

BMJ Open “It can’t be very important because it comes and goes” – patients’ accounts of intermittent symptoms preceding a pancreatic cancer diagnosis: a qualitative study

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ABSTRACT

Objective: This article explores how people with pancreatic cancer interpreted prediagnostic signs and symptoms, and what triggered them to seek medical help for symptoms that occurred intermittently.

Design: Thematic analysis of prediagnostic symptom descriptions drawn from a qualitative interview study of people with experiences of pancreatic cancer.

Participants: 40 people affected by pancreatic cancer (32 patients and 8 relatives of people who had died). Age at interview ranged from 35 to 84 years; 55% were men; and 57.5% of patients had been offered potentially curative surgery.

Setting: Respondents interviewed at home were recruited from different parts of the UK during 2009/2010.

Results: Analysis of the interviews suggested that *intermittent* symptoms were not uncommon in the months, or even years, before diagnosis but that the fact that the symptom did not persist was often taken by the patient as a reassuring indicator that it could not be ‘very important’. Such symptoms were rarely acted upon until a pattern became apparent, the frequency of symptom episodes increased, there was a change in the nature of the intermittent symptoms or additional symptom(s) appeared. These findings build on social science theories of consultation behaviour.

Conclusions: Our study—the largest reported collection of qualitative interviews with people with pancreatic cancer—reports for the first time that symptoms of an intermittent nature may precede a pancreatic cancer diagnosis. Patients (and potentially their doctors as well) may be falsely reassured by symptoms that come and go. Pancreatic cancer might be identified at a stage where curative treatment is more likely if there were greater awareness that intermittent gastrointestinal symptoms can have a serious cause, and if patients with intermittent pancreatitis-like symptoms were investigated more readily.

Strengths and limitations of this study

- As is appropriate for this qualitative approach, we aimed for maximum variation and not numerical representation; we included people with a wide range of backgrounds and experiences, not just those who had particular concerns about their prediagnostic symptom experiences or diagnostic delay.
- The finding on intermittent symptoms emerged during analysis—we did not ask specifically whether symptoms occurred intermittently.
- Our study is based on people’s recall of events, which is considered a bias in some research traditions, yet these accounts also emanate from those who, having been diagnosed with a life-threatening illness, are likely to have thought long and hard about how and when their cancer started. Using qualitative, interpretive methods allows us to analyse and learn from these recollections.

INTRODUCTION

Early symptoms of pancreatic cancer are vague and non-specific; more indicative signs such as jaundice occur late in the disease, hence most cases are diagnosed at an advanced stage.¹ As the ninth most common cancer in the UK with more than 8000 new cases diagnosed each year,² a general practitioner (GP) would see one new case approximately every 5 years. The 5-year-survival rate is less than 4% in the UK,³ a statistic that has not changed for 40 years despite improvements in survival of many other cancers. There have been a number of studies of prediagnostic symptoms in pancreatic cancer, including a prospective cohort study of a primary care database with a predefined list of symptoms,⁴ retrospective analyses of primary care data⁵ or hospital records,^{6–8}

structured interviews using predefined lists of symptoms^{9 10} or a combination of methods.¹¹ A range of non-specific signs and symptoms have been identified as occurring before a pancreatic cancer diagnosis, sometimes many months ahead of more indicative symptoms, suggesting that acting early on certain symptoms could expedite diagnosis^{12 9} and possibly lengthen survival.^{10 13}

How people perceive, evaluate and act on symptoms—known as ‘illness behaviour’¹⁴—has long been studied by health sociologists. A variety of theories and models have been proposed to explain help-seeking behaviour when symptoms are present.^{15–17} Zola¹⁸, for example, described a set of ‘triggers’ to consultation which include the person’s assessments about whether, and how, the problem is interfering with their main roles (work, social, home life, relationships), monitoring how long the symptoms have been present, considering the perceived seriousness of the symptom and expectations about whether there is something that the doctor can do about it, and the responses of family, friends and colleagues who may encourage the person to go to the doctor. Other theories about how people appraise symptoms and make decisions about seeking help include those described by Safer *et al.*,¹⁹ Andersen *et al.*²⁰ and Scott *et al.*²¹ Tackling the causes of ‘delay’ has become a key part of cancer policy in many countries. An international comparative study published in 2013 found that the UK has low awareness of age-related cancer risk and the highest perceived barriers to presenting symptoms; the barriers reported as unusually prevalent in the UK included embarrassment and ‘not wanting to bother the doctor’.²²

In this article, we present an analysis of one theme from a wider qualitative study of people affected by pancreatic cancer: we explore how they interpreted prediagnostic signs and symptoms, why lengthy intervals occurred before diagnosis and what triggered them to seek medical help for symptoms that were intermittent.

METHODS

We recruited participants from across the UK through distribution of volunteer information packs via pancreatic cancer specialist doctors and nurses, GPs, pancreatic cancer organisations, members of our project advisory panel and the snowball method (in which participants recruit other people they know with the same condition). Packs included an information sheet, reply slip and return envelope; those wanting to know more about the study contacted the research team. A few people responded to a newspaper advertisement or contacted the research team after hearing about the project in the media or by word of mouth. We aimed for a maximum variation sample,^{23 24} from different social backgrounds and ethnic groups from different parts of the UK. We wanted to capture a diverse range of experiences of pancreatic cancer including people who had been recently diagnosed, those in remission and those receiving palliative care. Using our experience we estimated that

around 40 interviews would be needed to reach data saturation (ref. 25, p.61) on a broad range of analytical categories; we continued recruiting participants and interviewing until no new themes occurred in the data. We recruited 40 participants, including 8 who had helped to care for a relative who had died from pancreatic cancer; 2 of the 40 had a neuroendocrine tumour.

AC or JE interviewed participants, usually in their home, during 2009/2010 about all aspects of their experience of having pancreatic cancer; interviews lasted between 40 min and 2 h. In the first, narrative, section of the interview, respondents were asked to tell, in their own words and without interruption from the researcher, what had happened to them from the time when they had first suspected something was wrong. A semistructured section followed to explore issues in more depth and to ask about topics that had not been mentioned. This included more detailed questioning about symptom recognition and interpretation, help-seeking actions taken and diagnostic investigations. The interviews were audio recorded, transcribed verbatim, checked for accuracy and returned to the participant so they could read the text and remove or clarify sections if they wished.

The authors read and re-read the data, constructed a coding frame, coded the data in QSR N6 (a qualitative data-indexing package) according to themes using the method of constant comparison,²⁵ and examined themes across the whole dataset, as well as in the context of each person’s interview. For the analysis, for this article, JE further categorised data from the narrative and semistructured interview sections about the prediagnostic period according to the ‘appraisal’, ‘help-seeking’ and ‘diagnostic’ intervals as defined in Walter *et al.*s²⁶ revised version of Andersen’s model of Total Patient Delay²⁰; this was carried out using framework analysis.²⁷ These intervals were then treated as themes and analysed using the one sheet of paper (OSOP) method.²⁸ The accounts of prediagnostic symptom episodes were subsequently recoded according to whether the symptoms described were intermittent or persistent in nature, and what triggered people to seek medical help. In addition, all the signs and symptoms mentioned in the interviews were listed, and where participants mentioned dates or time periods these time intervals were used as an approximate indication of any temporal delays.

We use participant pseudonyms throughout this article, and hesitations and repeated words have been removed from the quotes to aid readability. Further analyses and video and audio extracts from the interviews can be found at <http://healthtalkonline.org/peoples-experiences/cancer/pancreatic-cancer/topics>.

RESULTS

Nature of symptoms

People reported the approximate time from first recognising a symptom to diagnosis as ranging from less than

Table 1 Characteristics of the total sample

	People with pancreatic cancer	Relatives of people who had died of pancreatic cancer
Age at interview (years)		
35–44	3	2
45–54	7	4
55–64	9	0
65–74	10	2
75–84	3	0
Sex		
Men	17	5
Women	15	3
Occupation (or previous occupation if retired)		
Professional	15	6
Other non-manual	10	2
Skilled manual	5	0
Other, eg, housewife	2	0
Ethnic group		
White British	30	7
Indian	1	0
Pakistani	0	1
Afro-Caribbean	1	0
Year of diagnosis		
1995–1999	1	1
2000–2006	5	5
2007–2010	26	2
Approximate time from first symptom recognition to diagnosis or start of treatment		
≤1 month	4	2
2–6 months	18	5
7–12 months	4	0
>1 year	6	1
Treatment offered		
Potentially curative surgery ±adjuvant therapy	21	2
Chemotherapy±radiotherapy	9	5
Palliation only	2	1

a month to several years (see table 1). The signs and symptoms reported in our study mirror those from previous studies (see box 1), with the exception of: a perceived lump under the ribs, a pulsation under the ribs and intermittent rectal bleeding, all of which may have been signs of advanced rather than early pancreatic cancer or of an unrelated condition. We were struck by the participants' accounts of symptoms they had experienced on an intermittent basis and the reassurance they had gained from the periods in between when they felt relatively well.

Symptoms that occurred intermittently included epigastric pain, digestive difficulties, occasionally with fever, nausea or vomiting and bowel changes. These symptoms did not only occur intermittently in our study; some people recalled that one or more of these gastrointestinal symptoms had been persistent or gradually worsened since they first noticed it. Others said they had

Box 1 Signs and symptoms reported

(Those in italics sometimes occurred intermittently)

Pain (upper gastrointestinal)
Pain (back or shoulder)
Indigestion/burning sensation in chest/unusual belching/early satiety/abdominal distension or bloating
Nausea
Vomiting
Diarrhoea
Constipation
Steatorrhoea
Fever/sweats
Rectal bleeding
Fatigue/asthenia
Appetite loss/anorexia
Weight loss
Jaundice (yellow skin or eyes, dark urine, pale stools, itchy skin)
Taste changes
Diabetes
Palpable lump
Pulsation under ribs
Weakness and pallor

experienced isolated symptom episodes weeks or months apart, typically after consuming a large or particularly rich meal, or large quantities of alcohol, or at night. For some, the episodes had gradually become more frequent over time until the symptoms were constant. In some cases, intermittent symptom episodes preceded any other symptoms, while in others they occurred in parallel to other, persistent, symptoms. Some people recalled one isolated symptom episode before other persistent symptoms led to the cancer diagnosis.

People said they had often ignored their intermittent symptoms at first because they had been mild in nature so had not considered them serious enough to see a doctor about. For instance, Alice said she “started to have slight tummy upsets, so slight that, well, I just ignored them for quite a while” (Alice: diagnosed 2006; aged 73 at interview; treatment: potentially curative surgery, chemotherapy, radiotherapy). Similarly, Desmond described “a feeling of great weariness came over me, really heavy tiredness...”. He said, “it happened a lot and I couldn't put any reason on it other than that I had just been working and got tired, but it was more than that, and I think that was getting towards the time when I did find out what I'd got” (Desmond: diagnosed 2001; aged 72 at interview; treatment: non-curative surgery, chemotherapy).

Even when intermittent symptoms had been more severe, people had not always acted on them because they had been reassured by having felt well in between episodes and had not expected the symptoms to recur. For instance, Marcus' fever and indigestion had only occurred after occasionally consuming rich food and lots of wine.

R: Being in the wine trade we used to entertain a lot and we used to go down to Glyndebourne with customers to see the opera. And we'd obviously consume a few good bottles or five and I found, especially that after I'd drunk quite a lot, that I would suddenly wake up in the night getting the shivers, serious doses of the shivers and sort of incredible indigestion and I would then sort of sweat like mad for the next twelve hours and it really was pretty uncomfortable. [...]

I: How long was it before you took that to a doctor? Do you remember?

R: I never actually, I don't think I ever actually took that particular symptom because it would clear up pretty quickly. I suppose I would have it three or four times a year, so it wasn't something that happened frequently and only tended to happen I think when I sort of had rich food and quite a lot of vino. [Marcus: diagnosed 2007; aged 65 at interview; treatment: potentially curative surgery, chemotherapy, radiotherapy]

Part of the process of appraising a symptom is to seek a 'normal' explanation for its occurrence,²⁹ and it was common among our interviewees to attribute symptoms to things other than a new illness. For instance, some attributed abdominal pain or changes in bowel habits to possible irritable bowel syndrome (IBS). Some said they had previously been diagnosed by their doctor as having IBS; it seems likely that GPs are also sometimes reassured by the intermittent nature of gastric symptoms and do not suspect cancer.

I was diagnosed a couple of years ago with IBS symptoms generally the sickness, diarrhoea, stomach pains, etc. So I had some tests and that done. And it was decided that yes I did have IBS and probably getting older too or a sluggish digestive system. The tests that I had done showed nothing seriously wrong, so I just went away and really sort of changed diet, etc. and got on. It tended to sort of affect my life basically on a ... in a sense of fairly monthly cycle. I'd be ok and then it would flare-up and I'd have a few nights of discomfort and pains and upset stomachs, etc. But basically sort of had it in my life. [Martha: diagnosed 2009; aged 64 at interview; treatment: neoadjuvant chemotherapy]

Triggers to seek help for intermittent symptoms

Although Marcus (quoted above) recognised that his indigestion with fever recurred several times in similar circumstances, this alone was not enough to make him seek medical help. However, others did. Drawing on social science theories of consultation behaviour we have identified specific triggers to seeking help when symptoms have been intermittent. Such symptoms were rarely acted on until a pattern became apparent, the frequency of symptom episodes increased, there was a change in the nature of the intermittent symptoms or additional symptom(s) appeared. We illustrate these triggers below.

A pattern became apparent

Emily went to see her GP after experiencing a pattern of nausea and wind followed by passing a putty-coloured stool three times in 5 months.

It happened about three times that I had, I was getting an increasing amount of sort of wind almost and burping a lot. That was the other thing that was very odd. And my husband said, "That's very odd". And then I'd notice a few days later, sometimes I, each time I felt a little bit nauseous for a couple of days and then I'd pass a very abnormal coloured stool, as if I'd got a gallstone or something. Then months, and I hadn't noticed at that time that actually I had been feeling a little bit nauseous before. But the next time it happened when I was a bit nauseous and I think, "Well, I wonder if the same thing will happen again?" And it did. But that was very near Christmas and I thought, "Well, in my experience I know it's no good going to one's GP round about Christmas. I'll go straight after Christmas and then things will be looked into properly". And so I went to, and it happened again actually just over the New Year. [...] When I look back, I didn't spot it the first time. But the second time when I saw the stool then I thought, "Yes." I had been feeling slightly nauseous for about two days and burping; burping went on all the time. And it was then when I thought, "Right, I must do something about it now". [Emily: diagnosed 1995; aged 73 at interview; treatment: potentially curative surgery, radiotherapy]

Paddy also recognised that his repeated bouts of severe abdominal pain followed a pattern, but because they always occurred at night he did not see a doctor until the pain had disappeared.

And part of the early days that I remember was the sort of oddity of having these pains which they, if they started at say 7 o'clock in the evening, they followed a particular course till about sort of 2 or 3 o'clock that morning. They were absolutely the same each time. But they never seemed to happen when I could quickly get to a doctor. And one of the early sort of irritations I remember of this problem was that I never seemed to be able to get to a doctor when I was actually in the pain. So by the time I actually saw a doctor, perhaps the next morning if I was lucky, or a few days later, the pain had gone. [Paddy: diagnosed 2000; aged 59 at interview; treatment: neoadjuvant chemotherapy, potentially curative surgery]

Increased frequency of symptoms

Some people sought medical help after recognising that their symptom episodes had become more frequent or changed from intermittent to persistent.

I didn't go to the doctors you see because I was being sick once a week, twice a week. And then it got to three times a week, and built up to daily, you know, it seemed to be every time I got to the top of the stairs. I'd just made the toilet bowl and literally everything came up. ... I thought, "Well I'd better go and see what's happening". [Tom: diagnosed 2009; aged 66 at interview; treatment: potentially curative surgery, chemotherapy]

Change in the nature of the intermittent symptom

Others went to the doctor after they felt the nature of their intermittent symptom had changed. For instance, Paddy (quoted above) experienced a much worse bout of pain, which prompted him to be more 'aggressive' with his doctors about trying to ascertain its cause.

On the first morning of the new Millennium, when of course every hospital and every doctor, everything was closed, I did have the worst experience of pain, which went beyond anything I had had before, and did cause me to start anew; I then became much more aggressive in saying, "Look I, you know, up till now this has been an occasional oddity which, while unpleasant is making no difference to me really. I'm not having this anymore; we have to do something about it." [Paddy: diagnosed 2000; aged 59 at interview; treatment: neoadjuvant chemotherapy, potentially curative surgery]

Similarly, having lived for 2 years with gastric disturbances attributed by her GP to IBS, after one particular episode, Martha felt that the nature and position of the pain had changed, and she felt there was something in her body that should not be there, so she returned to her doctor.

Middle of July, went down to stay in Dorset, and went to some friends' for lunch. And that evening I felt really uncomfortable but put it down to sort of the IBS; I think the food was quite rich. But from then on I felt that the pain that I was getting was different and I felt there's something wrong. And I wasn't happy with the way I felt. ... I also got a sort of pain that seemed to correspond in a slightly lower area, which, again, wasn't a pain that I'd had with any of the IBS symptoms that I had, which is what kept giving me this strong feeling that there is something here in my body that just shouldn't be there. There's something definitely wrong. And, again, I think it was just more about being aware of my own body and knowing that it was a difference, it was a change from what had gone on before, any of the symptoms. [Martha: diagnosed 2009; aged 64 at interview; treatment: neoadjuvant chemotherapy]

Appearance of additional symptoms

The fourth trigger was the arrival of another symptom on top of the original intermittent one(s). For instance, Desmond did not seek medical advice for his episodes of unexplained bad breath and 'really heavy tiredness' (see quote above) until some time later when he developed acute indigestion and jaundice. Marcus (quoted above) did not report his repeated indigestion and fever to his GP until he experienced an acute pain in his side. Ralph also waited until he had experienced several bouts of pain before acting on his earlier changed bowel habits:

My bowel movements were pretty horrendous at times with the, particularly floating stools and soft motions and the need to go to the loo suddenly very quickly, particularly after a meal. And at the time I put it down to the

male menopause and people thought it was perhaps irritable bowel syndrome. And that went on for some time. The first thing that made me realise there was something slightly wrong, I remember it well, I woke up one morning and I had a very slight stomach ache and I thought, "Oh, I've strained my stomach muscles doing sit-ups." And I thought, "I haven't done any sit-ups for a long time." And I put up with the stomach ache for quite a few weeks, thinking, "It can't be very important, because it comes and goes." And eventually I did go to the doctor's with it. [Ralph: diagnosed 2007; aged 63 at interview; treatment: chemotherapy and vaccine]

GPs' responses to intermittent symptoms

Some people told us that their GP ordered tests that quickly led to a pancreatic cancer diagnosis. For instance, when Emily (quoted earlier) told her GP about her three episodes of wind, nausea and putty-coloured stools, she was referred to a gastroenterologist who she saw 2 weeks later and went on to have scans that revealed her pancreatic cancer. In other cases, the diagnostic process was more protracted while the GP tested or treated for suspected benign causes of the intermittent symptoms. For instance, Alice was prescribed omeprazole for intermittent indigestion and had an endoscopy to rule out an infection, and Finlay's recurrent epigastric pain and indigestion were attributed to a probable hiatus hernia until his pain became so severe that he was suspected of having a heart attack and was taken to hospital.

Rachel's experience highlights how difficult it can be for either the patient or the GP to recognise that there is a serious problem when symptoms are intermittent and non-specific. Two years before her pancreatic cancer was diagnosed, Rachel consulted her doctor about a pain under her left rib, which she suspected was a pulled muscle after doing heavy gardening work. The GP examined her, agreed that it probably was a pulled muscle and suggested she should take paracetamol. The pain seemed to disappear but recurred a few weeks later and seemed to be worst when she was lying down at night. Rachel returned to see her GP who examined her 'very carefully' and reiterated the advice to take paracetamol. The pain continued to worsen and 4 months after it first occurred, Rachel once again returned to the GP. This time, after another careful examination that included being 'prodded everywhere', and having her heart and lungs listened to, the GP concluded that she should be referred to a heart specialist. A battery of tests at the hospital found no heart abnormality. The pain subsided for a while but returned about 3 months later:

So I returned back to my GP to have a chat with her again about it. And she examined me very carefully again and said perhaps there was a possibility of a digestive problem. So she prescribed some stuff for me to take before meals.



This had no effect. Meanwhile, Rachel had tried to eliminate fatty and other unhealthy foods from her diet. When she again returned to the GP, she was referred for a scan; a conversation with the scan technician indicated that the GP suspected a gallstone. Once again Rachel recalls that the pain seemed to subside for a while, but was still noticeable. Having had no formal results after the scan, Rachel asked her GP for an appointment:

And she said, “But everything’s come back clear, you know, there’s no gall stones there”. And I said, “Well, I’ve still got the pain and it’s back again”. So she then said, “Well, what do you want me to do?” So I said, “Well, I don’t know”, I said, “But clearly something’s not right”. [Rachel: diagnosed 2009; aged 66 at interview; treatment: chemotherapy and vaccine]

Rachel’s GP then sent her to see a hospital specialist who did an endoscopy and a scan but did not suspect cancer. He at first interpreted the images as suggesting a hiatus hernia but after reviewing the scan results decided that she had a cancer in the middle of her pancreas and secondaries in her liver.

DISCUSSION

Pancreatic cancer is notoriously difficult to diagnose because of the non-specific nature of the symptoms; difficulties in symptom interpretation by patients and professionals are, therefore, inevitable. In our study, symptoms often occurred in intermittent episodes, sometimes with long periods in between, during which the person felt relatively well. The symptoms that were described as occurring intermittently may occur in other gastrointestinal cancers or in pancreatitis. In the study by Gullo *et al.*,⁹ some patients had reported having pancreatitis months or years before their pancreatic cancer was diagnosed; in some cases, the condition had been chronic, while others had experienced recurrent episodes of acute pancreatitis. It is not clear whether these patients had been formally diagnosed as having pancreatitis or whether the authors had interpreted the patients’ accounts of their symptoms as being consistent with pancreatitis. In our study, pancreatitis-like symptoms had not always been reported to a doctor and no one mentioned pancreatitis by name or said they had been diagnosed with it. People will only consult if they recognise that their symptoms may be a sign of illness rather than some normal bodily process. The ‘symptom iceberg’ concept³⁰—that most symptoms and illness goes unreported to health professionals—is well recognised, and our study sheds some light on what might be going on just beneath the water line. Worsening symptoms and additional symptoms are well-known triggers to recognising illness and seeking medical help in other conditions.^{31 32} We found that symptoms that come and go provide false reassurance, and hence delay consultation. We contribute to social science understandings of help-seeking behaviour by identifying four triggers to consult

with symptoms that are intermittent as opposed to persistent: a pattern of symptoms becoming apparent, an increased frequency of symptom episodes, a change in the nature of symptoms and the occurrence of additional symptom(s).

We used qualitative methods to explore the prediagnostic symptom experiences of people with pancreatic cancer to better understand what signs and symptoms occur and how patients respond to them. Qualitative studies can sometimes illuminate issues that are hard to identify in a more structured format, and our study—the largest reported collection of qualitative interviews with people with pancreatic cancer—reports for the first time an unexpected theme: that symptoms of an intermittent nature may precede a pancreatic cancer diagnosis. As is appropriate for this qualitative approach, we aimed for maximum variation and not numerical representation. We included people with a wide range of backgrounds and experiences of pancreatic cancer, not just those who had particular concerns about their prediagnostic symptom experiences or diagnostic delay. Although most of the people included in our sample had potentially curable cancer at diagnosis, accounts of intermittent prediagnostic symptoms occurred in the interviews with people who had not been treated with potentially curative surgery as well as those who had; therefore, stage of disease at diagnosis is unlikely to have impacted on their symptom appraisal. The finding on intermittent symptoms emerged during analysis—we did not ask specifically whether symptoms occurred intermittently. None of the studies in the pancreatic cancer literature have drawn attention to the presence of intermittent symptoms or how patients appraise them, although intermittent symptoms have been reported in other cancer types.^{31 33 34} Our findings suggest that people respond differently to symptoms that are intermittent as opposed to persistent, so it might be productive for future research in pancreatic cancer to include questions about this mode of presentation.

Our study is based on people’s recall of events, which is considered a bias in some research traditions, for example, if patients are asked to complete a checklist of pre-diagnosis symptoms.³⁵ Yet these accounts also emanate from those who, having been diagnosed with a life-threatening illness, are likely to have thought long and hard about how and when their cancer started. In a qualitative study, we might view ‘recall bias’ through a different lens as the ‘benefit of hindsight’ and consider people’s reflections on how they made sense of their symptoms and why they acted, or delayed acting. Using qualitative, interpretive methods allows us to analyse and learn from these recollections. What respondents report in research should also be treated as accounts that serve several functions, including to present oneself as a competent member of the community.^{36 37} Clearly the same is likely to apply to interview accounts from health professionals, and even clinical notes might lack detail, especially if the symptoms are not seen as important, therefore different sources of data may not match.

GPs may also feel reassured by symptoms that disappear and be keen not to overreact to those which are likely to have a benign cause. When testing or treating for apparently benign conditions, GPs should adhere to safety netting guidelines³⁸ to minimise diagnostic delays and to rule out the possibility of a serious cause. Our study suggests that upper gastrointestinal symptoms sometimes develop many months or even years before a pancreatic cancer diagnosis, and patients sometimes report symptoms to a doctor repeatedly before cancer is suspected.^{39 40} Intervals of months or years in reaching an upper gastrointestinal cancer specialist are very likely to affect the stage of the disease at diagnosis. Chronic pancreatitis is considered a rare condition but is known to be a possible precursor to pancreatic cancer.^{2 41 42} Episodes of acute pancreatitis have also been reported as preceding pancreatic cancer^{43 44} but whether it is a cause or a symptom of the disease is not clear. Our data suggest that pancreatitis, in particular acute pancreatitis, may be a more common precursor than previously thought, and more research is needed to establish whether scanning patients with acute pancreatitis in the absence of other symptoms could lead to earlier diagnosis of pancreatic cancer.

Gastrointestinal symptoms such as epigastric pain, digestive difficulties, appetite and weight loss, changed bowel habits and nausea may have a serious cause. The National Awareness and Early Detection Initiative aims to promote earlier diagnosis of cancer in the UK, and by doing so improves survival and reduces mortality.⁴⁵ As part of its work, it does research on public awareness of cancer and produces key messages for promotion to the public in an attempt to raise awareness of cancer symptoms. This work has not yet included pancreatic cancer.⁴⁶ Our findings suggest that information about pancreatic cancer might draw attention to the need to investigate intermittent as well as persistent symptoms especially if they occur in combination or with a sense of feeling generally unwell for no apparent reason. An algorithm has been developed to predict which patients presenting with selected 'red flag' symptoms are at highest risk of having pancreatic cancer,⁴ but we suggest that more research is needed to further develop this to incorporate a more comprehensive list of symptoms to include all those of pancreatitis. Use of such a tool could raise GPs' suspicions of cancer and help them to decide which patients to refer for hospital investigations.

In conclusion, our analysis of experiences of obtaining a pancreatic cancer diagnosis suggests that the public take reassurance when symptoms are intermittent, but that this reassurance may be false and health professionals may need to be alert to this possibility when taking histories. Although intermittent gastrointestinal symptoms are not a reliable predictor of pancreatic cancer, if, despite their intermittent nature, they were to be recognised and taken seriously, they could lead to earlier presentation and diagnosis of pancreatic cancer in some cases. Our observations about intermittent

symptoms, and the particular seriousness of the consequences, are drawn from pancreatic cancer but it seems reasonable to suppose that intermittent symptoms may generally be appraised with different criteria. We propose that existing understandings of triggers to the consultation might be extended to consider how patients and their doctors respond to a history of intermittent rather than persistent symptoms.

Contributors JE and AC conducted the interviews. JE and AC analysed the data. JE drafted the article; JE, AC, HS, PC and SZ contributed to the subsequent drafts and final version. JE and AC will act as guarantors for the work. All researchers had access to all the data and can take responsibility for the integrity of the data and the accuracy of the data analysis.

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Data sharing statement The participants were invited to review their interview transcript and mark any sections they did not want to be used, before transferring copyright to the University of Oxford for use in research, teaching, publications and broadcasting. These carefully anonymised transcripts form part of a University of Oxford archive which is available to other *bona fide* research teams for secondary analysis.

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