

# BMJ Open Experiences and supportive care needs of UK patients with pancreatic cancer: a cross-sectional questionnaire survey

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## ABSTRACT

**Objectives** Patients diagnosed with pancreatic cancer have the poorest survival prognosis of any cancer. This survey aimed to describe their experiences of care and supportive care needs to inform future service provision.

**Design** Cross-sectional questionnaire survey of patients with pancreatic cancer in the UK.

**Setting** Individuals at any stage along the care pathway were recruited via five National Health Service sites in the UK, and online, from January to June 2018.

**Participants** 274 individuals completed the questionnaire (78% (215) were completed online). Approximately half of participants were diagnosed within the last year (133/274). Of 212 providing gender details, 82 were male and 130 were female. Ninety per cent (192/213) described themselves as White British.

**Primary outcome measures** Experiences of communication and information; involvement in treatment decisions; supportive care needs.

**Results** Communication with, and care received from, clinical staff were generally reported positively. However, 29% (75/260) of respondents did not receive enough information at diagnosis, and 10% (25/253) felt they were not involved in decisions about their treatment, but would have liked to be. Supportive care needs were greatest in psychological and physical/daily living domains. 49% (108/221) of respondents reported one or more moderate/high unmet needs within the last month, of which the most commonly reported were: dealing with uncertainty about the future; fears about the cancer spreading; not being able to do things they used to; concerns about those close to them; lack of energy; anxiety; feelings of sadness and feeling down/depressed. Experiences were poorer, and unmet supportive care needs greater, in patients with unresectable disease.

**Conclusions** Patients with pancreatic cancer have unmet information and support needs across the cancer trajectory. Psychological and physical support appears to be the biggest gap in care. Needs should be assessed and supportive care interventions implemented from the point of diagnosis, and monitored regularly to help patients live as good a quality of life as possible.

## INTRODUCTION

Pancreatic cancer is the 11th most common cancer in the UK, accounting for 3% of all new cancer cases (2015).<sup>1</sup> There are around 9800

## Strengths and limitations of this study

- Patients with pancreatic cancer are under-represented in psychosocial research and this survey provides important insight into their experiences and needs.
- Cognitive testing of the questionnaire was undertaken with a sample of patients, to maximise consistency of responses.
- The study achieved a good sample size, but generalisation is limited by the sampling method used.
- Recruitment through National Health Service clinics was low and most participants were recruited using online methods.
- The sample over-represented people with resectable (better prognosis) disease.

new pancreatic cancer cases in the UK every year (2013–2015).<sup>1</sup> Around a fifth (21%) of people diagnosed with pancreatic cancer survive their disease for 1 year or more, and only around 3% for 5 years or more.<sup>1</sup> Survival has shown little improvement in the last 40 years, and pancreatic cancer is the fifth most common cause of cancer death in the UK.<sup>1</sup>

Poor prognosis results from a combination of late diagnosis, aggressive tumour biology, complex surgical procedures and a lack of effective systemic treatments. Only around 10%–15% of patients are eligible for tumour resection, and approximately 28% of patients have chemotherapy as part of their primary cancer treatment.<sup>2</sup> Newer treatments offer optimism, and can help some patients to live for many months or even years.<sup>3</sup> For most, however, supportive care is the mainstay of management.

Pancreatic cancer is associated with marked symptoms that have a severe impact on quality of life. The early identification and palliation of symptoms is therefore an important aspect of patient care. There is evidence to suggest that the severity of these symptoms can predict prognosis and survival.<sup>2</sup> Given the nature and prognosis of the disease, it

is unsurprising that studies have reported diminished quality of life in patients with pancreatic cancer when compared with other cancer populations and the general population.<sup>4</sup> However, the literature on patient experiences of pancreatic cancer is limited.

Patient experience is increasingly recognised as one of the central components of healthcare quality, and positive associations have been identified between patient experience, patient safety and clinical effectiveness.<sup>5</sup> Therefore, it is essential to understand people's experiences of care to inform where there is room for improving care delivery and quality. The National Cancer Patient Experience Survey has been conducted annually in England since 2010 to understand and monitor national progress on cancer care. However, the survey is generic to all cancer types, and samples only those with a hospital inpatient stay or day attendance for treatment within a specific 3-month sampling period, with invites sent several months later.<sup>6</sup> An examination of non-response to this survey found that patients with pancreatic cancer were around five times more likely to have died between sampling and survey mail-out.<sup>7</sup> As a result, the number of patients with pancreatic cancer responding to the survey is relatively low, and data specific to these patients are not available and are instead grouped alongside other cancer types.

There is a clear need for improved understanding of the physical and emotional well-being of patients with pancreatic cancer, and factors that may help improve their quality of life. This study therefore set out to explore the care experiences and supportive care needs of patients in the UK diagnosed with pancreatic cancer.

## METHODS

### Design

The study used a cross-sectional survey design. We used the Strengthening the Reporting of Observational Studies in Epidemiology cross-sectional checklist when writing our report.<sup>8</sup>

### Survey development

A draft question set was developed drawing on Picker's existing bank of validated patient experience questions, guided by the Principles of Person-Centred Care,<sup>9</sup> to enquire about experiences of care at the time of diagnosis, during treatment and beyond.

With permission from the authors, a modified version of the *Supportive Care Needs Survey-Short Form (SCNS-SF)* (34 items)<sup>10 11</sup> was incorporated into the questionnaire. It measures needs across five domains: psychological; physical/daily living; health system/information; patient care/support; sexuality. Participants were asked to score their need for help in the last month for each item as either no need, need met, low need for help, moderate need for help, or high need for help. The SCNS measure is generic to all cancers, so while we did not remove any items, we included an additional five items specific to pancreatic cancer. These were identified in our literature review and

discussions with clinical experts as being particularly relevant to patients and related to:

- ▶ Problems with sleeping.
- ▶ Nausea and vomiting (eg, feeling/being sick).
- ▶ Digestion problems (eg, bowel problems, bloating, wind, discomfort).
- ▶ Changes to appetite/body weight.
- ▶ Itchiness.

Standard sociodemographic information was also collected.

The cognitive process of responding to the survey questions was also considered,<sup>12 13</sup> seeking to establish consistency in question comprehension, information retrieval and response. Thirteen cognitive interviews were conducted with patients with a pancreatic cancer diagnosis. Minor amendments to the format and instruction of the SCNS were made following these interviews. Comparability was maintained with the original version, yet the questions were found by participants to be easier to complete once the amendments had been made. In addition, some of the patient experience questions were reworded for clarity; for example, the question, 'How do you feel about the amount of information you were given when first diagnosed', was changed to, 'How do you feel about the amount of information you were given around the time you were diagnosed'. This was in response to feedback that patients struggled to recall the conversation at the exact time of diagnosis.

The final questionnaire addressed the following topic areas: experiences of care (communication and information); supportive care needs (SCNS-SF+five additional items); financial impact of diagnosis; overall quality of life and health rating; and demographic details. The questionnaire also included four open-ended questions where participants could add more detail about their responses (data not presented). A copy of the questionnaire, and the free-text data set, is available on request from the authors.

### Patient and public involvement

Pancreatic Cancer UK provided comments on the draft questionnaire and study design. Thirteen individuals with pancreatic cancer, identified with the help of Pancreatic Cancer UK and the Oxford University Hospitals Foundation Trust pancreatic cancer team, helped to test the questionnaire.

### Study population

Anyone aged 18 and over in the UK with a diagnosis of pancreatic or ampullary cancer was eligible to take part in the survey. A small proportion of patients who are initially suspected to have pancreatic cancer eventually prove to have ampullary cancer. They are treated similarly.<sup>14</sup> The authors therefore felt that it was preferable to include both diagnoses and acknowledge that a small minority of patients included in the survey may not have pancreatic cancer.

## Sampling

Recruitment took place between January and June 2018. Five National Health Service (NHS) centres (four in England and one in Scotland) distributed questionnaires to eligible patients attending oncology clinics during the recruitment window. Centres were asked to approach all eligible patients and give them brief information about the survey and, to those who were interested, a study information pack (containing an invitation letter, study information sheet, copy of the study questionnaire and a reply paid envelope). The approach to patients was made by a member of the clinical team, most often the clinical nurse specialist.

In addition, an online version of the questionnaire was made available. This was promoted by Picker, Oxford Brookes University and Pancreatic Cancer UK, using relevant websites and social networks including Twitter, Facebook and Health Unlocked. Events hosted by Pancreatic Cancer UK, and attended by health professionals and patients, were also used to publicise the survey.

## Consent

As approved by the National Research Ethics Service, informed consent was implicit by return of a paper completed questionnaire. This was made clear in the study information. Consent for the online survey was indicated by a respondent submitting their responses or by indicating at the beginning of the survey that their partial responses may be used should they not reach the end.

## Statistical analysis

The completed paper questionnaires were returned to the research team for manual data entry. The online questionnaire was created in Snap (version 11). Snap WebHost was used to collect online responses. At the end of fieldwork, the online data were imported into SPSS (V.25) and combined with paper responses. Frequencies and proportions were used to summarise questionnaire responses. We did not impute values because we were unable to reject the hypothesis of missing not at random in what was already a non-randomised sample. Instead, we used all the data for each individual analysis and provide the denominator used in each case. Where appropriate, results were cross-tabulated by patients with resectable (undergone surgery) and unresectable (had not undergone surgery and/or no surgery planned) disease. Individuals who indicated surgery was planned were removed from these analyses. Statistical tests of inference were not conducted, as the non-random sample precludes generalisation to the population without bias. CIs (95% CIs) for proportions are provided to give insight into differences within the sample. For analysis of the SCNS-SF34 questions, the original 34 items were used to calculate five domain scores: psychological, physical/daily living, health system/information, patient care/support, and sexuality. Mean normalised domain scores were calculated using the SCNS authors' published procedure.<sup>11</sup> Briefly, this involved assigning a score of 1 (no need) to 5

**Table 1** Participant sociodemographic and clinical characteristics

	n	%
<b>Gender</b>		
Male	82	38.7
Female	130	61.3
Missing	62	
<b>Age group</b>		
31–50 years	25	11.8
51–60 years	50	23.7
61–70 years	82	38.9
>70 years	54	25.6
Missing	63	
<b>Ethnic group</b>		
White—British	192	90.1
White—Other	12	5.6
Other	9	4.2
Missing	61	
<b>Time since diagnosis</b>		
<6 months	82	29.9
6 months to 2 years	104	38.0
>2 years	88	32.1
<b>Treatment</b>		
Surgery	29	11.3
Surgery+chemotherapy	114	44.4
Chemotherapy	85	33.1
Surgery and/or chemo planned	7	2.7
No active treatment	17	6.6
Treatment plan unknown	5	1.9
Missing	17	

(high unmet need) to each SCNS item. The item scores are summed for each domain for each person, and the normalised score calculated, adjusting for the number of questions and maximum response value.

## RESULTS

### Study population

Two hundred and seventy-four completed questionnaires were received (215 online; 59 paper). Sample sociodemographic and clinical characteristics (self-reported) are summarised in [table 1](#). Some participants did not provide answers to all demographic questions asked, and individual questions were analysed according to the number of respondents to those questions. The mean age of participants was 64 years. Sixty-one per cent (130/212) were female. Forty-nine per cent (133/274) of the sample were diagnosed within the last year. Fifty-five per cent (143/258) had undergone surgery to remove part of the pancreas; 34% (87/258) were not going to have such

surgery, 4% (11/258) reported surgery was planned and 7% (17/258) did not know if they would undergo surgery.

### Experiences of communication and information

Most patients reported positive experiences of care. Thirty-eight per cent (103/271) of patients felt their diagnosis had definitely been given in a sensitive way. Participants who had had a pancreatic resection were more likely than unresectable patients to feel that their diagnosis had definitely been given sensitively (39%; 55/142, 95% CI 31% to 47% vs 31%; 27/86, 95% CI 22% to 42%).

Over one-quarter of participants felt they had not been given enough information around the time of diagnosis (29%, 75/260). A greater proportion of unresectable patients (37%; 32/87, 95% CI 27% to 42%) than those who had had a pancreatic resection (27%; 38/143, 95% CI 20% to 34%) responded in this way.

### Involvement in treatment decision-making

Ten per cent of all participants (25/253) felt they had not been involved in decisions about their treatment and care, and would have liked this, with unresectable patients more likely than resectable patients to report this (16%; 13/83, 95% CI 9% to 25% vs 6%; 9/140, 95% CI 3% to 11%). Less than two-thirds of participants (60%; 164/251) responded that staff definitely talked to them about their care and treatment in a way they could understand. Fewer patients with unresectable disease responded in this way (52%; 43/82, 95% CI 42% to 63% vs 72%; 100/139, 95% CI 64% to 79%).

### Dietary information and therapy

Most participants in this survey reported receiving pancreatic enzyme replacement therapy (PERT, 83%; 214/259). A further 5% (14/259) had been prescribed PERT but were not currently taking it. Thirty-three per cent (76/228) of participants prescribed PERT felt they had received insufficient information about it.

### Supportive care needs

The mean normalised domain scores for the SCNS-SF34 items were highest (indicating a greater need) for the psychological and physical/daily living domains (both scoring >25), and lower in the information, care and sexuality domains (scores <20) (table 2). For the SCNS-SF34

items, 86% (190/220) of respondents reported having at least one supportive care need, and 48% (105/220) reported one or more moderate or high unmet needs. Using our extended 39-item version of the SCNS, 87% (193/221) of participants reported having one or more unmet supportive care needs and 49% (108/221) reported one or more moderate or high unmet needs. All SCNS scores were higher in unresectable patients compared with resectable patients. The 10 individual survey items which were most commonly cited as a moderate or high unmet need are presented in table 3 for the overall sample, with the corresponding proportions for resectable and unresectable patients. The level of unmet need was greater in the unresectable group. For unresectable patients digestion problems (29%; 18/62) and feelings about death and dying (27%; 17/63) were included in the 10 most commonly reported moderate/high needs, whereas for the resectable group having access to a professional counsellor (18%; 19/105) was included (data not shown).

### Financial impact

Just over half of participants (52%; 111/214) felt the diagnosis of pancreatic cancer had negatively impacted on their day-to-day financial situation. Around a third (30%; 64/212) of participants had received financial advice, which they found useful. However, 28% (59/212) needed financial advice or did not find the advice they had received to be helpful.

## DISCUSSION

This study provides valuable information on the care experiences and supportive care needs of patients living with a diagnosis of pancreatic cancer in the UK. While overall patient experiences of care were positive, the study highlights some important gaps across the patient pathway, including for longer term survivors. Participants with unresectable disease expressed greater unmet needs and poorer experiences overall than patients who had received surgical resection. In the UK, surgical resection rates are around 10%–15%,<sup>2</sup> and our sample therefore considerably over-represented patients with resectable disease (56%) and therefore a better prognosis. The

**Table 2** SCNS-SF34 domain scores

Domain score	Total sample*			Resectable patients			Non-resectable patients		
	n	Mean	SD	n	Mean	SD	n	Mean	SD
Psychological	212	31.2	30.6	120	27.8	29.3	67	36.5	33.7
Physical	206	25.6	25.4	117	24.8	24.4	65	28.3	26.8
Information	203	19.7	26.4	114	15.8	23.2	67	25.3	30.6
Care	201	15.9	24.9	114	13.8	22.0	65	20.3	30.4
Sexuality	194	25.9	25.9	112	12.3	26.0	65	12.7	25.9

\*The number of missing responses varied by SCNS-SF34 items. SCNS-SF34, Supportive Care Needs Survey-Short Form (34 items).

**Table 3** Most common unmet supportive care needs

Supportive Care Needs Survey items*	Total sample		Resectable patients†		Unresectable patients‡	
Uncertainty about the future	31.4%	58/185	28.6%	30/105	37.3%	22/59
Fears about the cancer spreading	30.1%	56/186	29.5%	31/105	33.9%	21/62
Not being able to do the things you used to	25.0%	47/188	27.3%	30/110	24.1%	14/58
Concerns about the worries of those close to you	24.7%	47/190	23.4%	26/111	30.7%	19/62
Lack of energy/tiredness	23.5%	44/187	23.4%	26/111	28.1%	16/57
Anxiety	22.4%	43/192	20.9%	23/110	28.3%	17/60
Worry that the results of treatment are beyond your control	21.1%	39/185	16.0%	17/106	31.0%	18/58
Feelings of sadness	20.5%	39/190	17.8%	19/107	27.9%	17/61
Being informed about things you can do to help yourself feel better	20.4%	39/191	17.3%	19/110	28.6%	18/63
Feeling down or depressed	20.4%	40/196	18.0%	20/111	25.8%	16/62

\*The number of missing responses varied by Supportive Care Needs Survey (SCNS) item.

†Patients who were unsure if they would be having a resection or not were excluded.

‡Patients for whom a resection was planned were not included.

findings, thus, clearly indicate considerable room for improvement in the delivery of patient-centred care to patients diagnosed with pancreatic cancer.

More than one-quarter of participants felt information was lacking around the time of diagnosis, and 1 in 10 participants did not feel involved in decisions about their treatment and care, and would have liked to have been. This finding is supported by a previous UK-based qualitative study, which explored decision-making experiences of patients with pancreatic cancer. Participants reported a sense of being pressured to accept treatment, a sense that in a life-threatening situation there are no ‘real options’, and reported the confusion that can be caused when clinical opinions differ.<sup>15</sup> Another study highlighted that the patient’s perceived level of involvement in decision-making depended on the quality of information, communication and involvement during the care period.<sup>16</sup>

One-third of participants felt they had received insufficient information about PERT. This finding is concerning given that enzyme supplementation, when taken correctly, helps prevent weight loss and improve quality and duration of survival.<sup>17</sup> It is recommended for the majority of patients.<sup>18</sup> A previous qualitative study also reported poor understanding of the impact of advanced pancreatic cancer on digestion, a lack of awareness of potential interventions to treat pancreatic exocrine insufficiency and a lack of understanding about the symptoms of pancreatic exocrine insufficiency on the part of the participants.<sup>19</sup>

In relation to supportive care needs, we found needs were greatest in the psychological and physical/daily living domains, concurring with the findings of a recent review of the unmet needs of patients with advanced cancer.<sup>20</sup> Correspondingly, psychological concerns were prominent in the most commonly reported individual moderate or high unmet need, including: dealing with uncertainty, fear of progression of cancer, concerns about

family members and feelings of sadness or depression. Lack of energy and not being able to do the things they used to do were commonly reported physical unmet needs. Interestingly, the five additional pancreatic cancer-specific items we included did not emerge in the 10 most common moderate/high unmet needs for the overall sample, although digestion problems were included in the top 10 for patients with unresectable disease.

Our findings regarding supportive care needs differ in some respects from a previous Australian study, which also used the SCNS-SF34 to explore the unmet needs of patients with pancreatic cancer.<sup>21</sup> Overall, they found a higher level of supportive care needs and whereas we found the scores to be highest for the psychological domain they found the highest score for the physical/daily living domain, followed by the psychological, health system/information and patient care domains, which all scored equally. They also found 69% of respondents reporting at least one moderate to high unmet need. However, the median time from diagnosis of study participants was 3 months, whereas 70% of our respondents were diagnosed more than 6 months ago, which may explain this difference in findings. Nonetheless, 6 of the top 10 reported moderate to high unmet individual needs items were the same.

The findings from our study suggest that despite the recommended introduction of holistic needs assessment and survivorship care planning to cancer care services,<sup>22</sup> the psychological aspects of being diagnosed with pancreatic cancer are not being adequately addressed in the UK. Recent guidance on the diagnosis and management of pancreatic cancer<sup>18</sup> highlights the importance of assessing for and supporting the management of psychological distress. However, many services are stretched and do not have the resources in terms of manpower or skills to address psychological concerns. In some centres, there

are very limited psychological services available. In other centres, the waiting list may be long and thus problematic for patients with a poor prognosis disease. Referral to psychological services provided in the community (in the UK, via the Improving Access to Psychological Therapies programme<sup>23</sup>), and signposting to charity counselling and advice services could be helpful for some patients and carers.

There are few psychosocial intervention studies in the literature targeting patients with pancreatic cancer. A small pilot study trialled an interdisciplinary supportive care planning intervention comprising quality of life assessment, case presentation at interdisciplinary care meeting and two nurse-administered educational sessions addressing quality of life concerns.<sup>24</sup> Patients found the intervention useful but further work is needed to confirm this. A previous study has indicated that a home-based walking programme with regular self-monitoring was feasible, safe and significantly improved fatigue, physical functioning and quality of life compared with usual care,<sup>25</sup> although again further research in this area is needed. A survey of survivors treated for resectable pancreatic cancer in the USA found that over two-thirds of patients expressed interest in exercise and diet intervention programmes.<sup>26</sup>

Our study has also indicated the level of concern patients have about those close to them, and previous research has indicated the health of caregivers is diminished.<sup>27</sup> The development of interventions to support caregivers as well as patients is therefore important.

### Strengths and weaknesses

Patients with pancreatic cancer are very under-represented in psychosocial research. The nature and prognosis of the disease makes this a hard-to-reach patient group, yet one with potentially huge needs. This survey provides responses from 274 individuals in the UK and gives important insight into the experiences and needs of people affected by pancreatic cancer. However, our sample cannot be considered representative of the pancreatic cancer patient population in the UK. Response to recruitment through NHS clinics was low. Online recruitment was much more successful, but introduced greater potential for selection bias. The proportion of resected patients (who have a better prognosis) in our sample is much higher than the national average. Related to this, almost one-third of our sample received their diagnosis more than 2 years ago whereas Public Health England's National Cancer Registration and Analysis Service for the period 2006–2015 indicates a 2-year survival in only 11% of patients and 3-year survival in 8% of patients. However, our findings provide novel and valuable data on longer term survivors with pancreatic cancer.

### CONCLUSION

Patients with pancreatic cancer have unmet information, communication and support needs across the cancer trajectory, particularly those with unresectable

disease. Needs should be assessed, and supportive care interventions implemented from the point of diagnosis, with regular monitoring thereafter to help patients with pancreatic cancer live as good a quality of life as possible. Psychological support emerged as an important gap in care, and interventions to provide psychological support to patients and their families are required. The use of qualitative research methods and potentially the inclusion of carers as well as patients in future research would further our understanding of patient needs and the types of intervention that would be most useful.

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**Contributors** EW, JB, ZS: project inception, management and clinical input. AT: project inception, questionnaire design. HH, CW, AP: project management, questionnaire design, qualitative analysis. AJP and SS conducted statistical analysis and interpreted the findings. All contributed to this manuscript and approved the final draft.

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**Data availability statement** Data are available in a public, open access repository. Data are available upon reasonable request. All data relevant to the study are included in the article or uploaded as supplementary information.

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