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SUMMARY WITH CRITICAL APPRAISAL

Experiences and Perspectives on Endoscopic Ultrasound for the Diagnosis and Treatment of Pancreatic Diseases: A Rapid Qualitative Review

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Abbreviations

EUS	endoscopic ultrasound
EUS-FNA	endoscopic ultrasound-fine needle aspiration
PERT	pancreatic enzyme replacement therapy

Context and Policy Issues

Endoscopic ultrasound (EUS) can play an important role in the diagnosis and treatment of suspected pancreatic diseases. EUS is a procedure where a device called an echoendoscope is passed through the esophagus, stomach and duodenum to take pictures of the gastrointestinal tract including the pancreas. The echoendoscope is a thin tube with a light, a camera, and an ultrasound transducer on its tip and can provide camera and ultrasound images. The images can be very detailed and provide information on pancreatic tumours, lesions and cysts.¹

Patients often are referred to undergo an EUS after having another form of radiographic imaging such as an MRI, CT scan, or an abdominal ultrasound. EUS is typically done by a gastroenterologist and an anesthesiologist as an outpatient procedure in specialized setting. The procedure is done while patients are under sedation, and there is a small risk of potential complications, including bleeding, perforation, infection and acute pancreatitis.

When EUS is combined with fine needle aspiration (EUS-FNA), a tissue sample can be collected. This can provide further information on the staging and grading of cancer. Additionally, EUS-FNA techniques can be combined with other procedures for example to insert stents into the pancreatic duct and drain fluid for the treatment of chronic pancreatitis, and also as a first-line therapy for pancreatic cancer.²

Within some Canadian jurisdictions, access to EUS remains limited outside of urban specialist facilities.³ In considering expanded access to, and the role of, EUS for people with pancreatic diseases, there is a need to understand the perspectives of those with suspected or confirmed pancreatic diseases. This report aims to address this need by providing insight using qualitative studies on how people with suspected or confirmed pancreatic disease experience accessing, deciding on, and undergoing diagnostic EUS and potential treatment using EUS. Given that EUS is situated in a care pathway that includes other diagnostic and treatment options, this report looks at the broader care pathway for pancreatic diseases.

Research Questions

- What are the experiences and perspectives of people with suspected or confirmed pancreatic disease on the process of being diagnosed and treated?
- What considerations do they raise or describe as important when making decisions around undergoing diagnostic investigations and/or treatment?
- How do they describe their ability to access diagnosis and timely treatment?

Key Findings

This review identified 1,342 citations and included 17 publications reporting on the results of 15 studies on people's experiences of engaging in the diagnosis and treatment of pancreatic diseases. With a focus on pancreatic cancer, the included studies provided limited information about those with suspected or diagnosed acute or chronic pancreatitis. Additionally, the included studies provided limited information on diagnostic testing and decision-making. The key findings from this review are:

- Many who were investigated for suspected pancreatic cancer became aware of their symptoms over time, seeking medical care once their symptoms worsened and they could no longer explain them or self-manage them.
- People with a familial risk of pancreatic cancer saw engaging in surveillance as a way of 'doing something' to prevent cancer. Some questioned the tests and the usefulness of their results, and all found waiting for results a time fraught with worry.
- Receiving a diagnosis of pancreatic cancer was often a shock and emotionally charged.
- For those diagnosed with acute pancreatitis, a formal diagnosis was found to be comforting and helped them self-manage their condition.
- People who had received diagnosis of pancreatic cancer placed their trust in and deferred to their physician's treatment recommendations.
- People with a diagnosis of pancreatic cancer found it important to continually find ways to be optimistic and have hope in light of their prognosis.
- In the face of a poor prognosis of pancreatic cancer, people had varying views on when and how to decide to stop active treatment. Once discharged from care, people were left feeling that they were no longer supported.

Methods

Literature Search Methods

A limited literature search was conducted by an information specialist on key resources including Ovid MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and SCOPUS. The search strategy was comprised of both controlled vocabulary, such as the National Library of Medicine's MeSH (Medical Subject Headings), and keywords. The main search concept were pancreatic diseases This enabled the broad capture of the experiences and views of people with suspected or confirmed pancreatic disease who might be eligible for or receive EUS. Search filters were applied to limit retrieval to qualitative studies. The search was also limited to English language documents published between January 1, 2010 and May 20, 2020.

Selection Criteria and Methods

Retrieved citations were reviewed by one reviewer. The first level of screening consisted of reviewing titles and abstracts, and the full-text of potentially eligible articles were retrieved and assessed for inclusion. The final selection of full-text articles was based on the inclusion criteria presented in Table 1.

Table 1: Inclusion Criteria using SPIDER⁴

Sample	Adults with suspected or confirmed pancreatic disease
Phenomenon of Interest	Diagnosis and treatment of pancreatic disease
Design	Any qualitative design using qualitative methods of data collection and analysis; qualitative component of mixed method studies using qualitative methods of data collection and analysis
Evaluation	Perspectives and experiences on: <ul style="list-style-type: none"> • undergoing diagnostic investigations and receiving a diagnosis • available diagnostic and treatment options and decision-making • accessing diagnosis and care (i.e., wait times, travel burden or costs) • undergoing treatment and recovery • ongoing surveillance
Research Type	Qualitative studies; qualitative component of mixed method studies

Exclusion Criteria

Articles were excluded if they did not meet the inclusion criteria outlined in Table 1, were duplicate publications reporting on the exact same data and the same findings or were published prior to 2010.

Critical Appraisal of Individual Studies

One reviewer assessed the quality of the included publications using the ten item Critical Appraisal Skills Programme (CASP) Qualitative Checklist.⁵ The results of the critical appraisal were used to understand the methodological and conceptual limitations of the included publications, specifically in relation to the research questions. Study quality was not used to exclude studies from this review. The critical appraisal contributed to the analysis by identifying the limits of transferability of the results of included studies to this review in terms of differences in setting, study populations and interventions.

Data Analysis

A framework analysis was used to organize and analyze results of the included studies.⁶ The a priori framework consisted of orienting concepts that were identified through project scoping, which included reading background materials on pancreatic diseases, including pancreatic cancer, and on EUS. The initial framework included topical concepts related to how people: suspect they have a pancreatic disease and seek care, receive a diagnosis of a pancreatic disease, and undergo treatment and being to recover, as well as the potential for ongoing surveillance.

One reviewer conducted the analysis. Included primary study reports were read and re-read to identify findings, concepts, and raw data (quotations) that mapped on the framework, which was modified as new and relevant concepts emerged. During the reading and re-reading of study reports, memos were made, noting details and observations about the study's methodology, findings, and interpretations, and connections to other studies and concepts in the framework. Diagramming was used to make connections between concepts and to map them across studies.

Using these techniques, concepts were re-ordered and organized into thematic categories. Re-reading, memoing and diagramming continued until themes were well-described and supported by data from the included publications. During the analysis, issues with

transferability and the results of the critical appraisal were reflected on to aid with interpretation. The goal of the analysis was to provide a description of the views and experiences of those who receive care for suspected pancreatic diseases to inform the use of EUS.

Summary of Included Literature

Quantity of Research Available

A total of 1,342 citations were identified in the literature search. Following screening of titles and abstracts, 1,320 citations were excluded and 22 potentially relevant reports from the electronic search were retrieved for full-text review. Of these 22 potentially relevant articles, five publications were excluded because the focus was an irrelevant sample or phenomenon of interest, or the publication described an irrelevant study design. Seventeen publications, representing 15 unique studies, met the inclusion criteria and were included in this report. Two studies^{7,8} each reported on findings from their interview data in two separate publications⁷⁻¹⁰ Appendix 1 presents the PRISMA¹¹ flowchart of the study selection process.

Summary of Study Characteristics

Details regarding the characteristics of included publications and their participants are provided in Appendix 2 and Appendix 3.

Study Design, Analytic Method and Data Collection

Nine of the 17 included publications did not report using any specific type of study design.^{7,9,12-18} Two reported using a qualitative descriptive design^{10,19}, and two used a phenomenological design.^{20,21} One each described using phenomenographic,²² qualitative exploratory,⁸ participatory action research,²³ or grounded theory²⁴ design.

Seven of the 17 included publications described using thematic analysis^{7,12-14,17,18,23} to analyze their data. Three publications described using content analysis,^{8,10,19} two used Framework analysis.^{9,15} One each described using phenomenological analysis,²¹ grounded theory,²⁴ phenomenographic analysis,²² thematic discourse analysis,¹⁶ and thematic content analysis.²⁰

Thirteen publications representing 10 studies described using interviews to collect data.^{7-10,12-14,16,18,20-22,24} One publication each described their data as transcripts of in-office interactions between patients, caregivers and their health care providers,¹⁹ group discussion using photovoice,²³ unstructured conversations,¹⁷ or a mixture of focus groups and interviews.¹⁵

Country of Origin

Of the 15 included studies, three were conducted in the USA,^{19,20,23} three studies reported on in four publications were conducted in the UK,^{7,9,13,14} two studies in Sweden,^{21,22} and one study was reported on in two publications was conducted in Denmark.^{8,10} One study was conducted in each of New Zealand,¹² Canada,²⁴ Australia,¹⁶ Germany,¹⁸ Ireland¹⁷ and the Netherlands.¹⁵

Study Population and Interventions

Eight studies reported on in nine publications described their participants as having pancreatic cancer.^{7,9,12,13,18,19,21,23,24} Three studies reported on in four publications included participants the majority of whom had pancreatic cancer and a portion of whom had another closely-related cancer (i.e., duodenum, bile duct, ampullary or colon).^{8,10,15,16} One study each included participants with chronic pancreatitis¹⁷ and acute pancreatitis.²² One study included participants with suspected pancreatic cancer¹⁴, and one study included people at high familial risk for pancreatic cancer.²⁰

Two studies included patients who had undergone surgery for pancreatic cancer.^{16,21} One study reported on in two publications included patients with pancreatic cancer who had had surgery and were undergoing chemotherapy.^{8,10} One study included participants with pancreatic cancer who were on chemotherapy.¹⁸ Two studies reported on in three publications included patients across the care pathway for pancreatic cancer.^{7,9,23} Two studies did not report the interventions participants were receiving for their pancreatic cancer.^{15,19} Two studies included patients undergoing PERT therapy for pancreatic cancer.^{12,13} One study included people who had been treated for pancreatic cancer and were under surveillance.²⁴ One study included people with a high familial risk of pancreatic cancer who underwent surveillance.²⁰ One study included participants undergoing diagnosis investigations for symptoms suggestive of pancreatic cancer.¹⁴ One study focused on living with chronic pancreatitis¹⁷ and another on recovering from acute pancreatitis²² and did not report the interventions participants were receiving.

Summary of Critical Appraisal

The credibility of the included studies was affected by rigour in data collection and/or analysis. These two interrelated issues influenced whether the reported findings were coherent and consistent with the collected data. For example, multiple studies collected data from people who had the experience in a long time frame (e.g., 1-5 years post-treatment) and analyzed those data as capturing the same phenomenon (e.g., recovery).^{15,17,24} This failed to account for the ways that people's understandings and views of recovery from treatment change over time, and their description as static affected the credibility of those study findings. Similarly, studies where the description of the findings was superficial, not supported by data, or were judged to be not coherent with the study data and objectives were considered to be less credible.^{7,9,14-17,22,24}

An additional issue affecting three studies was that caregivers or relatives participated in data collection and their perspectives were reported on although the consent process was not reported and the nature of their participation was not described in the methods section.^{14,15,24} This raised questions about the informed consent of those participants and how those data were collected, and influenced the judgement of lower credibility of those studies.

The final issue affecting the critical appraisal of the included studies was their transferability. Four studies were judged to have limited transferability. Two studies were of limited transferability because they focused on advanced pancreatic cancer.^{12,13} Additional studies had limited transferability because of a narrow focus on a specific treatment experience (e.g., recovery post-pancreatic surgery).^{8,19} The limited transferability of these studies affected how relevant the study findings were to the review questions. Details regarding the critical appraisal of included publications are provided in Appendix 4.

Results

Becoming aware of symptoms and seeking care

People described that they became aware of the symptoms that eventually led them to present to medical care and be investigated for suspected pancreatic cancer over time.^{9,14} The time between when people became aware of their symptoms to when they decided to seek medical care was reported as ranging between less than one month to five years.^{9,14} This highlights the way in which coming to awareness of symptoms that led to investigations for pancreatic cancer was a process for most people. Symptoms people reported included pain and digestive troubles, sometimes accompanied by fever, nausea or vomiting, and changes in their bowel movements.^{9,14} Much of the time, people who eventually sought care for suspected pancreatic cancer described their symptoms as intermittent and mild, although re-occurring.^{9,14} Some described that they ignored the symptoms, hoping they would naturally resolve, or in other cases, people attributed them to common conditions like viruses or colds, or a pre-existing health condition such as diabetes.^{9,14}

A key approach that people described using to manage their symptoms was changing their dietary patterns, and through doing so they sought to isolate the cause of their digestive symptoms.¹⁴ This included things like limiting the amount they ate, what they ate, and when they ate. By engaging with self-management and developing alternative plausible explanations for their symptoms, people described that they did not see a need to seek medical care. One participant articulated how she adapted to her symptoms as: “I think you learn to live with it and you just adapt to it and start to make the changes so it doesn’t happen... I think what had happened with me is I couldn’t control it any longer, no matter if I stopped eating things, didn’t eat out, it was happening anyways.”¹⁴

As this participant’s words reveal, it was once people could no longer self-manage their symptoms that they began to consider medical care. People’s ability to normalize or attribute their symptoms to other causes changed once their symptoms changed, specifically once they experienced an increase in the frequency or severity of existing symptoms, or that new symptoms arose.^{9,14} New or more intense pain was highlighted by many people with potential pancreatic disease as being the trigger for seeking medical care.^{9,14}

[I] 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 [irritable bowel syndrome]; 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... 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.(p. 5)⁹

Interestingly, none of the participants raised suspicion of pancreatic disease except for those who had family history of the disease.¹⁴

The findings under this heading draw into view how many people first entering the care pathway for pancreatic cancer may have been living with the disease for some time and may not be aware that their symptoms are consistent with those of a serious, life-limiting condition.

Engaging in surveillance: preventing cancer but causing worry

One study explored the experiences of people with a hereditary risk of pancreatic cancer and how they engaged with being monitored for pancreatic cancer.²⁰ Participants described how undergoing pancreatic cancer surveillance, in the form of and MRI and EUS, was a way for them to “do something.” People with a hereditary risk for pancreatic cancer viewed surveillance as a form of prevention, as they hoped it could help them catch the cancer early and avoid the fate of their family member(s).

Despite undergoing surveillance, some expressed uncertainty over the benefit of it in terms of the procedure and the ability of the results to inform a course of action. For example, one participant said: “you guys you [health care providers] don’t have any real screening device for this yet...”²⁰ as he felt that EUS and MRI created exposure to perceived risk (not described) that provided limited benefit. Some did not want to undergo testing if it did not provide actionable information as in the ability to cure the cancer.²⁰

Waiting for test results was described as full of worry and fear and culminated with the wait for the appointment for receiving results. People with a familial risk were troubled as they remembered how their family member(s) had undergone testing and their subsequent journey with cancer. . The shorter the time between testing and the return of test results was found to be helpful to reduce their fear and worry.²⁰

Receiving a diagnosis

Once they decided to seek medical care, people reported different paths to their diagnosis of pancreatic cancer.⁹ Some described being quickly guided through diagnostic testing by their family doctor, whereas others talked about having to return again and again and persist in bringing up their symptoms before more testing was ordered.⁹

During the process of undergoing diagnostic investigations for pancreatic disease, people described their frustration when they had a scheduled examination without knowing what it was, or were expecting it to be something else: “I was so disappointed that it was an MRI because the physician had told me ‘We will investigate you and then we will go down with a camera into your belly.’”²²

For many, a diagnosis of pancreatic cancer came as a shock.^{16,23} This was especially true for those who were asymptomatic and self-identified as “healthy”: “I was not unwell, I was fit, I was healthy and that’s about it, and my first 55 years I’ve not spent a day in hospital other than to have my children and fix a broken ankle, so it was a huge shock to us all.”¹⁶ This reinforces that people often did not have pancreatic disease or pancreatic cancer in mind as a possible cause for their unexplained symptoms. People described being angry at receiving a diagnosis of pancreatic cancer, angry that they had it and searched for answers as to why they did:²³ “The ‘why me’ came on really strong... I couldn’t shake that. This has been thrown at me. I did nothing to deserve it... I never smoked, I don’t drink, I was health conscious, I’m not diabetic. I went through all of the risk factors and had none of them.”²³

In the case of those who received a diagnosis of acute pancreatitis, some described they felt a sense of relief and feeling positive once diagnosed, as they had an explanation for their symptoms.²² For those who did not receive a diagnosis, or their diagnosis was idiopathic, they longed to know the cause of their symptoms.²² One participant with idiopathic acute pancreatitis described how: “[i]t is hard that they do not really know why I had it, perhaps it would had felt a little calmer if I knew why... I can’t do anything, I can’t choose not to avoid certain things, I do not know what to do, I guess that’s the problem.”²²

Knowing the cause of their pancreatic disease symptoms helped people both emotionally by providing certainty and stability, but also helped them chart a course of action to have some control over their health.

Patient-provider relationships and decision-making

People with pancreatic cancer described how, in light of learning that they had an urgent and life-threatening condition, they relied almost entirely on their physician's recommendations.^{7,15,18,24} Some described this as though they felt they had no choice in their treatment decision-making.^{18,24} They reported being overwhelmed with their diagnosis, and that they had limited interest in details about treatment: "And I didn't want a second opinion, and I didn't want to know more about the operation than I already knew. I really, I didn't want to know. I just wanted someone to look after me and make the decision at that stage, and tell me what to do."⁷

Trust was, however, established rather than a given, through the way in which physicians provided information and communicated in an empathetic and kind manner:^{15,24}

He [surgeon] comes across as being a very caring person, a very trustworthy person. I had every confidence in him, and a lot of that was built up over the time that I knew him. I just thought that he was great. He has a wonderful personality, a wonderful character. You know, he always made me feel like I could trust him 100%, he was going to do the best for me.(p. 616)²⁴

Having trust in their physician was a source of emotional support for people navigating their pancreatic cancer and provided reassurance:^{18,24} "The confidence that [the surgeons] had rubbed off on me, eventually, and we just felt they know what they were doing and they gave you the faith that you're going to be okay."²⁴

Trust was placed in their physician, but also in the facility. Participants noted that they appreciated having access to a "cancer centre" or other high-volume specialist centre:¹⁸ "Yes, where they do most of the operations. That was the most important thing... [the facility] actually had a very good reputation. And as the head physician told me: Go to X, to Prof. Y. You are in good hands there."¹⁸

This placing of the responsibility for decision making into the recommendations of physicians was also described by people with pancreatic cancer as a recognition of their expertise. People with pancreatic cancer expressed that they did not have the knowledge or expertise to make treatment decisions, and that it was not their role:^{7,15} "I'd only relied on the information they'd given me through the ward staff and I chose that because I always feel that if you try to go into territory that you're not familiar with then you can only confuse yourself."⁷

However, many people who had pancreatic cancer reported that they used the internet throughout their diagnosis and treatment, to help make sense of their diagnosis and what their physicians had said.⁷ People also used the internet to find out about clinical trials, complementary treatments, and self-management strategies.^{7,18}

People with pancreatic cancer reported that their first encounters with their physician and facility shaped their expectations and experiences of their subsequent visits.⁸ Bad encounters were described as being where the health care providers appeared to be busy and did not seem to be responsive to patients' needs. People reported that prior negative

experiences led them to remain alert and anxious at their following encounters.⁸ Having initial positive consultations were seen as facilitating trust throughout follow-up.⁸

As they engaged in treatment, people with pancreatic cancer described how they began to take a more active role in their care. In particular, they noted that they sought to keep the focus during treatment on their personal priorities.¹⁸ A participant said how they negotiated their treatment schedule, saying: “During the operation, one abandons oneself, all parallel planning was put aside; then with the recovery, the desire to go into private planning again returns. And the schedule of the chemo, it competed with the holiday.”¹⁸

The role of hope and optimism

People with pancreatic cancer consistently described how they sought out hope even as their condition advanced¹⁸ or knew the prognosis was not good.¹⁶ In the face of a poor prognosis of pancreatic cancer, people wanted to hear positive messages about their situation.

This desire for optimism was articulated by people as they continued to search for other treatment options such as clinical trials or complementary treatments, and was grounded in the desire for a longer life with family and grandchildren.^{16,23} Optimism provided security for people, and helped alleviate the uncertainty and anxiety raised by their cancer diagnosis.¹⁶ People with pancreatic cancer found this optimism reflected in their consultations with physicians at times: “So you look on the positive side and all the doctors say, ‘No you’ll be right. We’ve caught it nice and early; it hasn’t spread, you haven’t had bad symptoms.’” Keeping optimistic and hopeful was seen by many as part of the “battle” against their cancer, and that not going through treatment was “giving up.”¹⁶ Information that offers optimism was appreciated by people who were being diagnosed or treated for pancreatic cancer.

Undergoing treatment

For those people who had pancreatic cancer and who were eligible, pancreatic surgery (e.g., Whipple procedure, pancreatic resection) was viewed a source of hope.²⁴ However people described that their body changed post-surgery and left them ill at ease.^{10,21}

When monitoring their response to treatment, specifically through cancer antigen testing, people with pancreatic cancer found positive results offered reassurance, while negative results left them anxious and worried.⁸ People responded to the “double-edge sword” of antigen testing in a number of ways, with some growing tired of testing and not wanting to know the results. One participant’s experience vividly describes their rejection of testing, and at the same time the perception that their needs were not being met or considered in going through with testing:

I’d already said that I didn’t want any scans. I don’t want any blood tests either. I know it [cancer antigen] has gone up. I know there’s something wrong. I know... again, the nurse pressured me into having it... So, if I’d said no all along I would have been better off and not had all those negative thoughts in my head all the time. And I regret so much I got pressured. Because if I was not pressured the last year [would] have been TOTALLY different from now.(646)⁸

Others described feeling that the emphasis on antigen testing and scans overshadowed their symptoms and left them unable to discuss them with their physician.¹⁰

People also described that once treatment for their pancreatic cancer was completed, they worried how they would fare without frequent surveillance which offered some a sense of security.^{21,23} Part of this was the ability to get support for symptoms and how to self-manage them.²¹ “Now that I have been discharged they do not care about me as much as before. So now I’m discharged, written off somehow.”²¹ People recovering from pancreatic cancer were reported as appreciating access to rehabilitation programs as it offered this support in the community and enabled them continued access to support.¹⁰

Some articulated that they struggled to decide when to stop active treatment.^{16,18} People differed in their views on whether it was the physician’s responsibility to stop treatment, or theirs.¹⁸ On one view, as they had gained experience as a patient, they sought to take more control over their treatment decisions.

Well, so a chemo-patient who just went from chemotherapy to chemotherapy also becomes a specialist... And he drifts more and more into a life decision, a life situation, where he knows that he has to now take decisions and responsibility for himself, and this can’t be done by a doctor...(p. 2447)¹⁸

For those who chose it, contrary to “giving up”, ending treatment moved them towards a “good death” and was to assert control over their lives in the face of a terminal cancer diagnosis.¹⁶ People sought to live in the present and make the most of the time they had left, as one person with advanced pancreatic cancer said of their decision to end treatment: “[I]t probably took a couple of months for us to say right well we need to move on and just make each day count.”¹⁶

Recovery and an uncertain future

After surgical resection for their pancreatic cancer, some people transitioned again to feeling healthy. Health was not only physical, but was grounded in the ability to control their symptoms so that they could do activities that gave their lives meaning, including their independence and return to hobbies.²¹ One participant described their sense of health and independence again as uplifting: “Because I can, that I’m feeling well and can go out, can do various things without having to ask for help, just the fact that I’m able to do it gives you a kick being able to manage things.”²¹

However, others with pancreatic cancer continued to struggle with symptoms, including pain, fatigue, abnormal bowel movements, decreased appetite and nausea and vomiting.^{8,19} Their disrupted gut and fatigue affected their ability to do activities they enjoyed. They described a variety of self-management strategies, including self-medicating, adjusting their treatment regime, and stopping treatment.^{10,19} People with pancreatic cancer described how they experimented with dietary modifications, including different types or amounts of food during and post-treatment.^{10,16,21}

Many people with both pancreatic cancer and chronic pancreatitis reported feeling that uncertainty hung over their sense of a future because of the likelihood of the cancer returning²³ or having another life-threatening exacerbation.¹⁷ As one participant put it: “No matter what kind of wonderful day you’re having, you know that these black clouds are there and on any day, life could change again in a minute. So you never ever really are without feeling that.”²³ People coped by living in the present, and focusing on short-term planning.²³

Limitations

The key limitations of this review and its findings stem from the focus of the included studies. The set of included studies largely focused on the experiences of people living with pancreatic cancer, and contained limited information on people's experiences engaging with care for other pancreatic disease. This means that the experiences of those with pancreatic disease other than pancreatic cancer are underrepresented in this review. Additionally, the majority of the included studies focused on specific aspects of treatment and recovery from pancreatic cancer and were of limited relevance to the review question about the process and decision-making around diagnosis and treatment.

Conclusions and Implications for Decision or Policy Making

This review used a framework analysis to synthesize the results reported in 17 included publications from 15 studies and described the views and experiences of people with suspected or confirmed pancreatic disease on the process of undergoing diagnosis and treatment.

Many with pancreatic disease described becoming aware of their symptoms over time, and seeking medical care when their symptoms worsened and could no longer be self-managed, and common conditions or comorbidities could no longer account for them. This means that people may have lived with their symptoms for a long time prior going to the doctor and were likely unaware that pancreatic cancer was a possible diagnosis or explanation for their symptoms. Taking care during the diagnostic process to not blame people for not presenting earlier may be an important strategy to support people with the emotional burden of the process of being diagnosed. Also, people are likely to have existing self-management strategies that they use to deal with their symptoms that may need to be accounted for in their treatment plan.

Those with a hereditary risk of pancreatic cancer found engaging in surveillance to be a way of 'doing something' to prevent cancer. Although it was unclear why, some questioned the tests (both MRI and EUS) and the usefulness of their results, but all found waiting for results a time fraught with worry. These findings point to the need to ensure continued informed consent during ongoing surveillance and acknowledge that people's evaluation of risks and benefits may change over time. Waiting for test results is a time of anxiety for all, and efforts to ensure the timely return of results help lessen people's worry.

A diagnosis of pancreatic cancer was often a shock and a highly emotional experience. For those diagnosed with acute pancreatitis, a formal diagnosis was found to be comforting and helped them self-manage their condition. This highlights the benefits of having a diagnosis, particularly in the case where it allows for intervention and self-management. Such relief was not experienced by those with chronic pancreatitis or pancreatic cancer, however. This draws into light the ways in which medical procedures such as EUS that are used for multiple conditions may be experienced differently by people with different conditions.

As they grappled with their diagnosis of pancreatic cancer, people made initial treatment decisions by placing their trust in their physician's recommendations. Trust was established through the actions of their physician, and initial experiences shaped people's journey throughout their treatment. It may be particularly important to support people during the diagnostic process and ensure that their understandings and expectations of the process of care are accurate yet succinct, as many may be overwhelmed. Having multiple opportunities to provide relevant information and answer questions throughout the

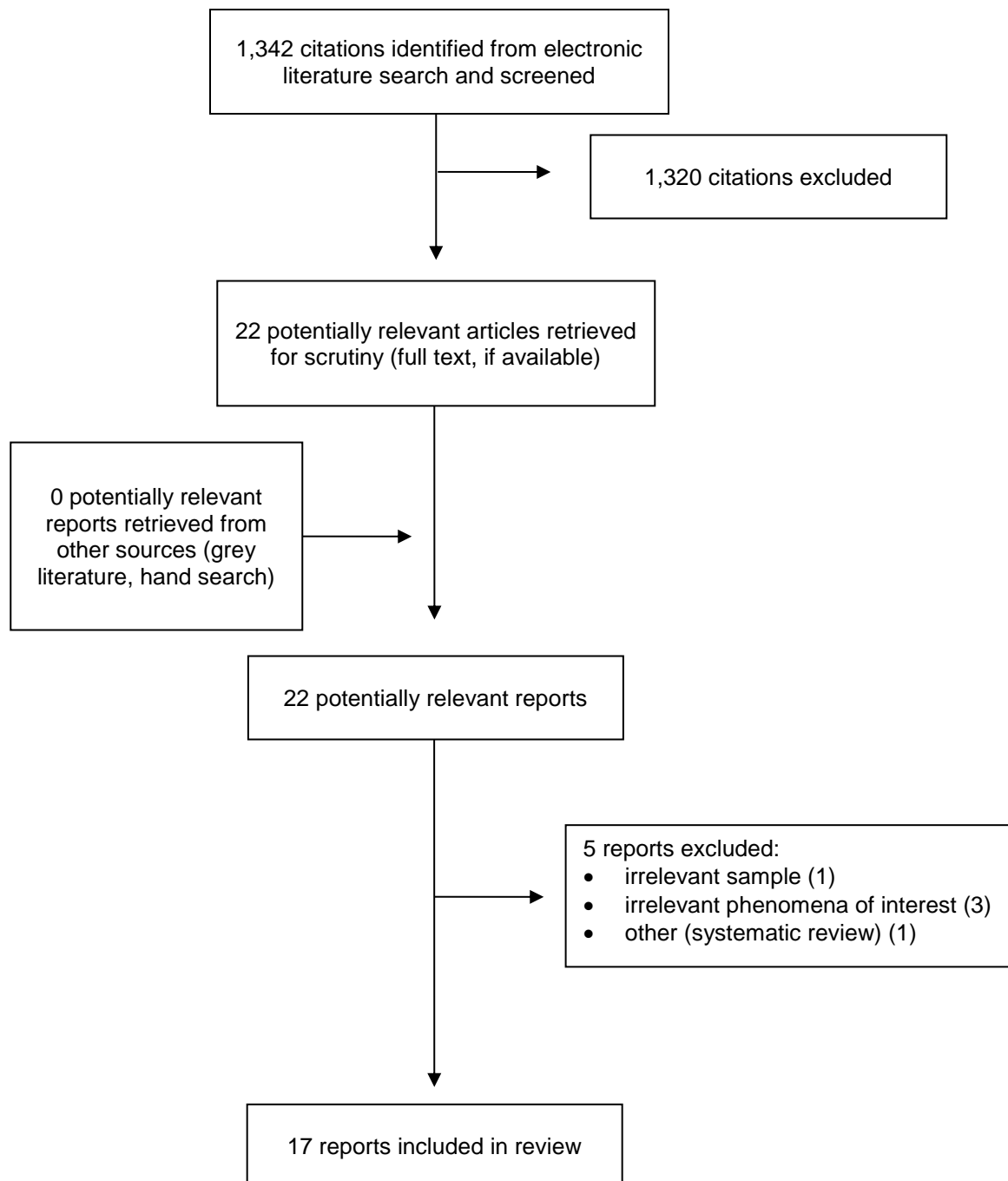
diagnosis process may offer comfort and support understanding. The findings on trust and positive health care experiences highlight how people experiences a particular procedure or treatment is shaped by the prior health care they have received.

Recovery from pancreatic cancer and chronic pancreatitis was a process. Once discharged from care, people were left feeling that they were no longer supported. Participation in ongoing surveillance, including EUS, may offer people recovering from pancreatic diseases a point of contact with health care providers that allows them to gather further support. However, the additional worry and stress that accompanies testing is likely worth considering in the process of surveillance.

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Appendix 1: Selection of Included Studies



Appendix 2: Characteristics of Included Publications

Table 2: Characteristics of Included Publications

First Author, Publication Year, Country	Study Design; Data Analysis	Study Objectives	Inclusion Criteria	Data Collection
Landers, 2020, New Zealand ¹²	NR; thematic analysis	To explore the experiences of patients with PERT and how the medication is taken and tolerated	People with Palliative Performance Score of at least 60% or above who had pancreatic cancer and not commenced PERT, and were able to give consent to participate in English and were 18 years old or older	Semi-structured interviews
Boije, 2019, Sweden ²²	Phenomenography	To describe patients' perceptions of recovering from acute pancreatitis	People diagnosed with acute pancreatitis and discharged from hospital; 18 years old or older and able to communicate in Swedish	Semi-structured interviews
Elberg Densgø, 2019, Denmark ^{10*}	Qualitative descriptive design; content analysis	To explore patients' experiences of follow-up in the first year after surgery and adjuvant chemotherapy to understand their rehabilitation	Patients with cancer in the pancreas, duodenum or bile-ducts attending current follow-up after curative surgery and, if indicated and accepted by the patient, adjuvant chemotherapy, no evidence of advanced disease at the start of follow-up, and 18 years old or older	Three separate interviews at 1 week, 6 months and 9 months following entry into the study
Wong, 2019, USA ²³	Participatory action research using photovoice; thematic analysis	To gain a richer understanding of the factors associated with psychological distress for pancreatic cancer patients and their caregivers	People diagnosed with pancreatic ductal adenocarcinoma in the past 5 years and their self-identified caregivers (patients and caregivers could participate independently, and did not require the participation of the other); 18 years old or older; able to communicate in English	Small group discussions reflecting on photographs collected by participants
Densgø, 2018, Denmark ^{8*}	Qualitative explorative design; content analysis	To explore patients' experiences of their gut, digestion, recovery and uptake of everyday life after curative surgery for pancreaticoduodenal cancer	Patients with cancer in the pancreas, duodenum or bile-ducts attending current follow-up after curative surgery and, if indicated and accepted by the patient, adjuvant chemotherapy, no evidence of advanced disease at the start of follow-up, and 18 years old or older	Semi-structured interviews
Dunleavy, 2018, UK ¹³	NR; thematic analysis	To gain explore patients' experiences of self-management of PERT following surgery for pancreatic cancer	Adult patients who had undergone surgery for pancreatic cancer and were prescribed PERT post-operatively	Semi-structured interviews

First Author, Publication Year, Country	Study Design; Data Analysis	Study Objectives	Inclusion Criteria	Data Collection
Tang, 2018, USA ^{19**}	Qualitative descriptive design; content analysis	To understand the symptom experiences of advanced pancreatic cancer patients as told to healthcare providers	Patients who have staged 3-4 pancreatic cancer and are participants in an RCT (Values and Options in Cancer Care), and their caregivers and their oncologists	De-identified transcripts of patients' audio recorded office visits
Blakely, 2017, Canada ²⁴	Grounded theory	To understand the information needs and communication experiences of patients treated surgically for pancreatic cancer	Patients who had undergone surgical resection with curative intent for periampullary cancer within the past three years and currently undergoing disease surveillance Surgeons managing between 20 and 30 patients with periampullary cancer per year	Semi-structured interviews
Geessink, 2017, Netherlands ¹⁵	NR: Framework analysis	To identify elements of optimal treatment decision-making for colorectal or pancreatic cancer	Patients were >65 years old and diagnosed with either pancreatic or colorectal cancer in the previous 5 years Surgeons and relatives: NR	Focus groups and in-depth interviews
Mills, 2017, UK ¹⁴	NR; thematic analysis guided by the Pathways to Treatment model	To understand symptom appraisal and help-seeking decisions among patients' symptoms of pancreatic cancer to contribute to the development of interventions to promote earlier or more timely cancer diagnosis	Patients who had been referred to specialist care by their GPs for symptoms suggestive of pancreatic cancer; patients aged 40 or older	Interviews
Gibson, 2016, Australia ¹⁶	NR; thematic discourse analysis	To explore how people negotiate, and respond to, identity transitions following a diagnosis of pancreatic cancer	Participants in a case-control study of primary invasive pancreatic cancer	Semi-structured interviews
Underhill, 2015, USA ²⁰	Phenomenological design; thematic content analysis	To understand the meaning and experience of living with familial pancreatic cancer risk and explore experiences related to screening and prevention of pancreatic cancer	People over the age of 21 who did not have a diagnosis of pancreatic cancer; had personal, genetic, or familial factors that indicated they were at an elevated risk for pancreatic cancer	Semi-structured interviews
Evans, 2014, UK ^{9**}	NR; Framework analysis based on the Total Patient Delay model	To explore how people affected by pancreatic cancer their symptoms pre-diagnosis and why they sought medical help	NR	Semi-structured interviews
Cronin, 2013, Ireland ¹⁷	NR; thematic analysis	To develop an understanding of what it means to live with chronic pancreatitis	NR	Multiple, unstructured conversations
Schildmann, 2013, Germany ¹⁸	NR; thematic analysis	To explore pancreatic cancer patients' perceptions and preferences on	Diagnosis of pancreatic cancer and at least one regime of chemotherapy	Semi-structured interviews

First Author, Publication Year, Country	Study Design; Data Analysis	Study Objectives	Inclusion Criteria	Data Collection
		information and treatment decision-making		
Andersson, 2012, Sweden ²¹	Phenomenological - hermeneutic method	To explore the lived experience of the symptoms, health, and illness reported by patients recovering after surgery for pancreatic or periampullary cancer	Patients who had undergone pancreaticoduodenectomy ad modum Whipple for a pancreatic or periampullary tumour and had been discharged in the last 30 days; additional criteria included that they had no other major surgery/reoperation, no mental disorder, and no drug or alcohol abuse	Interviews
Chapple, 2012, UK ^{7**}	NR; thematic analysis	To describe how people affected by pancreatic cancer use the internet for information	NR	Semi-structured interviews

NR = not reported; PERT = pancreatic enzyme replacement therapy; RCT = randomized controlled trial;

* Densgø 2019 and Densgø 2018 use the same study data

** Evans 2014 and Chapple, 2012 use the same study data

Appendix 3: Characteristics of Study Participants

Table 3: Characteristics of Study Participants

First Author, Publication Year, Country	Sample Size	Sex (% female)	Age (range in years)	Type of Pancreatic Disease	Treatment or Care Received
Landers, 2020, New Zealand ¹²	12 patients	67	56-79	Advanced pancreatic cancer	Undergoing PERT treatment and referred for palliative care
Boije, 2019, Sweden ²²	16 patients	25	26-81	Acute pancreatitis	Recovery
Elberg Densø, 2019, Denmark ^{10 8}	12 patients	42	51-73	Cancer in the pancreas, duodenum, or bile-duct	2-9 months after surgery and receiving adjuvant chemotherapy
Wong, 2019, USA ²³	13 patients 7 caregivers	Patients: 54 Caregivers: 57	Patients: 40-79 Caregivers: 50-69	Pancreatic cancer	Patients could either be undergoing active treatment or surveillance without treatment
Dunleavy, 2018, UK ¹³	9 patients	56	43-73	Pancreatic cancer	Patients undergoing PERT following surgery for pancreatic cancer
Tang, 2018, USA ¹⁹	37 patients 34 caregivers	Patients: 57 Caregivers: NR	Patients: 44-92 Caregivers: NR	Pancreatic cancer (stage 3 or 4)	NR
Blakely, 2017, Canada ²⁴	10 patients 10 surgeons	Patients: NR Surgeons: 30	Patients: NR Surgeons: NR	Pancreatic cancer	Patients who had surgery in the past three years and were under surveillance
Geessink, 2017, Netherlands ¹⁵	22 patients 14 relatives 23 surgeons	NR	Patients (focus groups): mean 73.5 Patients (interviews): mean 80.6 Relatives and surgeons NR	Pancreatic cancer (focus groups): 50% Pancreatic cancer (interviews): 67%	NR
Mills, 2017, UK ¹⁴	13 patients with cancer 13 patients with non-cancer	Patients with cancer: 46 Patients with non-cancer: 62	Patients with cancer: 50-84 Patients with non-cancer: 49-84	Pancreatic cancer (n=9) Pancreatitis (n=2) Other (n=15)	Patients undergoing specialist consultations and diagnostic investigations for suspected pancreatic cancer
Gibson, 2016, Australia ¹⁶	19 patients	32	40-83	Pancreatic or ampullary cancer	42% had undergone surgical resection, 58% were unable to undergo resection due to local advancement or metastases

First Author, Publication Year, Country	Sample Size	Sex (% female)	Age (range in years)	Type of Pancreatic Disease	Treatment or Care Received
Underhill, 2015, USA ²⁰	19 participants	53	37-80	Hereditary risk of pancreatic cancer	Screening for pancreatic cancer
Evans, 2014, UK ^{7,9}	32 patients 8 relatives	Patients: 47 Relatives: 38	Patients: 35-84 Relatives: 35-74	Pancreatic cancer	Participants ranged from recently diagnosed to in palliative care
Cronin, 2013, Ireland ¹⁷	14 patients 5 relatives	Patients: 29 Relatives: NR	Patients: 26-58 Relatives: NR	Chronic pancreatitis	Recovery
Schildmann, 2013, Germany ¹⁸	12 patients	50	40-76	Pancreatic cancer	At least one regime of chemotherapy
Andersson, 2012, Sweden ²¹	13 patients	69	54-76	Pancreatic cancer	Pancreaticoduodenectomy

NR = not reported; PERT = pancreatic enzyme replacement therapy

Appendix 4: Critical Appraisal of Included Publications

Table 4: Critical Appraisal of Included Publications

Qualitative Studies Assessed Using CASP Qualitative Checklist ⁵										
First Author, Year	Clear statement of the aims of the research?	Qualitative methodology appropriate?	Research design appropriate to address the aims of the research?	Recruitment strategy appropriate to the aims of the research?	Data collected in a way that addressed the research issue?	Relationship between researcher and participants been adequately considered?	Ethical issues been taken into consideration?	Data analysis sufficiently rigorous?	Clear statement of findings?	Relevant to the current review?
Landers, 2020 ¹²	+	+	+	+	+	-	-	+	+	-
Elberg Densø, 2019 ¹⁰	+	+	+	+	+	+	+	+	+	-
Wong, 2019 ²³	+	+	+	+	+	-	+	+	+	+
Densø, 2018 ⁸	+	+	+	+	+	+	+	+	+	-
Dunleavy, 2018 ¹³	+	+	+	+	+	+	+	+	+	-
Tang, 2018 ¹⁹	+	+	+	+	-	+	+	+	+	-
Blakely, 2017 ²⁴	+	+	+	-	-	+	-	-	+	-
Boije, 2017 ²²	+	+	+	-	+	+	+	-	+	-
Geessink, 2017 ¹⁵	+	+	-	-	-	-	+	-	-	-
Mills, 2017 ¹⁴	+	+	+	+	+	-	-	-	+	+
Gibson, 2016 ¹⁶	+	+	+	+	+	+	+	+	+	-
Underhill, 2015 ²⁰	+	+	+	+	+	+	+	+	+	+
Evans, 2014 ⁹	+	+	+	+	+	+	+	-	+	+
Cronin, 2013 ¹⁷	+	+	+	-	-	+	+	-	+	+
Schildmann, 2013 ¹⁸	+	+	+	-	+	+	+	+	+	+
Andersson, 2012 ²¹	+	+	+	+	-	+	+	+	+	+
Chapple, 2012 ⁷	+	+	+	+	+	+	+	-	+	+

+ = yes; - no