.2)	0.096*	16	57.0 (7.1)	0.567
Yes	44	58.5 (7.7)		42	55.7 (7.9)	
Had a care coordinator/care plan[a]						
Yes	10	57.7 (8.8)	0.883	18	56.2 (6.8)	0.821
No	34	58.1 (8.3)		32	55.6 (8.6)	
Referred to a mental health professional (psychologist or social worker) at initial treatment[a]						
Yes	21	56.6 (8.0)	0.172	29	55.6 (8.3)	0.999
No	20	60.0 (7.6)		19	55.6 (7.5)	
Referred to palliative care[a]						
Yes	11	60.2 (7.0)	0.251	40	55.3 (8.4)	0.313
No	41	57.0 (8.5)		18	57.6 (5.8)	
Quality-of-care score[a]						
Worst tertile	14	59.4 (10.1)	0.318	23	56.9 (7.1)	0.140
Middle tertile	18	55.3 (7.8)		19	57.7 (5.6)	
Best tertile	20	58.5 (7.0)		16	52.9 (9.8)	

[a] Data from the medical record.
[b] Two-sample t-test for dichotomous factors and analysis of variance (ANOVA) for factors with three or more categories.
* Clinically significant.

significant factors associated with a poorer care-coordination score included being younger than 70 years of age, having a partner, and a shorter time since diagnosis. Sex, education, place of residence, initial place of treatment, having a care plan, referral to a mental health professional, referral to palliative care, and the quality-of-care score derived from medical records were not associated with care-coordination scores in either group.

Associations between Care Coordination Scores and Health Outcomes

Among participants who had undergone resection of their primary tumor, better communication and navigation care-coordination scores were significantly associated with better quality of life, lower anxiety and depression scores, and fewer disease-specific symptoms (Table 4). Significant associations also occurred for all the well-being subscales, except for social well-being. For those with no tumor resection, no significant associations with patient-reported outcomes were found.

Perceptions of overall cancer care coordination was not associated with survival in participants who had a resection (hazard ratio $[HR] = 1.00$, $CI_{95\%} = 0.95{-}1.05$, $p = 0.981$) or who did not have a resection ($HR = 0.98$, $CI_{95\%} = 0.93{-}1.02$, $p = 0.262$). Similarly, there was no association between the communication or navigation care-coordination domain scores and survival in either group (data not shown).

DISCUSSION

The care of patients with pancreatic cancer can be complex. Prognosis is guarded for most operable cases, and in Australia people with locally advanced disease have a median survival of 8.7 months, while those with metastatic disease have a median survival of 2.5 months (Burmeister et al., 2015). Pain and other disease-related symptoms are common and debilitating features of this cancer. Our present study indicates that people with pancreatic cancer were satisfied with their clinicians' knowledge of their case, communication about treatments, waiting times, and their understanding of their clinicians' roles and about who to contact. In contrast, people were less satisfied with such other aspects of their care as support with managing the emotional impact of their disease on themselves and their family; having access to additional services that they felt they needed (e.g., counseling, cancer support groups, nutritional advice); and being taught how to monitor their symptoms. Furthermore, we found that for participants who had undergone resection of their tumor, a perception that their care was poorly coordinated was significantly associated with a worse quality of life, disease-related symptoms, and anxiety and depression. Although not statistically significant, we also saw a similar trend for the group who did not undergo resection. This suggests that improving peoples' perceptions of care coordination may lead to improvements in patient-reported outcomes or that poorer quality of life influences perceptions of how well care works.

Internationally, there has been a move toward development of better models of cancer care in order to optimize survival times and quality of life (Clinical Oncology Society of Australia Model of Survivorship Care Working Group, 2016). There is a consensus that people with pancreatic cancer should be fully aware of the risks and benefits of treatments, should be advised of the limitations of chemotherapy, and that there should be careful attention paid to pain control (Burmeister et al., 2016*c*). Our previous work identified 18 medical record items that can be indexed to establish a quality-of-care score that is associated with better survival in people with pancreatic cancer (Burmeister et al., 2016*a*). Somewhat surprisingly, the self-perceived care-coordination score was not associated with the objective quality-of-care score or with survival for participants who did or did not undergo resection. This is most likely because these two scores measure different aspects of care, with one measuring such objective criteria as the size of the hospital in which the surgery occurred, and the other including more subjective items such as communication. Both measures are arguably important to consider if we are to deliver best-practice person-centered healthcare that addresses the needs of the person with cancer and that maximizes survival.

There are few population-based studies of peoples' cancer care-coordination experiences with which to compare our results (Ayanian et al., 2005; Hawley et al., 2010; Jackson et al., 2015; Durcinoska et al., 2017). It is likely that factors at the person level (e.g., referral pathways, patient empowerment strategies); health professional level (e.g., patient navigators, care coordinators); health service level (e.g., documented care pathways, multidisciplinary team meetings); and funder/system level (e.g., policy and funding mechanisms) are important for effective care coordination (Clinical Oncology Society of Australia Model of Survivorship Care Working Group, 2016). Studies of patients with colorectal and breast cancer have found that those who saw a higher number of health providers or who had more comorbid conditions, little or no understanding of the health system, poorer language skills, ethnic background, early-stage disease, a high symptom burden, no written pretreatment plan, no care coordinator, or no regular general practitioner experienced poorer care coordination (Ayanian et al., 2005; Hawley et al., 2010; Jackson et al., 2015; Durcinoska et al., 2017). While we found few factors that were associated with care coordination, the statistical power of our study was limited due to small sample size and the necessity to stratify analyses by whether or not participants had undergone tumor resection. However, we found that being younger than 70 years of age, having a partner, and being closer to the time of diagnosis were associated with poorer perceptions of care coordination among people with no resection of their tumor. Possible explanations for these associations are that older people may have more experience

Table 4. *Association between care-coordination scores (including communication and navigation domains) and patient-reported outcomes, stratified by whether or not the participant had undergone resection of their tumor*

	Quality of life (0 worst to 180 best) LS mean ($CI_{95\%}$)	Physical well-being (0 worst to 28 best) LS mean ($CI_{95\%}$)	Social well-being (0 worst to 28 best) LS mean ($CI_{95\%}$)	Emotional well-being (0 worst to 24 best) LS mean ($CI_{95\%}$)	Functional well-being (0 worst to 28 best) LS mean ($CI_{95\%}$)	Disease-specific symptoms (0 worst to 72 best) LS mean ($CI_{95\%}$)	Anxiety (0 best to 21 worst) LS mean ($CI_{95\%}$)	Depression (0 best to 21 worst) LS mean ($CI_{95\%}$)
Resection completed ($n = 52$)								
Communication								
Highest tertile	143.2 (132.6–153.7)	21.3 (18.5–24.1)	24.4 (22.6–26.2)	19.4 (17.5–21.3)	20.2 (17.2–23.2)	57.9 (53.5–62.2)	4.5 (2.9–6.1)	3.9 (2.0–5.8)
Middle tertile	125.1 (113.2–137.0)	16.8 (13.6–20.0)	22.4 (20.4–24.4)	18.1 (15.89–20.2)	16.8 (13.4–20.2)	51.1 (46.2–56.0)	5.6 (3.8–7.4)	6.0 (3.8–8.1)
Lowest tertile	114.5 (103.1–125.9)	15.4 (12.3–18.4)	22.0 (20.1–24.0)	14.9 (12.8–17.0)	14.0 (10.8–17.3)	48.1 (43.4–52.9)	8.3 (6.6–10.1)	8.0 (5.9–10.0)
p value	$<$0.001	0.009	0.119	0.005	0.016	0.006	0.004	0.011
Navigation								
Good ($>$ median)	140.5 (132.3–148.7)	20.8 (18.6–23.0)	23.5 (21.9–25.0)	19.0 (17.5–20.6)	19.6 (17.2–22.0)	57.6 (54.4–60.8)	4.7 (3.4–6.0)	4.1 (2.6–5.6)
Poorer ($\leq$ median)	112.7 (103.6–121.8)	14.4 (12.0–16.8)	22.4 (20.7–24.1)	15.6 (13.8–17.4)	14.0 (11.3–16.7)	46.3 (42.7–49.9)	7.8 (6.3–9.3)	8.1 (6.5–9.8)
p value	$<$0.001	$<$0.001	0.351	0.004	0.002	$<$0.001	0.002	$<$0.001
No resection ($n = 58$)								
Communication								
Highest tertile	123.5 (106.9–140.1)	16.2 (12.0–20.5)	24.7 (21.4–28.0)	17.3 (14.1–20.6)	16.5 (12.7–20.3)	47.5 (40.8–54.1)	6.1 (3.8–8.3)	5.1 (2.9–7.4)
Middle tertile	119.1 (105.2–133.0)	17.8 (14.3–21.4)	20.3 (17.5–23.0)	17.9 (15.2–20.6)	15.8 (12.6–19.0)	48.3 (42.7–53.9)	5.3 (3.4–7.2)	5.2 (3.3–7.1)
Lowest tertile	109.1 (96.0–122.2)	14.5 (11.1–17.9)	21.3 (18.6–23.9)	14.6 (12.0–17.1)	13.4 (10.3–16.4)	45.1 (39.8–50.5)	6.4 (4.6–8.2)	7.1 (5.3–8.9)
p value	0.370	0.423	0.097	0.203	0.400	0.724	0.702	0.272
Navigation								
Good ($>$ median)	119.7 (107.3–132.1)	17.4 (14.2–20.6)	22.1 (19.5–24.6)	17.2 (14.7–19.6)	14.8 (11.9–17.7)	48.9 (44.0–53.9)	5.5 (3.8–7.2)	5.8 (4.0–7.5)
Poorer ($\leq$ median)	113.0 (102.0–123.9)	15.1 (12.3–17.8)	21.4 (19.2–23.6)	15.8 (13.6–17.9)	15.1 (12.6–17.6)	45.2 (40.9–49.5)	6.3 (4.8–7.7)	6.2 (4.7–7.7)
p value	0.427	0.272	0.695	0.411	0.890	0.256	0.488	0.729

LS means from general linear regression adjusted for age, sex, education, months postdiagnosis. Other factors associated with care coordination, including marital status and place of residence, were not significant confounders in any of the regression analyses.

$CI_{95\%}$ = 95% confidence interval.

with navigating the healthcare system and that those without partners are not concerned with dual coordination of care for them and their caregivers who, in the pancreatic cancer setting, have been shown to have more psychosocial symptoms than the person with the cancer (Janda et al., 2017). Additionally, the first months after diagnosis is when many people with pancreatic cancer are still coming to terms with their impending mortality, and they may have heightened anxiety associated with decisions about the primary treatment and symptom management. Thus, improvements could potentially be achieved by providing emotional care, symptom education, and timely referral pathways to specialists. Moreover, support of both the person with cancer and their caregiver could be beneficial.

STUDY LIMITATIONS

This study adds important information and enhances our understanding of how patients with pancreatic cancer perceive their healthcare. It does, however, have several limitations. The small sample size resulted in limited statistical power. The proportion of participants with tumors able to be resected was higher than in the broader patient population. We overcame this issue by stratifying all analyses by whether or not resection had occurred. Participants with low quality of life or shorter survival times, as well as those with a poorer perception of their care coordination, may have been less likely to participate. There may be some reverse causality in the associations between care-coordination score and patient-reported outcomes, whereby those people with a higher symptom burden, higher distress, and poorer quality of life have a more negative outlook and therefore perceive their care coordination to be worse. Furthermore, it would have been interesting to examine the association between management by a multidisciplinary team or the level of involvement of a primary healthcare provider and perception of care coordination. However, in practice, multidisciplinary team management varies significantly from hospital to hospital and was too difficult to classify from our data, and we did not have information about primary healthcare involvement in patient care.

CONCLUSIONS

In summary, to our knowledge, this is the first study to focus on perceptions of care coordination in people with pancreatic cancer. Our research suggests that, while many core clinical aspects of care are perceived to be done well for this group of people, improvement should be made with respect to referral pathways to enable timely access to additional specialist services for psychosocial needs and symptom-based care as well as better education about monitoring symptoms. These findings inform the priority setting of care coordinators, nurse navigators, and other health professionals who assume the responsibility for care coordination. As many patients do not receive their primary care in a cancer center or are not managed by a multidisciplinary team (Burmeister et al., 2016*b*) and because needs can arise during and after hospital admissions, it is important that this type of supportive care be coordinated in the community setting, accommodating geographical distances. Moreover, our research suggests that improvements to models of care may have the potential to improve quality of life and reduce symptoms, anxiety, and depression among people with pancreatic cancer.

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DISCLOSURES

The authors hereby declare that they have no conflicts of interest to disclose.

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