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'You know where we are if you need us.' The role of primary care in supporting patients following pancreaticoduodenectomy for cancer: a qualitative study

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Abstract

Background: Ten percent of patients diagnosed with pancreatic cancer undergo pancreaticoduodenectomy. It is known that these patients have unmet psychological support needs, and GPs are key in enabling effective coordination of care for people living with life-shortening conditions.

Aim: To explore patients' perspectives on the role of primary care in their management, and their sources of support.

Design and setting: Inductive qualitative study of patients who had undergone pancreaticoduodenectomy between six months and six years previously for pancreatic or distal biliary duct cancers. Participants were recruited by Clinical Nurse Specialists from a single National Health Service Trust in Northwest England.

Method: Semi-structured interviews, either face-to-face or via video link, were conducted with 20 participants. Interviews were audio-recorded, transcribed and anonymised. Thematic analysis utilized principles of constant comparison.

Results: Participants described immense treatment burden and uncertainty around the role of the GP in their ongoing care. They recognized that GPs may have little experience of patients who have undergone pancreaticoduodenectomy, but felt that GPs can play a vital role in offering support. Participants wished for emotional support post-operatively, and valued support networks including family and friends. However, they found expressing their deepest fears difficult. Participants felt they would value greater recognition by primary care of both physical and psychological sequelae of major pancreatic surgery, and the impact on their families.

Conclusion: Patients may feel a 'burden' to both healthcare professionals and their own support networks following pancreaticoduodenectomy. Primary care is in a key position to proactively offer psychological support.

Keywords

Primary health care, general practice, pancreatic cancer, qualitative research

How this fits in

Pancreatic cancer is distinct from other cancers due to its high mortality and limited treatment options. Patients undergoing pancreaticoduodenectomy have high levels of unmet need. There has been limited qualitative research exploring the experience of

support-seeking by these patients and how they perceive the role of primary care. This study makes explicit that patients identify their GP as a key potential source of psychological support but they frequently lack the confidence to seek out their GP for such support.

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Background

Pancreatic cancer is the tenth most common cancer in the UK¹, with most diagnosed after metastasis². However, approximately 10% of patients diagnosed with pancreatic and biliary duct cancers have surgery, with or without chemotherapy or radiotherapy³. The most common type of surgery performed for pancreatic adenocarcinoma, distal cholangiocarcinoma and periampullary tumours is a pancreaticoduodenectomy (or Whipple's procedure).

There is limited research focusing on the experiences of patients living with pancreatic cancer; most qualitative studies have focused on decision-making around treatment^{4,5}, secondary care surveillance^{6,7}, and symptom appraisal prior to diagnosis^{8,9}. However, it is known that patients who undergo pancreaticoduodenectomy due to adenocarcinoma report lower quality of life¹⁰. Half the participants in a 2019 cross-sectional study reported had at least one moderate/high unmet need, such as anxiety, uncertainty, or fear¹¹. People aged over 70 may experience high levels of distress persisting for five years after cancer diagnosis¹²; since the incidence of pancreatic cancer is strongly related to age¹, recognizing and managing psychological distress is vital.

Patients with pancreatic cancer usually develop pancreatic exocrine insufficiency, which leads to malabsorption and symptoms such as steatorrhoea, bloating, cramping and weight loss¹³. This often persists following surgery due to the volume of pancreas removed; patients report that these gastrointestinal symptoms and dietary changes significantly impact upon their physical, social and emotional wellbeing¹⁴⁻¹⁶. Pancreatic enzyme replacement therapy (PERT) has been shown to significantly improve fat digestion and reduce symptoms of malabsorption, with few side effects reported^{17,18}. Prescription of PERT (such as Creon) is now standard practice in patients with pancreatic cancer and is done so by primary care^{19,20}.

General practitioners (GPs) are crucial in enabling the effective coordination of care for patients living with life-limiting conditions, and identifying unmet support needs which negatively impact on patients' lives. However, it is often unclear whether the responsibility for care of those living with and beyond cancer lies with primary, secondary or tertiary care²¹. A large cross-sectional survey found that 59% of patients with a previous cancer

expressed a need for increased GP involvement in cancer care, with the majority also stating that GPs are well-placed to listen to patients' concerns and discuss their priorities in order to support shared decision-making²². Patients who perceive the GP to be informed about their cancer were more satisfied with treatment decisions²³, and those who speak with their GPs between diagnosis and commencement of treatment have improved satisfaction²⁴. Satisfaction with GP involvement has been shown to be higher if the GP is the initiator of contact^{22,25}, but GPs may be reluctant or unable to do this due to lack of time and perceived lack of knowledge, of, and expertise in, the specific cancer^{26,27}. A systematic review of the views of patients on the role of the GP highlighted that patients desire a biopsychosocial approach and for GPs to be better engaged in cancer care²⁸.

There has been little exploration of patients' perceptions of the role of the GP in the provision of ongoing care of patients following a Whipple's procedure for cancer. Similarly, neither the burden of ongoing recovery nor other sources of support sought by such patients have been examined.

Methods

We used qualitative methodology to explore the perspectives of patients about their care following pancreaticoduodenectomy for cancer. Semi-structured interviews allowed participants to talk about areas they felt were important, while ensuring all topics were covered^{29,30}. This article conforms to appropriate qualitative reporting guidelines³¹. Ethical approval for this study was granted by the National Health Service (NHS) Health Research Authority (REC Wales 7; reference 19/WA/0321).

Clinical nurse specialists (CNSs) identified potential participants currently under the care of a tertiary hepatopancreaticobiliary (HPB) centre in Northwest England. Inclusion criteria were if they had had pancreaticoduodenectomy six months to six years previously for either head of pancreas cancer, distal cholangiocarcinoma or periampullary cancer, and had completed chemotherapy. Patients were excluded if they were under the age of 18, if they had a current diagnosis of a severe mental illness (determined through review of GP coded diagnoses), lacked capacity to consent, did not speak sufficient English, or were in their last days of life. Fifty-two patients met these criteria. All participants had completed

active treatment following diagnosis (surgery +/- chemotherapy), although some had had recurrence since.

A random number generator selected five patients at a time. They were telephoned by a CNS and told about the study; if they consented to further contact they were emailed or posted the participant information sheet and invited to contact the researcher conducting the interviews (AKT).

Between December 2019 and February 2020, 16 interviews were conducted at the hospital or in participant's homes, depending on their preference. Recruitment was halted due to COVID-19 restrictions and then recommenced in July 2020 with four interviews being conducted via a virtual video platform.

Prior to interview, participants gave written consent to participate and for audio recording. The topic guide was developed using the existing literature and with input from a patient advisory group, and was used flexibly with open questioning to generate data. Interviews explored participants' experience of surgery and chemotherapy, the impact of cancer on their life, sources of support and access to primary and secondary care. No time limit was imposed on the interview and all came to a natural end. Participants were offered a £20 gift card to thank them for their time.

Following recording, interviews were transcribed verbatim and anonymised. The research team included one junior doctor (AKT), two HPB surgeons (DC and AK), one member of the patient advisory group (AP), and one GP (CCG). Line-by-line coding and inductive thematic analysis of all transcripts³² was undertaken by one researcher (AKT), and the other researchers (AK, DC, AP, CCG) each analysed a subset of transcripts. Researchers (AK and DC) did not analyse or see the transcripts of any patients whose care they were directly responsible for in order to avoid bias. Codes were discussed collaboratively to identify and agree key themes, and the analysis was continually refined using the principles of constant comparison³³⁻³⁵. Good agreement and triangulation of themes and codes was achieved. Data saturation, the point at which no new themes were derived³⁶, was reached at 18 interviews; two further interviews were undertaken to confirm this before recruitment was stopped.

Patient and public involvement and engagement

A patient advisory group (PAG) was convened to discuss the aims and methods of the study with patients who had undergone pancreaticoduodenectomy at least six years previously and were thus ineligible for inclusion in the study. PAG members commented on the topic guide, invitation letter and participant information sheet, which were all refined to reflect their suggestions. The PAG was reconvened following completion of the interviews to discuss preliminary analysis, invite reflection, and suggest dissemination strategies. One member of the PAG joined the authorship team to engage in further analysis and writing. Finally, a lay summary was circulated to participants following completion of analysis.

Results

Twenty participants were interviewed (demographics reported in Table 1). Interviews lasted between 51 and 187 minutes (mean 105 minutes). Four patients approached declined to be interviewed, stating that they felt that reflecting on their cancer diagnosis would distress them; eleven who were eligible for inclusion at the start of the recruitment period died before they could be invited to participate. One eligible patient developed a new primary malignancy during the recruitment period and was therefore not invited to participate.

The following themes will be presented in this paper, with illustrative quotes identified by a pseudonym for each participant: feeling a burden and being burdened, sources of support, and what I would like my practice to do.

Feeling a burden and being burdened

The majority of participants reflected that following treatment they often felt unsure about who to approach if they had questions, and did not seek help from their GP.

'After my Whipple I remember thinking "I don't really know where I stand now, whether I see my GP or the oncologist or [surgeon]".' Helen

Participants recognized that GPs may have little experience managing patients who had had a pancreaticoduodenectomy for cancer, and these opinions were sometimes compounded by negative comments from secondary care about their GP's knowledge, which made help-seeking difficult.

'She doesn't seem to know anything about my condition, that's the trouble. They probably haven't got another patient that's had a Whipple's procedure.' Margaret

'The specialist nurses said to me "your GP surgery won't even know anybody that's had a Whipple, it's a very big operation, you'll be lucky if they've had a patient that's had it". Which I found a bit upsetting, I thought well how are they supposed to look after me?' Janet

Some participants felt that sometimes the burden had been placed on them to educate their GP about aspects of their care.

'She's OK but she's not one of the best GPs, and essentially whatever I ask she does, she's never suggested anything. The thing is, I know more about it than they do. There's no getting away from it.' Alice

'It's been written down that you take two [PERT] three times a day, and, but that is no good because say I went out and had fish and chips I would need at least five. So they give me 300 a month, but sometimes 300's not enough. So I'll put on my repeat prescription, please ask the doctor if I can have 400 this month. No, I get 300. And I said "do you not read what I've written?" "But your thing says two three times a day" and they still put that on my tablets and that's rubbish.' Theresa

In addition to feeling a burden when help-seeking, many participants felt that they were a burden on their family, feeling guilty for being unable to support them while were undergoing treatment or dealing with recurrence.

'[My wife] was a brick for me. She was... I've tried to make it up since... I used to apologise to her and say "I really hate this"' but she said "well you'd do it for me if I

was the same"... We've been through it together. And I couldn't imagine it without her.' Joseph

'My wife is quite capable of coping when I'm gone but I apologized to her, I said "I'm so sorry" and she said "what are you sorry for?" and I said "because I'm gonna be leaving you".' Thomas

Participants also felt the burden of managing their new medication, particularly PERT and insulin.

'I'm injecting the basal insulin, I'm injecting that twice a day, and the other insulin, I've to inject that every time I have food but before I can eat I've got to work out how many carbs there are in the food and then assess how much insulin I need... life is just hard, it really really is hard.' Margaret

'They ran out of the 25,000 so they put me on 10,000 but that meant that instead of taking 6 with a meal I had to take 15... So I'd be going through a pack of 100 in two days... it's a lot of tablets to take... but now we've got the normal tablets again it's easier.' Raymond

'Although he said that I would be on tablets for the rest of my life I somehow thought that they would be like my husband's metformin, you know one in the morning and one at night.' Mary

Others felt that their medications were a visible and troubling reminder of their illness.

'I'm reminded of it every meal when I take creon. Every morning I have lansoprazole. I was hoping I could come off drugs altogether and further put it behind me, but that isn't going to happen.' Tim

Sources of support

Participants reported seeking support from a variety of sources including family, friends, and faith communities.

'It's been tough for her as it has for me, but we've hacked through it together... I've got somebody to talk to and my wife will keep me in check, have you done this, have you done that. She's fantastic. So that is the major part of it. I would feel for somebody who didn't have that kind of backup. Even when people are telling you things, it's nice to have somebody else listening cos at the critical stages so much is flying over your head you cannot possibly take it all in, but if you've got a second person there it helps.' Frank

'I had a lot of support from people at church... we're like a community you know... that makes me feel a lot better because I've got friends there.' Margaret

Although participants identified these sources as supportive, there were often tensions in their accounts. They reflected that they did not share their deepest fears and anxieties due to not wanting to upset others, and frequently worried about the impact of their illness on their family. Some highlighted the lack of support for family members of people with cancer.

'I feel guilty for this. Because it's me that's caused this... Because it doesn't just affect you, it affects all your family... I don't want to talk about it to them... Cos we're really close, you know. They rely on me emotionally... My daughter and granddaughters knew I had cancer but... if I broke down in front of them then they would get upset.' Theresa

'[My husband] doesn't want to talk about it... I have tried. And I think he thinks... it'll come back if we discuss it... My fear in that way is that if I had a recurrence I don't know how he would cope, this time around. Having been through it once... And nobody asks how he is. Carers are going through it just as much if not more, because they've got to try and be strong for everybody.' Helen

Many participants were aware of support groups, either online or in person, but most had not engaged with them consistently or found them beneficial.

'I did actually sign up for a couple [of online groups] but I found it a bit depressing... All people saying such-a-body died on this date 12 months ago and stuff like that. I thought "I don't need this" so I came out of them.' James

What I would like my practice to do

Participants felt that their general practice should be proactive in offering both physical and psychological support, and share the burden of being a patient with them.

'We thought the doctor would come round to see me after I was discharged. And in the end my husband sent for the doctor, said "why has nobody come to see her or anything" and he did come... but he just said "you know where we are if you need us" and that were it, sort of thing... You should have more support from medical people.' Margaret

Some participants highlighted that a lack of continuity of care made it more challenging for them to seek help from someone they felt knew them.

'I've been with that surgery, though they're all different doctors now, from being a baby. And some of the good doctors what were there in the last 10 years have all left... You can't get a blooming appointment and that. And every time you go there was somebody different.' Patricia

Most participants felt that their GP should play a key role in supporting their ongoing physical and psychological care. A minority reported that they had regular follow-up instigated by the same GP and had been asked about their psychological recovery. These participants said they felt more confident about being able to approach their GP if they did have concerns or needed support, and considered their GP a vital person in their support network.

'One of the senior GPs rings me once every couple of weeks and says "are you OK to talk for ten minutes?" and he asks me if I need anything or if there's anything I want... they've said anything I need whether it's support, somebody to chat to, a doctor to talk to, don't hesitate to ring them.' Thomas

'I was in there a long time, more than the five or ten minutes you're allowed, you know. And he was very supportive and he said "my door is always open"... I was very depressed at one time... And I would see him quite a lot, it was like once a month. He's a doctor that you can talk to.' Elizabeth

Discussion

Summary of findings

The accounts of our participants illustrate the burden of being a patient in terms of both the treatment itself but also the burden of having a less-common cancer with unusual and complex surgical treatment. Many participants also felt guilt from perceiving themselves as a burden on their family. Participants sought support from family, friends and faith communities but reflected that they often felt unable to share their deepest worries, and were often concerned about the impact of their illness on their family. Few participants had found support groups helpful.

Participants felt that their GP practice should proactively offer physical and psychological support in their cancer journey. Lack of continuity of care was cited as a barrier to support-seeking. A minority had had regular follow-up prompted by the GP but these participants felt more confident in approaching their GP if they had concerns or needed support.

Strengths and limitations

This study is, to our knowledge, the first to explore the sources of support and the role of primary care for patients following pancreaticoduodenectomy for cancer. Semi-structured interviews enabled participants to speak in depth about experiences that they felt were important, 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, which mitigated bias. The sample included participants of a range of ages and at a range of points in their journey, including those who had only recently completed adjuvant chemotherapy and those with recurrence. Bias was also mitigated through independent coding, and there was good agreement between researchers when refining themes. It is a particular strength that the authors have differing backgrounds, including surgery, primary care, psychiatry, and lived experience of pancreatic cancer. This, along with the perspectives of members of the PAG, enabled richer exploration of the data³⁷.

A particular limitation is that the findings from this single-centre qualitative study may not extrapolate to other geographical areas, particularly given a lack of racial diversity.

Comparison with previous literature

There is limited research focusing specifically on the role of primary care in supporting patients with pancreatic cancer. Our participants often felt unsure who to approach if they had questions or concerns, and for some this uncertainty was exacerbated by dismissive comments made by hospital staff about how GPs could help. Participants described the hard work of being a patient, which may have been exacerbated due to having had a comparatively unusual surgery. Previous studies report that patients with rare diseases are often forced to become more knowledgeable and self-directed in their healthcare utilization and help-seeking³⁸, despite the fact that those with severe illness (including pancreatic cancer) frequently prefer the physician to initiate and dominate decision-making conversations^{5,39}. Participants in our study reflected that when the GP had been proactive, they felt more confident initiating further consultations, demonstrating that help-seeking is often recursively dependent on previous experiences of health services⁴⁰.

On average, GP practices are increasing in size and there is evidence to suggest that larger practices provide higher-quality care; for example, larger practices have, on average, higher Quality Outcomes Framework (QOF) scores and fewer avoidable emergency admissions⁴¹. However, smaller practices achieve higher QOF scores for patient experience, perhaps because of a greater degree of continuity of care with a familiar GP⁴¹. For the participants in our study who did receive support from their practice, they described that it was usually provided by the same GP. This offers a parallel to the patient seeing the same clinical team at hospital appointments and allows a stronger therapeutic relationship to be forged between doctor and patient. However, with general practices increasing in size over time, people with unusual conditions may find it increasingly difficult to seek help from a GP who is familiar with them and their medical history.

Participants also highlighted the need for their family to receive emotional support. Family may take on the role of 'enlisted carer' without sufficient support or knowledge of what to expect, and, as patients themselves do, they may also hide their anxieties and present a

positive appearance to the person with cancer⁴². While family members can accompany the patient to hospital appointments, surgeons and oncologists do not have clinical responsibility towards them. On the other hand, family members may be registered with the same general practice, offering a unique opportunity for primary care to provide support to both the patient and their relatives.

It has been shown previously that although GPs feel that they are best placed to initiate and coordinate care for patients living with and beyond cancer, they feel that they lack the time, resources and knowledge²⁷. As a result, GPs may revert to a reactive rather than a proactive attitude towards patients with cancer, relying on the patient to contact the practice to engage in transactional care^{43,44}. 'Cancer care review' models may be beneficial but could lack the holistic approach of a more open discussion between the GP and the patient and/or their family about the impact of cancer²¹.

Instead of a transactional approach to patients with long-term conditions, relationship-based care may be more appropriate and has been highlighted as a priority by the Royal College of General Practitioners. This describes care in which process and outcomes are enhanced by a high-quality therapeutic relationship often developed over time. However, previous interactions between doctor and patient are not mandatory and a trusting, compassionate relationship can be built without this. Successful relationship-based care, which incorporates continuity of care as the relationship develops, may lead to better patient outcomes including greater patient satisfaction, lower mortality and reduced healthcare costs⁴⁵⁻⁴⁸. It may also increase GP job satisfaction⁴⁹.

In addition to the burden of uncertainty when help-seeking, patients with chronic illness also experience burden from the treatment itself. This may change over time and include physical side effects, attending appointments, managing inconvenient and restrictive treatment regimes, and dealing with interference to day-to-day life⁵⁰. Self-managing a long-term condition with complex medication regimes can be overwhelming for patients and caregivers and may require high levels of knowledge and skill⁵¹. This could offer an opportunity for other primary care staff such as community pharmacists or practice nurses to give ongoing support and education in this area, and could relieve some pressure from GPs⁵².

Implications for research and clinical practice

It is critical for GPs to recognize that some patients may not feel confident seeking support from primary care. Being proactive, and asking about the psychological impact of living with and after cancer, may mitigate this. It is important to recognize that patients may not be interested in support groups but may simply value someone to talk to without feeling 'a burden': this is the value of the relationship between clinician and patient in primary care. Other members of the primary care team, such as the pharmacist or nurse, may also be key in supporting patients in managing their medications. Flexibility should be enabled with prescriptions of PERT so that patients can easily access the necessary doses. Family members may be registered at the same GP practice, so the GP could identify their own unmet support needs. Future research should consider direct exploration of family members' needs, and the perspective of primary care about how the practice can support patients. Brief guidance for GPs about key issues faced by patients following pancreaticoduodenectomy could be created and its utility tested; this could be kept in the patient's notes for ease of access. Support interventions that could be delivered in primary care should be developed and their acceptability and efficacy assessed.

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Ethical approval

Ethical approval for this study was granted by the National Health Service (NHS) Health Research Authority (REC Wales 7; reference 19/WA/0321).

Declarations of interest

The authors declare they have no competing interests.

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Author contributions

DC and AKT conceived the study. AKT, DC, CCG and AK led on development of the protocol and study documents. AK, AKT and AP conducted the PPIE work. AKT conducted data collection. All authors were involved in analysis and writing, and all authors approved the final draft.

Data sharing statement

Due to the sensitive nature of the data and the potential for participants to be identified, the dataset is not publicly available.

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References:

1. Cancer Research UK. Pancreatic cancer statistics. [Online] Available from: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/pancreatic-cancer> [Accessed 20th July 2021]
2. Rawla P, Sunkara T, Gaduputi V. Epidemiology of pancreatic cancer: Global trends, etiology and risk factors. *World J Oncol.* 2019. 10(1);10-27.
3. National Cancer Registration and Analysis Service and Cancer Research UK. 'Chemotherapy, Radiotherapy and Tumour Resections in England: 2013-2014' workbook. 2018. [Online] Available from: <http://www.ncin.org.uk/publications/reports/> [Accessed 20th July 2021]
4. Ziebland S, Chapple A, Evans J. Barriers to shared decisions in the most serious of cancers: a qualitative study of patients with pancreatic cancer treated in the UK. *Health Expectations.* 2015; 18(6): 3302-3312.
5. Schildmann J, Ritter P, Salloch S, et al. 'One also needs a bit of trust in the doctor...': a qualitative interview study with pancreatic cancer patients about their perceptions and views on information and treatment decision-making. *Annals of Oncology.* 2013; 24: 2444–2449.
6. Deobald RG, Chieng ESW, Ko YJ, et al. A qualitative study of patient and clinician attitudes regarding surveillance after a resection of pancreatic and peri-ampullary cancer. *HPB.* 2015. 17, 409–415.
7. Blakely K, Karanicolas PJ, Wright FC, Gotlib Conn L. Optimistic honesty: understanding surgeon and patient perspectives on hopeful communication in pancreatic cancer care. *HPB.* 2017; 19: pp.611-619.
8. Evans J, Chapple A, Salisbury H, et al. 'It can't be very important because it comes and goes' – patients' accounts of intermittent symptoms preceding a pancreatic cancer diagnosis: a qualitative study. *BMJ Open.* 2014;4:e004215.
9. Mills K, Birt L, Emery JD, et al. Understanding symptom appraisal and helpseeking in people with symptoms suggestive of pancreatic cancer: a qualitative study. *BMJ Open.* 2017;7:e015682.
10. Huang JJ, Yeo CJ, Sohn TA. Quality of Life and Outcomes After Pancreaticoduodenectomy. *Annals of Surgery.* 2000; 231(6): 890-898.
11. Watson E, Brett J, Hay H, et al. Experiences and supportive care needs of UK patients with pancreatic cancer: a cross-sectional questionnaire survey. *BMJ Open.* 2019;9:e032681

12. Dauphin S, Jansen L, De Burghgraeve T, et al. Long-term distress in older patients with cancer: a longitudinal cohort study. *BJGP Open*. 2019; 3(3): bjpgopen19X101658.
13. Landers A, Brown H, Strother M. The effectiveness of pancreatic enzyme replacement therapy for malabsorption in advanced pancreatic cancer, a pilot study. *Palliat Care*. 2019; 12: 1178224218825270.
14. Gooden HM, White KJ. Pancreatic cancer and supportive care--pancreatic exocrine insufficiency negatively impacts on quality of life. *Support Care Cancer*. 2013 Jul; 21(7):1835-41.
15. Labori KJ, Hjermsstad MJ, Wester T, et al. Symptom profiles and palliative care in advanced pancreatic cancer: a prospective study. *Support Care Cancer*. 2006 Nov; 14(11):1126-33.
16. Dengso KE, Tjornhoj-Thomsen T, Dalton SO, et al. Gut disruption impairs rehabilitation in patients curatively operated for pancreaticoduodenal cancer – a qualitative study. *BMJ Cancer*. 2018 18:1017.
17. Guarner L, Rodriguez R, Guarner F, et al. Fate of oral enzymes in pancreatic insufficiency. *Gut*. 1993; 34: 708–712.
18. Domínguez-Muñoz JE. Pancreatic enzyme replacement therapy: exocrine pancreatic insufficiency after gastrointestinal surgery. *HPB*. 2009, 11 (Suppl. 3), 3–6.
19. Pancreatic Section of the British Society of Gastroenterology, Pancreatic Society of Great Britain and Ireland, Association of Upper Gastrointestinal Surgeons of Great Britain and Ireland, et al. Guidelines for the management of patients with pancreatic cancer periampullary and ampullary carcinomas. *Gut*. 2005; 54(Suppl. 5): v1–v16.
20. National Institute for Health and Care Excellence. Pancreatic cancer in adults: diagnosis and management. 2018 [Online] Available from: <https://www.nice.org.uk/guidance/ng85/chapter/Recommendations#nutritional-management> [Accessed 20th July 2021]
21. Gopal DP, de Rooij BH, Ezendam NPM, Taylor SJC. Delivering long-term cancer care in primary care. *British Journal of General Practice*. 2020; 70 (694): 226-227
22. Noteboom EA, Perfors IAA, May AM, et al. GP involvement after a cancer diagnosis; patients' call to improve decision support. *BJGP Open*. 2020; Feb 23;5(1):bjgpopen20X101124

23. Wallner LP, Abrahamse P, Uppal JK, et al. Involvement of primary care physicians in the decision making and care of patients with breast cancer. *J Clin Oncol*. 2016; 34(33): 3969–3975.
24. Wieldraaijer T, Meij M, Zwaard S, et al. Introducing a time out consultation with the general practitioner between diagnosis and start of colorectal cancer treatment: patient-reported outcomes. *Eur J Cancer Care*. 2019; 28(6):e13141.
25. Brandenburg D, Roorda C, Stadlander M, et al. Patients' views on general practitioners' role during treatment and follow-up of colorectal cancer: a qualitative study. *Fam Pract*. 2017; 34(2): 234–238.
26. Anvik T, Holtedahl KA, Mikalsen H. "When patients have cancer, they stop seeing me" — the role of the general practitioner in early follow-up of patients with cancer — a qualitative study. *BMC Fam Pract*. 2006; 7(1): 19.
27. Walter FM, Usher-Smith JA, Yadlapalli S, Watson E. Caring for people living with, and beyond, cancer: an online survey of GPs in England. *Br J Gen Pract*. 2015; 65(640): e761-768.
28. Meiklejohn JA, Mimery A, Martin JH, et al. The role of the GP in follow-up cancer care: a systematic literature review. *J Cancer Surviv*. 2016 Dec;10(6):990-1011.
29. Bryman A. Social research methods. 2004. Oxford, UK: Oxford University Press.
30. Gilbert N. Researching social life (3rd ed.). 2008. London, UK: SAGE Publications Ltd.
31. O'Brien BC, Harris IB, Beckman TJ, et al. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med*. 2014; 89(9): 1245–1251.
32. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006; 3(2): 77-101.
33. Glaser B. The Constant Comparative Method of Qualitative Analysis. *Social Problems*. 1965; 12(4): 436-445.
34. Boeije H. A purposeful approach to the constant comparative method in the analysis of qualitative interviews. *Quality & Quantity*. 2002; 36, 391-409.
35. O'Connor MK, Netting FE, Thomas ML. Grounded theory: Managing the challenge for those facing institutional review board oversight. *Qualitative Inquiry*. 2008. 14(1), 28-45.
36. Braun V, Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative*

- Research in Sport, Exercise and Health*. 2019. DOI: 10.1080/2159676X.2019.1704846.
37. Henwood KL, Pidgeon NR. Qualitative research and psychological theorising. *British Journal of Psychology*. 1992. 83(1): 97-112.
38. Budyk K, Helms TM, Schultz C. How do patients with rare diseases experience the medical encounter? Exploring role behavior and its impact on patient–physician interaction. *Health Policy*. 105 (2012) 154– 164
39. Ende J, Kazis L, Ash A, Moskowitz MA. Measuring patients' desire for autonomy: decision making and information-seeking preferences among medical patients. *Journal of General Internal Medicine*. 1989;4(1):23–30.
40. Rogers A, Kennedy A, Nelson E, Robinson A. Uncovering the limits of patient-centeredness: implementing a self-management trial for chronic illness. *Qual Health Res*. 2005 Feb; 15(2):224-39.
41. Institute for Fiscal Studies. Does GP Practice Size Matter? GP Practice Size and the Quality of Primary Care. [online] Available from: <https://ifs.org.uk/publications/7445> [Accessed 17th July 2021]
42. Gerhardt S, Dengso KE, Herling S, Thomsen Thordis. From bystander to enlisted carer – A qualitative study of the experiences of caregivers of patients attending follow-up after curative treatment for cancers in the pancreas, duodenum and bile duct. *European Journal of Oncology Nursing*. 2020; 44:101717
43. Lawrence RA, McLoone JK, Wakefield CE, Cohn RJ. Primary care physicians' perspectives of their role in cancer care: a systematic review. *J Gen Intern Med*. 2016; 31(10): 1222–1236.
44. Salisbury H. Is transactional care enough? *BMJ*. 2020;368:m226.
45. Baker R and Streatfield J. What type of general practice do patients prefer? Exploration of practice characteristics influencing patient satisfaction. *British Journal of General Practice*. 1995 Dec; 45(401): 654-659.
46. Atlas SJ, Grant RW, Ferris TG, et al. Patient–Physician Connectedness and Quality of Primary Care. *Annals of Internal Medicine*. 2009 Mar 3;150(5):325-35.
47. Pereira-Gray DJ, Sidaway-Lee K, White E, et al. Continuity of care with doctors-a matter of life and death? A systematic review of continuity of care and mortality. *BMJ Open*. 2018;8:e021161.
48. Hussey PS, Schneider EC, Rudin RS, et al. Continuity and the Costs of Care for Chronic Disease. *JAMA Intern Med*. 2014 May;174(5): 742-8.

49. Ridd M, Shaw A, Salisbury C. 'Two sides of the coin'—the value of personal continuity to GPs: a qualitative interview study, *Family Practice*. 2006 Aug; 23(4): 461–468.
50. Sav A, King MA, Whitty JA, et al. Burden of treatment for chronic illness: a concept analysis and review of the literature. *Health Expectations*. 2015. 18(3), 312–324.
51. Mair FS, May CR. Thinking about the burden of treatment. *BMJ*. 2014;349:g6680
52. Hindi AMK, Schafheutle EI, Jacobs S. Community pharmacy integration within the primary care pathway for people with long-term conditions: a focus group study of patients', pharmacists' and GPs' experiences and expectations. *BMC Fam Pract*. 2019; 20:26.

Table 1: Participant Demographics

% female	10 (50.0%)	
% White British	20 (100.0%)	
% tertiary referral	12 (60.0%)	
Mean age at diagnosis (range)	65.2years (45-79y)	Median 66, IQR 14.8
Mean age at interview (range)	67.9years (47-82y)	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
% chemotherapy prior to surgery	1 (5.0%)	
% chemotherapy after surgery	16 (80.0%)	
% recurrence	4 (20.0%)	
Initial presentation as emergency	10 (50.0%)	