


BMJ Open 'It's always in the back of my mind': understanding the psychological impact of recovery following pancreaticoduodenectomy for cancer: a qualitative study

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ABSTRACT

Objectives Ten per cent of patients diagnosed with pancreatic cancer undergo pancreaticoduodenectomy. There is limited previous research focusing on psychological well-being; unmet support needs impact negatively on quality of life. This paper reports the psychological impact of a pancreatic cancer diagnosis and subsequent pancreaticoduodenectomy, exploring how patients' lives alter following surgery and how they seek support.

Design Inductive qualitative study involving in-depth semistructured interviews with 20 participants who had undergone pancreaticoduodenectomy for pancreatic or distal biliary duct cancer. Interviews were audiorecorded, transcribed and anonymised, and thematic analysis used principles of constant comparison.

Setting Single National Health Service Trust in Northwest England.

Participants Patients were eligible for inclusion if they had had pancreaticoduodenectomy for head of pancreas cancer, periampullary cancer or distal cholangiocarcinoma between 6 months and 6 years previously, and had completed adjuvant chemotherapy.

Results Analysis identified the following main themes: diagnosis and decision making around surgery; recovery from surgery and chemotherapy; burden of monitoring and ongoing symptoms; adjusting to 'a new normal'; understanding around prognosis; support-seeking. Participants seized the chance to have surgery, often without seeming to absorb the risks or their prognosis. They perceived that they were unable to control their life trajectory and, although they valued close monitoring, experienced anxiety around their appointments. Participants expressed uncertainty about whether they would be able to return to their former activities. There were tensions in their comments about support-seeking, but most felt that emotional support should be offered proactively.

Conclusions Patients should be made aware of potential psychological sequelae, and that treatment completion may trigger the need for more support. Clinical nurse specialists (CNSs) were identified as key members of the team in proactively offering support; further training

Strengths and limitations of this study

- We believe that this is the first qualitative study using semistructured interviews to explore the psychological impact of living with and after pancreaticoduodenectomy.
- Semistructured interviews generated rich data, and use of constant comparative principles enabled simultaneous analysis with refinement of the topic guide and exploration of key themes that were important to participants.
- The sample included a wide range of ages and number of months since surgery, equal numbers of participants were male and female, and the sample included those who had had a recurrence.
- The authors have differing backgrounds (surgery, primary care and psychiatry), which offer different perspectives on the analysis and findings.
- Generalisability may be limited by the fact that this is a single-centre study and there was limited ethnic diversity in the sample.

for CNSs should be encouraged. Understanding patients' experience of living with cancer and the impact of treatment is crucial in enabling the development of improved support interventions.

INTRODUCTION

Pancreatic cancer is the 10th most common cancer in the UK, accounting for 3% of all new cancer cases in 2017.¹ However, the incidence is rising, which is thought to reflect an increased prevalence of obesity and diabetes as well as an ageing population.^{2 3} Most cancers present and are diagnosed at a late stage, and its global mortality/incidence ratio is 94%.⁴

In 2013–2014, 10%⁴ of patients diagnosed with pancreatic and distal biliary duct cancers in England had surgery to remove

their primary tumour, with or without adjuvant chemotherapy or radiotherapy.⁵ The most common type of surgery performed for pancreatic adenocarcinoma, distal cholangiocarcinoma and periampullary tumours is a pancreaticoduodenectomy (or Whipple's procedure). This high-risk surgery has a mortality of up to 3% and morbidity of up to 30%.⁶

There is limited previous qualitative research reporting the psychological impact of patients diagnosed with, and following surgery for, pancreatic cancer. However, it is known that patients who undergo pancreaticoduodenectomy due to adenocarcinoma report significantly lower quality of life compared with healthy individuals and those undergoing surgery for non-cancer disease.⁷ Tang *et al*⁸ reported that psychological symptoms receive insufficient attention in pancreatic cancer research but that psychological stress may be common. This view is supported by several observational studies which suggest that as many as 20% patients may meet criteria for anxiety or depression.^{9 10} Pancreatic Cancer UK,¹¹ in a 2018 survey of 274 people living with pancreatic cancer, identified that 87% of patients had one or more physical or psychological unmet need, with 68.1% reporting uncertainty about the future and 67.0% reporting fears about recurrence. Distress may be related to an unexpected cancer diagnosis, changes in identity, coping with symptoms related to cancer and fear of the future.¹²

People living with and after cancer frequently perceive it as a biographically disruptive event, where there is an abrupt change in the structures of everyday life and relationships with family and friends, in addition to individual recognition of suffering and mortality.¹³ This leads to a change in the way survivors view themselves, their lives and their own mortality.¹⁴ People with long-term conditions, including cancer, are two to three times more likely to experience mental health problems, such as anxiety and depression, than the general population.¹⁵ Patients with comorbid physical and mental health problems also have poorer clinical outcomes, lower quality of life, and reduced ability to manage physical symptoms effectively.¹⁵ Strong *et al*¹⁶ found that in a study of patients attending a regional cancer outpatient department, 22% (674/3071) were experiencing emotional distress. More recently, Dauphin *et al*¹⁷ found that older patients (aged 70 years and over) with cancer had high levels of distress persisting for 5 years after diagnosis, while middle aged patients' (aged 50–69) distress decreased after diagnosis and then remained stable with a prevalence of 23%. The incidence of pancreatic cancer is strongly related to age; in the UK between 2014 and 2016, 47% of new cases were in people aged 75 and over and incidence rates rise steeply from around the age of 50.¹ Pancreatic cancer is distinct from other cancers due to its high mortality and limited treatment options.^{4 5} Recognising and managing psychological distress is, therefore, particularly important in this population.

Much of the previous qualitative research has explored symptom appraisal and helpseeking.^{18–20} Other studies

have considered the symptoms experienced by patients following pancreaticoduodenectomy and how patients view and manage these.^{21 22} Few studies have focused solely on those with resectable disease. However, National Institute for Health and Care Excellence guidance recommends that further research be conducted specifically focusing on the psychological support needs of patients with pancreatic cancer.²³ In this qualitative study, we explored the psychological impact of diagnosis and surgery, how patients' lives change following surgery, support they accessed for their psychological well-being, and further support they need.

METHODS

This paper reports a qualitative study in which semi-structured interviews were conducted with patients following pancreaticoduodenectomy surgery. Semistructured interviews ensured that all topics were covered, while enabling participants to talk without limitation about the areas they felt were most important.^{24 25}

Recruitment

Clinical nurse specialists (CNSs) identified potential participants who were under the care of a tertiary hepatopancreaticobiliary (HPB) centre in the North West of England. Patients were eligible for inclusion if they had had pancreaticoduodenectomy surgery between 6 months and 6 years previously for either head of pancreas cancer, periampullary cancer or distal cholangiocarcinoma, and had completed surgery and adjuvant chemotherapy. Patients were excluded from the study if they were under the age of 18, if they had a current diagnosis of a severe mental illness (determined through review of general practitioner (GP) coded diagnoses), lacked capacity to consent, or were in their last days of life. Fifty-two patients met these criteria.

Five patients at a time were invited to participate by a CNS, selected from the list of eligible patients using a random number generator. Patients were telephoned by a CNS and given information about the study; if they consented to further contact, they were then posted or emailed the participant information sheet and invited to contact the research team to arrange an interview with a researcher with expertise in qualitative research methods (AKT).

Data collection

Between December 2019 and February 2020, 16 semi-structured interviews were conducted by the researcher (AKT) in patient's homes or at the hospital, depending on participant preference. Recruitment was halted due to restrictions imposed during the COVID-19 pandemic and then recommenced in July 2020, with four further interviews conducted via a virtual video platform (to comply with COVID-19 restrictions). Written consent to participate and for digital (audio) recording was gained prior to interview. A topic guide, developed using the

existing literature and with input from a patient advisory group (PAG), was used to generate data; the interviewer employed the topic guide flexibly, using open questions to ensure all topics were covered while enabling participants to bring up subjects important to them. Interviews explored participants' experience of the diagnostic process and surgery, the impact of cancer and surgery on their life, sources of support and access to care. Participants were offered a £20 gift card to thank them for their time.

Data analysis

Demographic data, including date of birth, diagnosis and date of surgery were collected from clinical notes. Following recording, the interviews were transcribed verbatim and anonymised. The research team included two junior doctors (AKT and LR), two HPB surgeons (DC and AK) and one GP (CC-G). The six steps as outlined by Braun and Clarke²⁶ were followed: familiarisation with the data, generalising initial codes, searching for themes, reviewing themes, defining and naming themes, producing the report. These steps were operationalised as outlined. Line-by-line coding was undertaken by one researcher (AKT) for all interviews, and analysed initially using inductive and interpretive thematic analysis.²⁶ The other researchers (DC, AK, CC-G and LR) also used line-by-line coding to analyse a subset of transcripts, and the codes were discussed collaboratively at researcher meetings to identify, modify, agree and name key themes. However, the authors (DC and AK) did not see or analyse the transcripts of patients whose care they were directly responsible for, in order to avoid bias. The analysis was continually refined using principles of constant comparison,²⁷ enabling adjustment and triangulation of themes and codes^{28 29} until agreement was made by the research team.³⁰ Sample size was determined by data saturation, which was judged to be the point at which no new themes were derived from the analysis.³¹ Saturation was achieved

at 18 interviews; two further interviews were undertaken to confirm this.

Patient and public involvement and engagement

A PAG was convened with patients who had undergone a pancreaticoduodenectomy more than 6 years previously and were thus ineligible for inclusion in the study. The aims and methods of the study were discussed, and the PAG members commented on the topic guide, invitation letter and participant information sheet. The topic guide was refined to reflect their suggestions and priorities. The PAG was reconvened following completion of the interviews to discuss preliminary analysis and invite reflection, and were invited to make suggestions for dissemination. Finally, a lay summary was circulated to participants following completion of analysis.

RESULTS

Twenty participants were interviewed (see table 1 for participant demographics). Interviews were between 51 and 187 min in length (mean 105 min). Four patients declined, citing the desire to move on from their cancer diagnosis and stating that revisiting it would distress them. Eleven patients who were originally eligible for inclusion at the start of the recruitment period died before they were invited to participate, and one patient developed a new primary malignancy during the recruitment period.

The following themes will be presented in this paper, with illustrative quotes identified by a pseudonym for each participant: reactions to diagnosis and decision making; recovering from surgery and chemotherapy; monitoring burden and dealing with new symptoms; adjusting to a new normal; understanding around prognosis; support-seeking.

Reactions to diagnosis and decision-making around surgery

Most participants described a sense of shock when receiving the initial diagnosis of cancer. Only some of the

Table 1 Participant demographics

% female	10/20 (50.0%)	
% white British	20/20 (100.0%)	
% tertiary referral	12/20 (60.0%)	
Mean age at diagnosis (range)	65.2 years (45–79 years)	Median 66, IQR 14.8
Mean age at interview (range)	67.9 years (47–82 years)	Median 68.5, IQR 16.5
Mean months since surgery (range)	24.5 months (10–72 months)	Median 20.5, IQR 13.0
Mean length of hospital stay (range)	22.1 days (7–96 days)	Median 15.5, IQR 16.5
% neoadjuvant chemotherapy	1/20 (5.0%)	
% adjuvant chemo	16/20 (80.0%)	
% recurrence	4/20 (20.0%)	
Initial presentation as emergency	10/20 (50.0%)	
Fast tracked to surgery	6/20 (30.0%)	
Postoperative complication Clavien Dindo >grade 2	11/20 (55.0%)	

participants reported that they had considered the possibility of cancer prior to the diagnosis:

I was thinking well maybe it is just something that's quite benign. You know, a benign growth. So when they did say it's cancer that really... sledgehammered me... Cos I was still hanging onto this hope that it was benign you know... You just want things to happen quickly. It was really frightening, really scary. Joseph

It all happened very quickly, all out of the blue really. Totally unexpected... I saw the specialist within a week [of the blood tests investigating anaemia], and she operated the next week... It was very very quick, it was... [quiet laugh] what's happened here, I only came for a blood test. Janet

Although their initial reaction was shock, they also described worrying that the impact of the diagnosis was harder for their family members. Participants reflected that their families may have felt helpless, frightened, and unsure of how to support them. They also feared that if they were to die they would leave their family behind, and worried about how this would impact them.

One of the worst things I think is when you're diagnosed with cancer is I think it affects your partners worse in some respects because they can't do anything, they can't do anything about it can they? Theresa

Some participants also described feeling angry at the diagnosis, or felt that the life they had hoped for had been taken away:

All I could think was that I'd waited all this time for a grandchild and I wasn't going to be around. Helen

I were panicking about my wife and kids... Suddenly you think, your head's going 'I might not be here at Christmas, there are so many things I want to do with my family and my wife and I'm not going to get to do them'. I felt sorry for me, really, that I was gonna miss out on... I promised myself when I got told I was a chunky monkey and had diabetes, that I was gonna beat it and walk my daughter down the aisle. And then that idea was taken away from me, it felt like it was being taken away. Michael

Participants described how they quickly grasped the opportunity to have surgery when it was offered; they reported feeling that they had no choice but to undergo surgery, and they had little time to make the decision:

I just kept thinking about my children... From going in on that first day and meeting the consultant I just said 'I want it out, I don't care' you know. I could live with diabetes whatever, but you can't live with cancer and I wanted it out... I thought well, if I don't try I'm going to die anyway. So I'm gonna have to go for it, and I'm putting trust, a lot of faith in them. Deborah

The first thing he said was er, 'well you have got cancer, but' and straight away he said but, 'we can do something about it'... He said 'it'll be like running a marathon for you afterwards' because it's such a big operation. But you see at that

point probably I weren't listening to any of that because all I knew is that he'd given me a lifeline. Theresa

They reflected that they often had not fully absorbed the minutiae of the risks of the operation; neither had they had the chance to fully consider possible outcomes. Some participants, however, suggested that they would rather die during the operation than not proceed with surgery, because death was otherwise felt to be inevitable. Some also described making plans in case death was the outcome during surgery or soon after, even while acknowledging that they did not completely understand the risks of the operation at the time.

There's always a chance that I wouldn't come round again afterwards, or something like that and, uh, so you know I went and made sure my will was made and stuff like that before I went in, so I did have that thought. Margaret

Recovering from surgery and chemotherapy

All participants described the difficulties they faced in their recovery following surgery, emotional as well as physical:

I felt down. I felt emotional, weepy. I felt hopeless and couldn't do things around the house like I used to do. Uh. Couldn't do anything really. Joseph

However, it seemed that participants who had a short inpatient stay with few complications experienced similar concerns to those with more protracted admissions and postoperative complications.

Participants who had received chemotherapy in addition to surgery frequently commented that they had found chemotherapy more challenging than their operation to recover from. The impact was often felt to be two-fold: that the side effects of chemotherapy limited their ability to continue recovering from the physical insult of surgery, and the chemotherapy itself had its own side effects which occurred over months:

One of the worst things were the tiredness, because... I felt like I was getting better as in more energy before, and then I went on the chemo and it just seemed to knock me back. Theresa

In addition, some participants described a worsening of their feelings of anxiety when returning to the hospital for chemotherapy:

I just, as soon as we were going to the hospital I would shake. And like I say I'm a positive person, I'm not this nervous wreck. But I was. And it was awful. It was awful, I absolutely dreaded every session. Helen

This participant, like others, reflected that her usual personality ('a positive person') had been changed by the experience of surgery and chemotherapy. Others felt that the 'fear' involved in being treated with chemotherapy over many months was a constant reminder of the diagnosis of cancer that they were unable to control, which

was different to undergoing the comparatively shorter surgery.

Participants typically identified two points that they found the most challenging: the period of first discharge from hospital following surgery, and the period following the completion of chemotherapy.

The most difficult time was when I came out of hospital at first and I couldn't do anything, cos I could just manage to walk about and I was quite ill for quite a long, for a couple of months or so, not being able to do things, and then when I had the chemo that was a really bad time. Margaret

Burden of monitoring and dealing with new symptoms

As described above, participants commonly described anxiety around attending for treatment. They also experienced anxiety around attending for follow-up appointments or scans, and in the weeks before the appointment found themselves preoccupied with what their doctor might say to them or whether there could be bad news. However, they had to balance this with the value and reassurance of being closely monitored:

You're hoping against all hope there isn't but at the back of your mind... the logical part of your brain tells you you've had a really serious cancer, you've had it operated on, you've been told there's always a chance it could come back so you've gotta... it's fifty-fifty, it's either all clear or something there, there isn't an in-between really... You do think 'what will they find' but you've gotta try and shut it out of your mind really. Thomas

I always wonder what she's gonna say... I just hope it's gonna be good news at the time. Deborah

I like my six monthly scans, even though I get anxious before them. It's like... a comfort blanket around me. Helen

Many participants reported that they felt that their trajectory in life was being controlled by doctors, disease and monitoring.

You feel you've been re-defined and you don't know what your future is or what your future is going to be and the diagnosis and the prognosis measures your life out for you. Tim

Participants also described feelings of anxiety or distress when they developed new symptoms that they worried might indicate a recurrence of cancer:

And that's the only thing I do worry about is, will it come back? And I've been told, well, we don't know. So that is always at the back of my mind... The first different pain you get you start worrying, so. Elizabeth

However, the participants that had experienced a recurrence frequently found this as shocking as when they were first diagnosed as they had not always experienced any symptoms that could indicate the cancer had returned. These participants struggled to reconcile the new diagnosis with the fact that they had previously hoped they had recovered.

They couldn't tell me when it had come back, it had come back between the two scans... The trouble was you see I felt well, I really felt well. I didn't feel ill, I didn't feel any pain. Mary

I thought they wouldn't send me for an emergency scan if there wasn't something... and you think 'well it might just be a little dot somewhere or wherever'... well you think all sorts don't you, and you think has it come back, and that's what it turned out it had. Thomas

One participant, Mary, reflected that she had only fully understood how aggressive pancreatic cancer was when she was diagnosed with the recurrence:

I was going for the operation and that was going to cure it, you know and I mean it did but I didn't realise it could come back so quickly, obviously not in the same place cos you've already had it removed but it's come back in the abdomen. Mary

Adjusting to a 'new normal'

Following surgery, participants reported struggling with physical symptoms such as fatigue, which limited what they were able to do and sometimes prevented them from doing activities they had previously enjoyed:

I used to like doing the garden and I used to walk, but now I don't walk, I can't walk so far. I get tired. Elizabeth

I was definitely able to play with [grandson] a lot more energetically before this, you know. I was able to run round and play football with him... Joseph

Some felt that the role they had played within the family structure had been irreversibly changed by cancer, and were struggling to come to terms with this:

I didn't want to upset him any more than I knew he were already upset. Because you feel guilty for, you know, for... making them worry, because it's always been my job to look after them... I'm a bit of a matriarch... It's the person I've been all my life. So that's another thing that worries me all the time. Theresa

Participants described a desire to return to the life they had had before diagnosis and surgery, such as returning to normal family life or work, but most were uncertain about whether this was achievable:

I felt like, again the lack of control and having to go to appointments, having bloods done and stuff like that. And it was all focused on the illness bit. But lately with not being on the chemotherapy I've felt quite normal, you know, more or less. Deborah

I don't know who I am at the moment... I hope that I improve my stamina and I hope we get to do some of the things we want to do, and I hope I don't become unwell again. But I do not feel in control of that. At all. Tim

Those few participants who felt that they had managed to return to a 'normal' life reflected that a positive

attitude helped, but it had often taken several years to achieve this:

My head said I was gonna recover and nothing was stopping me getting back to normal. I think you've gotta have a positive attitude. Michael

Probably the last six months I've been better, a lot better, but it does take a while to get back to normal. James

A minority of participants reported that the negative impact on their social life was important to them, because they were unable to eat and drink as they might have done previously. They felt that treatment had changed their ability to uninhibitedly enjoy these aspects of their lives, and missed the person who enjoyed those things:

All the time I'm conscious of 'you can't have that' or 'you haven't to do that' because I've only got half a pancreas... But drinking was part of our life, our social life. Theresa
Even now I have difficulty eating... I do miss it. I used to have a good appetite. Elizabeth

Several people commented that they had been unable to go on holiday since their diagnosis; for some this was due to not feeling physically well enough, while for others the increased cost of travel insurance was prohibitive.

And you see the last holiday we booked I ended up having to cancel it because I wasn't well enough to go so... things are not like they used to be... it's something you've got to get used to I suppose really. Margaret

Many participants described how their priorities had changed since their diagnosis; some stated that they now wanted to focus more on activities that made them happy, while others wanted to spend more time with family.

I have realigned my priorities. I would say in my life there have been times my career has been more important than my family... I'm far more home-focused. Tim

I started thinking 'well she's only two, if anything happened to me she wouldn't remember me'. And that bothers me more than anything... I do so many things with her thinking... get all them memories in so she doesn't forget me. Helen

I've always been a good saver, but when this happened I just thought, I'm not waiting any longer, I've waited all my life... I've become a bit of a shopaholic... because I think I'm gonna die. I still think I'm gonna die. Theresa

These priorities impacted on close family members, sometimes negatively, and for many participants their priorities had changed because they still feared they could die prematurely. In addition, some participants disclosed mood changes, including becoming more irritable, again impacting on those close to them:

You're exhausted all the time and you can't cope... so you're lashing out at people. James

A minority of participants, however, felt that their temperament had changed for the better:

I do tend to be more caring yeah... I think more of other people. Not as I was selfish but I do think that little bit more, what they're going through and stuff like that like. Bit more tolerant as well. Thomas

All the participants recognised that their families had also struggled to adjust to their own 'new normal'. This often included family members' own 'scanxieties' around follow-up appointments as well as the increased practical and emotional support they had to provide the participants when they were undergoing treatment. Some participants felt guilty about how the cancer diagnosis and any lingering symptoms (such as pain or fatigue) had affected their family. They also reflected that sometimes their family members had struggled to access emotional support for themselves.

He [husband] were mithered to death... When they said I were clear and everything, he cried. Then after, he said 'don't tell anybody else'... He's always saying 'I love you, I love you'. And nothing's too much trouble for him, he'll do anything, anything at all. Patricia

I think [my husband] gets a bit fed up with it really. He's, you know... er... he'd just rather me be healthy... And I know he thinks I should do more. Margaret

I'm sure she's had moments where she's took herself off and collapsed but she's never shown it to me. She just says we need to think about the kids. Michael

Understanding around prognosis

Few participants seemed to fully understand the poor prognosis of their cancer and most acknowledged that they had not actively sought out more information, such as written information leaflets or resources online, preferring instead for their surgeon or oncologist to speak to them. Often this was due to a fear of coming across information that could be perceived as 'negative', such as mortality data, which could in some way impact their own disease course.

I read a bit but decided I didn't want to know too much. So I just left it to them really... I suppose if I'd've read more it would've been, it would've worried me more, so I just didn't read it, I just left it, cos it was making me worry just reading it really. I mean I thought, it's got to be done, there's nothing I can do about it, so I'd just leave it to them to do. Margaret

In those early days especially we didn't want to know, and I've never looked up anything to do with it. We've just listened to the professionals. Because you can latch on to something negative and it can throw you the other way, you know. Frank

Just three participants reported seeking information online, and only one of these found the internet a tool to find information and gain support from other people who had had a Whipples procedure.

There's a lot of questions that you think of but you don't know who to ask because they're really stupid questions, or you think that they're stupid, but you can ask them on there... And there might be ten people that have done it, and

you get ten responses of different ways a circumstance could go... and it's very supportive. Helen

Support-seeking

There were tensions in participants' comments on the support they felt they would like. Participants reflected that they would have valued more emotional support from their surgical team, particularly following surgery and then completion of chemotherapy. Those that wanted support suggested that they would prefer to be invited to talk, rather than feel that they had to proactively ask for help:

For two weeks you're there and you're being looked after and watched, and then all of a sudden you're home... after that really you didn't see anybody for a few weeks and you think 'well I hope everything's all right' or 'they haven't told me what my results were'... And so perhaps then, not necessarily [surgeon] but perhaps if, if I spoke more to the nurses even if they just rung up and said 'are you all right, is there anything you're bothered about'. Because obviously you know it's a massive operation and things are... not as they were. So that's the only time really that perhaps a bit more emotional support would have been... just so... because it's a bit frightening at first. Theresa

Participants recognised the value of the CNSs as a source of support, but often perceived them as too busy to deal with emotional problems; as a result, they felt guilty about asking for support:

[Everyone] probably needs to be doing other things without fussing about me... I didn't want to bother people... [if someone had asked] that would have broken the ice and uh, I would have felt that I'd been invited to, which is different to imposing on them, you know what I mean? Joseph

Some participants, however, reported that they had been offered help but had declined it, feeling at the time that they had sufficient support from family and friends:

They've asked me if I wanted emotional support from a therapist or like. I don't really because I've a very supportive family. You know, I don't need to really. Thomas

However, during the interviews, participants reflected that they had found it helpful to talk about their experiences during the interview to a person outside family, friends and clinical team:

I think possibly more than I thought. [long pause] Erm... [long pause] And like this rather than, because like [husband] always comes with me to the appointments and I said to him yesterday 'where are you going to sit', because I thought I'm not, I can't speak openly about things because I don't want to upset [him]. Theresa

DISCUSSION

Summary of findings

The accounts of the participants interviewed in this study illustrate the significant psychological impact of

living with and after pancreatic cancer. All participants described a similar journey from diagnosis to their current life. They described a sense of shock at diagnosis, seizing the chance to have a possibly curative surgery and frequently not absorbing the risks or their long-term prognosis. They reported preferring to rely on their surgeon or oncologist to advise them rather than seeking out information themselves. Participants found both surgery and chemotherapy difficult to recover from, although chemotherapy was frequently cited to be more challenging and caused a setback in their recovery from surgery. Although participants valued close monitoring, they reported anxiety around their appointments and reflected that their life trajectory was out of their control. They also described anxiety around new symptoms that could indicate recurrence. Several aspects of participants' lives had changed since surgery, including their physical stamina, social lives and ability to engage in activities they had previously enjoyed. Participants made conflicting comments on their support-seeking; some reported declining emotional support at the time of surgery or chemotherapy, but then went on to state that they would have wanted such support. Participants did reflect that they had found the interview a useful opportunity for reflection and discussion of what had happened to them.

Strengths and limitations

This is the first study using semistructured interviews to explore the psychological impact of recovery from pancreaticoduodenectomy for pancreatic cancer, and how patients experience and reflect on life after treatment. The use of qualitative methods with semi-structured interviews enabled participants to speak freely and in detail about topics that were important to them, while ensuring all aspects of the topic guide were covered. The researcher conducting the interviews (AKT) was not involved in any of the participants' direct patient care. The sample included a range of ages and participants who were at different points in their cancer journey including those with recurrence. Independent coding of the data by each member of the research of the team was conducted to mitigate against bias, and there was good agreement within the team. It is an additional strength that the authors have differing backgrounds (surgery, primary care and psychiatry), which offer varying perspectives.³² The study also benefited from perspectives of members of the PAG.

A significant limitation is that, as a single-centre qualitative study, our findings may not generalise to other geographical areas, particularly given a lack of racial diversity. Our study also only included one patient who had undergone neoadjuvant chemotherapy; although he described similar experiences to the other participants, our findings may not extrapolate to centres where most patients undergo neoadjuvant chemotherapy prior to surgery. Although our participants, on average, had survived slightly longer than many with pancreatic cancer,



they all described a similar journey and therefore we do not consider this a limitation.

Comparison with existing literature

There is little research specifically focusing on the psychological impact experienced by patients who undergo pancreaticoduodenectomy for pancreatic cancer, and whether this affects their quality of life. Participants felt a perceived lack of choice in opting for surgery; in a life-threatening situation they felt that had no real options.³³ A recent cross-sectional study identified that the most common supportive care needs in patients included uncertainty, fears of recurrence, inability to do usual activity, and feeling out of control³⁴; our findings explore these needs in more detail.

Cancer disrupts time and life, and a diagnosis means a confrontation with the prospect of death.^{35 36} The transition point of the end of treatment was a challenging one for participants to manage. This point often marks a change in identity from 'patient' to 'survivor'; the routines of treatment, which are often reassuring to patients, are stopped. Although this signifies cure, it can also cause isolation for the patient as their input from healthcare professionals acutely reduces and they assume more responsibility for monitoring.^{37 38} They may also be struggling with the ongoing symptom burden and the changes to their bodies; patients may find this difficult to communicate with family and may hide their individual needs, resulting in survivor loneliness and isolation.^{34 39 40} Previous studies report that the fear of recurrence and the challenge of managing and interpreting new symptoms arises at the end of treatment and affects ongoing quality of life.³⁶⁻³⁸

Surveillance itself was a source of anxiety for participants; they reflected on the desire for reassurance but feared a disruption of their 'new normal' with the experience of 'scanxiety' in the weeks approaching their appointments and results.⁴¹ The anxieties experienced by patients with a history of pancreatic cancer may be heightened compared with those with other cancers because of the high chance of recurrence.⁴

Participants suggested that CNSs would be an appropriate person to offer psychological support, but they would not feel comfortable asking for this. Most participants did not recall any psychological support being offered to them; only two participants had received any support (both in the form of counselling from psychologists). Verschuur *et al*⁴² suggested that patients with upper gastrointestinal (GI) cancers prefer to use professional care for physical issues, while they usually managed any psychological problems with their own social networks; these patients did not expect professional input despite depression (64%) and fear of metastasis (80%) being prevalent. Our results suggest that patients should be made aware that they may experience psychological distress during their treatment and follow-up; this may encourage them to seek and accept support at an earlier stage. Participants reflected that interviews had been of

therapeutic value and that they would in fact have benefited from a similar discussion earlier in their treatment journey.

Unlike other patient groups, our participant group did not use the internet to gain support or information, often due to fears around encountering inaccurate or negative information. Therefore, directing to online support may not be useful for these patients.^{43 44} The trust where the study was conducted had a policy of providing written information, but the data suggests that people were not always able to take that information in, or it was not given in a way that was acceptable. However, participants were interested in receiving more personalised information to support their needs; although this is resource-intensive, Jones *et al*⁴⁵ found that personalised information was more likely to give patients information they found more relevant.

CNSs can act as a constant supportive presence to patients, and with their knowledge of the patient's context and their own clinical experience may be particularly valuable.⁴⁶ However, the numbers of CNSs have not increased in line with increasing cancer prevalence, and the emphasis of their work has shifted towards more practical and administrative work.^{47 48} The resulting challenges of a resource-poor health system can limit CNS' opportunities to support patients fully from a psychological perspective.⁴⁹

Implications for research and practice

It is crucial to ensure that patients are aware that they may experience psychological distress following a diagnosis of cancer and that support is available; this may reduce patients' reluctance around accepting support. One way into the conversation could be through inviting the patient to complete a scale such as the Mental Adjustment to Cancer Scale,⁵⁰ with which our findings resonate, and use their responses to this to frame the conversation around their emotional needs. Psychological support should be offered throughout the diagnosis and treatment course, but the transition point of the completion of treatment can trigger a need for more support. More personalised information should be developed for patients, and this should be revisited with patients at multiple points in their follow-up. However, it is important to recognise that some patients may not want to look at this at all.¹⁸ CNSs should be encouraged to prioritise patients' psychological welfare, and engage in further training around psychological sequelae and how to identify and manage these in patients. Further research should be conducted to identify risk factors for the development of more severe psychological sequelae, and into the effectiveness of specific support interventions at different time points. Future qualitative research should focus on non-operative patients and on family members.

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