OPTIMISTIC

- OPTIMISing care and support for patients with inoperable pancreaTIC cancer and their family carers

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award of Doctor of Philosophy

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Abstract

This qualitative intrinsic case study explores the provision of supportive care to people with inoperable pancreatic cancer and their family carers (FCs) in England. The aim of the research was to develop recommendations for optimising supportive care provision for this cohort.

Sixty semi-structured interviews were undertaken with patients, their FCs, and HCPs, between May 2022 and November 2023. Patients and FCs were recruited through English NHS sites, Pancreatic Cancer UK (PCUK), and via social media. Thirteen patients and 12 FCs took part in interviews, with several participants from both groups interviewed on multiple occasions. Twenty-four HCPs, including specialist nurses, dieticians, and oncologists, were interviewed once only. Data were analysed thematically using the Framework Approach. Fitch’s Framework for conceptualising patient and FC’s supportive care needs (1994) was used as the theoretical framework for the study.

The findings show that the rapid progression of the disease and the symptom burden are often overwhelming and create challenges for care planning and co-ordination of care. While needs for patients are high in the physical domain, both patients and FCs report high needs in the emotion, psychological and information domains. The findings highlight the relentless nature of the FC role, and suggest that FCs’ needs are often not identified, let alone adequately addressed.

The findings also highlight the contextual service pressures of reduced capacity, constrained resources, and increasing workloads.

While healthcare resources are undoubtedly a limiting factor in what can be achieved, several issues raised by the findings are amenable to improvement. These include fundamental aspects of what constitutes a good quality patient and FC experience such as compassionate and empathetic interpersonal communication, timely and responsive care co-ordination, efficient communication between and within organisations, and the general provision of information and guidance to patients and their FCs.

Dedication

This thesis is dedicated to the wonderfully generous people who gave their time so willingly to talk to me for this research, but who did not survive to see the results of their contribution.

It is also dedicated to Mike, a man of great patience and forbearance!

Finally, the thesis is dedicated to my mother, Valerie.

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I am also grateful that so many healthcare professionals were prepared to take time away from their clinical commitments to contribute to the study and were open and honest about the challenges they face in their professional lives.

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Finally, I wish to thank the staff at Pancreatic Cancer UK for their support of the study and their ongoing commitment to improving the lives of people affected by pancreatic cancer.

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List of figures and tables

List of abbreviations or definitions used

Abbreviation/term	Definition
ACP	Advanced care planning
Adjuvant chemotherapy	Chemotherapy given after surgery
A&E	Accident and Emergency
Biomarker	A measurable indicator of some biological state or condition – these can be found in blood, urine, or soft tissues etc.
CAG	Clinical Advisory Group
Capecitabine	An anti-cancer drug used as a chemotherapy agent
CCR	Cancer care review
Chemoradiotherapy	Treatment with chemotherapy and radiotherapy together
Chemotherapy	Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. The drugs circulate throughout the body in the bloodstream
CNS	Cancer nurse specialist
CQUIN	Commissioning for quality and innovation
CREON®	Brand name for pancreatic enzyme replacement therapy
CT scan	Computed tomography – a diagnostic tool to see images of the inside of the body
DGH	District General Hospital
EoL	End of life - The NHS defines End of life as care that is provided within the last year of life (NICE, 2019)
ESC	Enhanced supportive care
EUS-CPN	Endoscopic ultrasound-guided celiac plexus neurolysis
FC	Family carer – the person nominated as an informal carer (person they get most informal support from) by a patient who was invited to participate
Gemcitabine	An anti-cancer drug used as a chemotherapy agent
GI	Gastrointestinal
GIRFT	Getting it Right First Time (NHS Quality Improvement Programme)
GP	General practitioner (family doctor)
GSF	Gold standards framework
HCP	Healthcare professional
HNA	Holistic needs assessment
HPB	Hepatobiliary
HRA	Health Research Authority

Abbreviation/term	**Definition**
IRAS	Integrated Research Application System
Metastatic cancer	Cancer cells spread from the initial or primary site to a different or secondary site
MDT	Multi-disciplinary team
MRI	Magnetic resonance imaging
Neoadjuvant chemotherapy	Chemotherapy that is given before surgery
NHS	National Health Service
NHS REC	NHS Research Ethics Committee
NICE	National Institute for Health and Care Excellence
NPaCA	National pancreatic cancer audit
Occult disease	Metastatic disease which is hidden
OCP	Optimal Care Pathway
PACT UK	Radiology reporting template
PCR	Palliative care review
PCUK	Pancreatic Cancer UK
PEI	Pancreatic enzyme insufficiency
PERT	Pancreatic enzyme replacement therapy
PNET	Pancreatic neuroendocrine tumour
PPIE	Patient and public involvement and engagement
QOF	Quality and Outcomes Framework- a financial incentive system designed to improve the quality of care patients receive within primary care
QoL	Quality of Life
RIN	Research Involvement Network
Radiosensitiser	A chemical agent that is included in the radiation volume which either increases the damage to cancer cells or protects normal tissues
Radiotherapy	Radiotherapy uses high energy x-rays to treat cancer cells
SCAN	Clinical pathway for urgent referral of suspected but unknown cancer
Study sponsor	A sponsor is an individual, organisation or group taking on the responsibility for securing the arrangements to initiate, manage and finance a study
Two week wait (2WW)	Clinical pathway for urgent referral of suspected specific cancer

‘As doctors, the interactions we have with our patients are a crucial part of the medical care we provide. Our empathy and professionalism shape a patient's experience almost as much as our diagnostic ability or surgical skills,… receiving my diagnosis reinforced for me that neat outcomes aren't the norm in most areas of medicine. Many doctors carry this weight, but kind words can soften the blow of bad news, and empathy and understanding undoubtedly ease the burden. There is no greater comfort than human connection…compassion …defines first-class care.’– Dame Claire Marx (Open letter on GMC website ‘A message from Dame Clare Marx – Stepping down as Chair of the GMC - Published 21 July 2021)

(Dame Claire Marx died from pancreatic cancer in November 2022)

Chapter 1 - Introduction

Pancreatic cancer is the tenth most common cancer in the UK with approximately 10,500 people diagnosed each year. However, it is the 5th highest cause of cancer mortality in the UK (Cancer Research UK, 2024a). Survival rates are low, approximately 1 in 4 (27.7%) people diagnosed with pancreatic cancer in England survive their disease for one year or more, and less than 1 in 10 (8.3%) survive their disease for five years or more (NHS Digital, 2024a). These rates have been disappointingly static over time, in contrast to the great improvements in survival seen in other cancers (Hand and Conlon, 2019).

Most people with pancreatic cancer are diagnosed when their cancer is at an advanced stage (NHS Digital, 2024a), and potentially curative surgery is not an option. While some people may receive tumour targeted treatment i.e. chemotherapy, to slow the progression of their disease, supportive care is provided as a means of keeping people as well as possible for as long as possible. Ensuring supportive care is delivered as optimally as possible is therefore of prime importance for most people affected by pancreatic cancer – both patients and their family carers (FCs).

1.1 Background to pancreatic cancer

The pancreas and its role in the body

The pancreas is a leaf-shaped gland which sits in the upper area of the abdomen behind the stomach and which is surrounded by a complex arrangement of organs, intestines, ducts, and blood vessels. It is approximately 15-20cm long and has four sections – the head, neck, body, and tail. The duodenum, the first part of the small bowel surrounds the head of the pancreas from where a small opening allows digestive enzymes produced in the pancreas to enter the gut. Two bile ducts that come out of the liver join together and meet the pancreatic duct at this same opening. The pancreas produces the hormones insulin and glucagon which help regulate blood sugar levels in the body. It is therefore an important organ, vital for digestive and other normal bodily functions (Cancer Research UK, 2024b).

The incidence of pancreatic cancer and risk factors

The incidence of pancreatic cancer is slightly higher in males at 52% of all cases. Age is a significant risk factor - almost half (47%) of pancreatic cancer cases are people aged 75 and over, while the incidence is highest among the 85-89 year old age group. Deprivation is also a risk factor (Cancer Research UK, 2024c).

It is estimated that 31% of pancreatic cancer cases are preventable (based on UK cases in 2015) with cigarette smoking and a high body mass index demonstrated to increase the risk of developing the disease (Cancer Research UK, 2024d). Evidence suggests that the risk of pancreatic cancer is 34% higher in people with type 1 diabetes compared with people without (Sona et al, 2018). A family history of the disease has also been associated with increased risk - approximately 5–10% of pancreatic cancer patients report a family history of pancreatic cancer (Jacobs et al. 2010). Genetic testing and surveillance programmes are increasingly available for those considered high risk individuals (Klatte et al, 2022).

Pancreatic cancer can affect any part of the gland but cancer of the head of the pancreas is most common, and symptoms tend to appear earlier than cancer of the body or tail of the pancreas. Most pancreatic cancers (80%) are the exocrine type which means that they start in cells that produce pancreatic digestive juices. Tumours that start in the endocrine pancreas, where insulin and other hormones are made and released directly into the bloodstream, are less common - these tumours are called pancreatic neuroendocrine tumours (PNETS) or islet cell tumours (Cancer Research UK, 2024e). The focus of this thesis is on people who have exocrine tumours, as PNETS are quite different to exocrine tumours in terms of treatment and survival rates (Brooks et al, 2018).

Diagnosis of pancreatic cancer

Early diagnosis is critical to improve survival outcomes for people with pancreatic cancer, yet currently, the majority of people present at a late stage (NHS Digital, 2024a), where the cancer has advanced significantly, and this reduces the options for treatment. Approximately 15% of people could potentially have surgery at diagnosis but only approximately 8% actually do (NICE, 2018). The difference between the two figures represents those patients who may become too frail or even die before surgery can take place, and those patients whose disease is subsequently found to be further advanced than initially anticipated meaning that surgery is no longer possible.

Common initial symptoms of the disease such as back pain, fatigue, weight loss or nausea can be vague, the severity can be untroubling initially, and the symptoms can be intermittent, indicating to people that there is nothing seriously wrong with them (Evans et al, 2014). Some patients with pancreatic cancer will present with jaundice, due to the location of the tumour, though this usually occurs at a later stage of the disease progression. Jaundice develops when the bile duct becomes blocked by the tumour and the yellow pigment (bilirubin) that is normally excreted naturally builds up in the body (Cancer Research UK, 2024f).

Given the incidence rate, many GPs will only see on average a case of pancreatic cancer every few years (Evans et al, 2014) and it is common for people to attend three or more GP appointments before a referral is made to secondary care for further investigation (Lyratzopoulos et al. 2012). Data suggests that just over a quarter of patients (27%) are diagnosed through a GP referral to a specialist (16%) or a cancer two week wait route (11%), while 50% of people with pancreatic cancer are reported to be diagnosed following an emergency presentation at an A&E department (Elliss-Brookes et al., 2012).

At present, there is no specific diagnostic test for pancreatic cancer and there are currently no reliable biomarkers, though progress is being made (O'Neill and Stoita,2021). The world's first breath test for pancreatic cancer, which could vastly improve the rates of early detection, is under development. The test is designed to be used by GPs to quickly identify patients with vague symptoms who may have pancreatic cancer (PCUK, 2023a).

The diagnostic process within secondary care routinely involves a CT scan. When this identifies an abnormality i.e. a 'mass' or suspected tumour, a tissue biopsy, where a sample of cells is taken from the suspected tumour, is performed to confirm a diagnosis of cancer. It is therefore usual for people to be given an initial suspected diagnosis of pancreatic cancer and then undergo further tests to confirm the diagnosis and to determine the extent of their disease and thus whether it is likely to be operable or not.

A system known as ‘staging’ using a series of letters (Tumour, Node, Metastasis - TNM), and numbers, classifies the grade of a cancer i.e., its size and location. It is this classification which will determine what treatment options are available to patients and ultimately what their prognosis is likely to be. The tumour element refers to the size of the tumour. The node element refers to whether the cancer has spread to the body’s lymph nodes and if so, to what extent. Cancer that develops in lymph nodes that are further away from the initial site of the tumour is called secondary cancer or metastatic cancer represented by the letter M.

Once the diagnosis has been confirmed and the tumour has been ‘staged,’ a specialist doctor will usually provide the patient with their prognosis i.e. the likely course of their disease. For people with inoperable pancreatic cancer, this is an estimate of how long they might be expected to live with their incurable cancer, and this prognosis may vary depending on whether they have chemotherapy. Table 1 below shows the staging system for pancreatic cancer tumours.

Table 1: Staging system for pancreatic cancer tumours

Classification	Equivalent TMN classification	Size	Location
1A	T1, N0, M0	Less than 2cm	Completely inside the pancreas
1B	T2, N0, M0	Between 2 and 4 cm	Completely inside the pancreas
2A	T3, N0, M0	Larger than 4cm	Completely inside the pancreas
2B	T1, 2 or 3, N1, M0.	Any size	Cancer has spread to no more than 3 nearby lymph nodes
3	T1, 2 or 3, N2, M0.	Any size	Cancer has spread to 4 or more nearby lymph nodes
3	T4, Any N, M0	Any size	Cancer has started to grow outside the pancreas into the major blood vessels nearby i.e., localised spread. It may or may not have spread into the lymph nodes.
4	Any T, Any N, M1	Any size	Cancer has spread to other areas of the body, such as the liver or lungs.

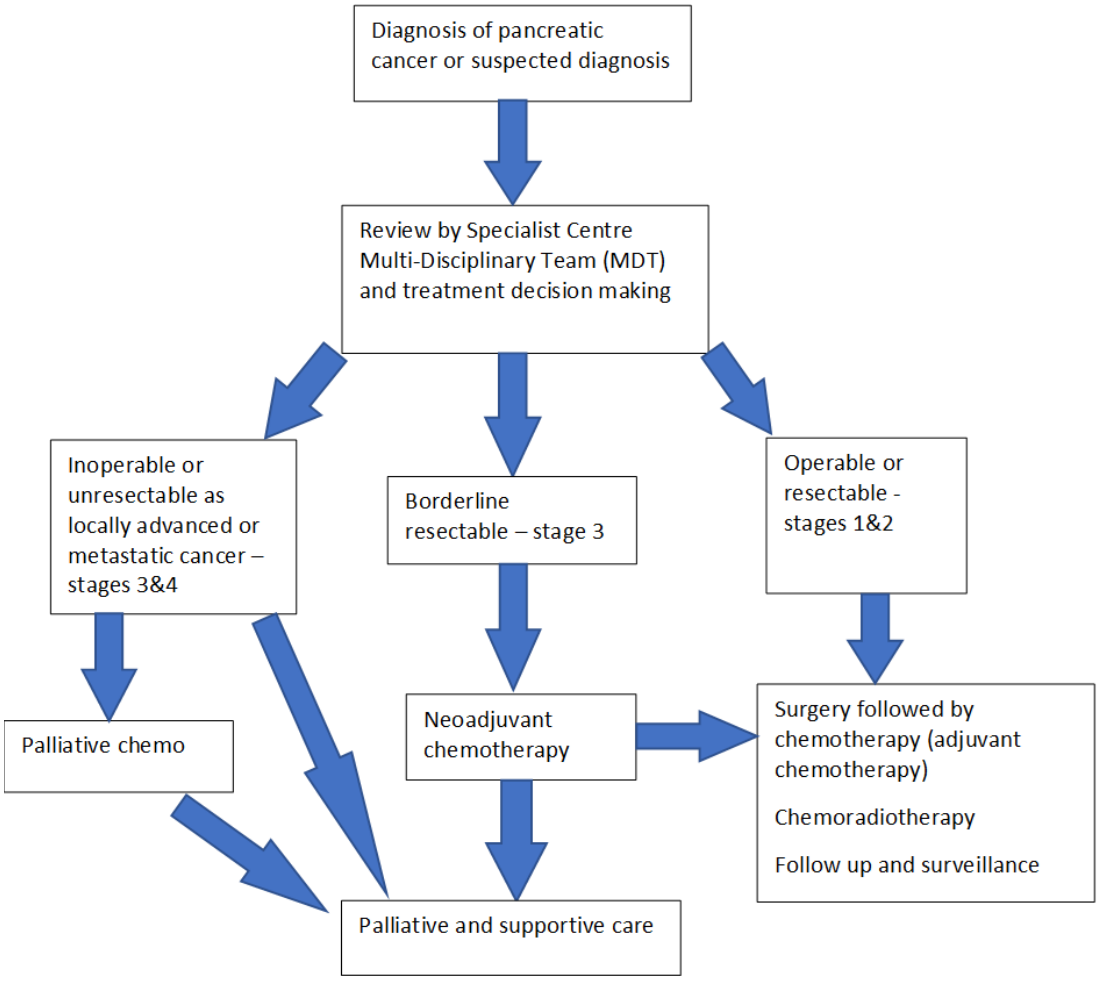
(Source: https://www.cancerresearchuk.org/about-cancer/pancreatic-cancer/stages-types-grades)

Treatment options and care pathways

Treatment for pancreatic cancer may include surgery, chemotherapy, radiotherapy, and/or supportive care (see Figure 1. below for an illustration of patient pathways). Surgery is the only curative treatment for pancreatic cancer but is usually only possible when patients are diagnosed with localised cancer i.e. where their cancer has not spread to other parts of the body. Clinical guidelines (NICE, 2018) recommend that systemic combination chemotherapy is offered to people with locally advanced pancreatic cancer who are well enough to tolerate it.

Some patients may be classed as ‘borderline’ resectable – this means that the tumour affects the surrounding blood vessels – a more complex and riskier surgical proposition. The care pathway for this cohort of patients will be less certain. In some instances, 'borderline' resectable patients may be offered chemotherapy to reduce the size or bulk of the tumour in order to improve the prospects of surgery taking place (Kaufmann et al. 2019).

Figure 1. An illustration of patient pathways



It is estimated that seven out of ten people with pancreatic cancer in the UK, receive no active treatment, including chemotherapy (PCUK, 2023b). Low rates of treatment are not simply a UK issue but have also been reported in Australia, the Netherlands and Canada (Pilgrim et al, 2023, Mavros et al., 2019, and Zijlstra et al., 2018 respectively).

If the cancer has spread to other parts of their body, then the patient is likely to be referred for 'supportive care' or 'palliative care' to manage symptoms and maintain optimal quality of life for as long as possible. Supportive care is defined by NICE as that which 'is given alongside disease modifying and life-prolonging therapies,' while 'palliative care is primarily conservative and aimed at giving comfort and maintaining quality of life in the last months of life' (NICE, 2019, p6). There has been some blurring of the distinction between palliative and supportive care services over time, but it is generally agreed that palliative care is part of supportive care (Benson et al, 2023).

Common symptoms of advanced pancreatic cancer

The physical symptoms self-reported by people with advanced pancreatic cancer are pain, fatigue and lack of energy, loss of appetite, dry mouth, taste change, digestive issues such as nausea, vomiting, altered bowel habits, indigestion, and flatulence, shortness of breath (e.g. dyspnoea), and poor sleep (Tang et al., 2018). Patients with advanced pancreatic cancer are likely to experience more symptoms and have a higher intensity of symptoms than those with early stage disease, with more than 25% of patients reporting moderate to severe intensity of symptoms (Tang et al., 2018).

Pancreatic cancer directly affects the way in which people can absorb nutrition from their food, as well as causing obstructions within the digestive tract. Pancreatic enzyme insufficiency (PEI) is highly prevalent in people diagnosed with pancreatic cancer with those with advanced disease showing an increased prevalence ($>$ 80% of resected patients versus 95% of patients with advanced disease) (McCallum et al, 2016). Poor management of PEI creates a vicious downward spiral, and cachexia anorexia syndrome (muscle wasting and progressive weight loss) is a common symptom of the disease (Roberts et al, 2019). This will affect the individual patient's functional performance status[1] and they may end up being considered too frail to withstand the effects of any treatment.

Abdominal pain is the third most common symptom of pancreatic cancer after weight loss (92%) and jaundice (82%) with 72% of patients experiencing pain (Koulouris et al., 2017). Patient reports of pain change across the cancer trajectory, with only 30-40% reporting pain at diagnosis but 80% of patients reporting pain as the cancer progresses, with 44% of those patients describing their pain as severe (Koulouris et al., 2017). There are two basic mechanisms for pain in pancreatic cancer patients – pancreatic duct obstruction and pancreatic neuropathy. Pain can also affect performance status and may limit opportunities for treatment. Pain relief is usually managed with conventional drug therapy, with half of patients affected by pain requiring strong opioid analgesics, such as morphine. When

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[1] The World Health Organisation performance status classification categorises patients from 0 (able to carry out all normal activity without restriction) to 4 (completely disabled).

conventional drug therapy is not sufficient to manage a patient’s pain, endoscopic ultrasound-guided celiac plexus neurolysis (EUS-CPN) - an invasive procedure - may be undertaken (Koulouris et al., 2017).

It is estimated that at the time of diagnosis for any cancer, approximately half of all patients will experience levels of anxiety and depression that affect their quality of life, and approximately a quarter of people diagnosed with cancer will continue to be affected in this way over the first six months following diagnosis. In the year following diagnosis, around one in ten cancer patients will experience symptoms severe enough to warrant intervention by specialist psychological/psychiatric services, while a further 15% will require some form of personalised psychological support, (NICE, 2004). Psychological distress is not uncommon among people with pancreatic cancer – 37% prevalence, while people with pancreatic cancer and lung cancer report the highest mean depression and anxiety scores among those with the more common types of cancer (Zabora, et al.,2001).

1.2 Defining supportive care

The definition of supportive care used within this thesis is taken from the Multinational Association of Supportive Care in Cancer (MASCC) 2015 http://www.mascc.org/ as follows: *‘Supportive care in cancer is the prevention and management of the adverse effects of cancer and its treatment. This includes management of physical and psychological symptoms and side effects across the continuum of the cancer experience from diagnosis, through anticancer treatment, to post-treatment care.’*

The thesis also draws on the Supportive Care Framework for Cancer Care (Fitch, 1994). Supportive care was defined by Fitch as, '…the provision of the necessary services for those living with or affected by cancer to meet their physical, emotional, social, psychological, informational, spiritual and practical needs during the diagnostic, treatment, and follow-up phases, encompassing issues of survivorship, palliative care and bereavement,' (Fitch, 1994).

Fitch's Framework conceptualizes what type of support cancer patients might need and subsequently how to plan for the delivery of such services. The Framework's categories of need are set out in Table 2 below, together with Fitch's definitions of the categories and examples of what needs would be most relevant for people with inoperable pancreatic cancer.

Table 2. Definition of need categories and examples of needs most relevant for people with inoperable pancreatic cancer

Definition of need categories	**Examples of supportive care needs, most relevant for inoperable pancreatic cancer**
Physical - *'Needs for physical comfort and freedom from pain, optimum nutrition, ability to carry out one's usual day-to-day functions'*	Pain, fatigue, nausea, vomiting, changes in bowel habits, loss of appetite, difficulties with diet/fluid intake, weight loss, cachexia
Informational - *'Needs for information to reduce confusion, anxiety and fear; to inform the person's or family's decision-making; and to assist in skill acquisition'*	Cancer treatment options and side effects, procedures, and test results, managing symptoms and side effects, care processes, help with decision-making, communication with caregivers, navigating the care system
Emotional - *'Needs for a sense of comfort, belonging, understanding and reassurance in times of stress and upset'*	Fear, distress, anxiety, depression, anger, guilt, grief, abandonment, hopelessness, powerlessness, self-blame, shame, isolation

Definition of need categories	Examples of supportive care needs, most relevant for inoperable pancreatic cancer
Psychological - *'Needs related to the ability to cope with the illness experience and its consequences, including the need for optimal personal control and the need to experience positive self-esteem'*	Changes in lifestyle, loss, loss of personal control, major depression, anxiety disorders
Social - *'Needs related to family relationships, community acceptance and involvement in relationships'*	Changes in roles, difficulty in dealing with responses of family members/children, social relationships, interpersonal communication, telling other people
Spiritual - *'Needs related to the meaning and purpose in life and to practice religious beliefs'*	Search for meaning, existential despair, examine personal values/priorities, spiritual crisis/resolution, feelings of hopelessness
Practical - *'Needs for direct assistance in order to accomplish a task or activity and thereby reduce the demands on the person'*	Daily home help, shopping, transportation, childcare, travel to and from appointments, assistance in activities of daily living, provision of family relief, stressors involving family, children, parents, financial issues, legal issues, employment issues, food preparation

Source: Adapted from the Supportive Care Framework (Fitch, 2008)

A 'significant need' is defined within the thesis as 'a need that is deemed to be important or very important' by the patient or carer. A 'significant unmet need' is one that is 'perceived as not satisfied' by the patient or carer (Soothill et al., 2001).

1.3 The role of family carers

There are variations in the terms used to describe people who provide informal support to others with cancer. In policy and clinical guidance, adult carers are determined as people over the age of 18, who provide unpaid care to anyone over the age of 16 with health or social care needs (NICE, 2020). The American Cancer Society defines a caregiver as a 'family-like' individual, nominated by the patient, who is the one individual providing consistent help to the patient (Romito et al, 2013). It is this definition, which is applied in this thesis, as all caregivers were relatives of the patient. However, in this thesis, the term family carer (FC) is used rather than the term caregiver, to refer to the study participants fulfilling this role.

The role of an FC is varied and depends on the patient's type of cancer and stage of disease, with exact tasks changing over time, either as the patient's disease is successfully treated, or as the disease progresses. Tasks may be practical in nature, like assisting the person with cancer with the activities of daily living such as washing or dressing, or emotional, such as providing reassurance and comfort to the patient. The FC may accompany the patient to appointments and consultations as a companion and for moral support and may be involved in the organisation of appointments and treatment, liaising with healthcare professionals (HCPs) and agencies. Undertaking these tasks, or fulfilling this role, can lead to FCs experiencing their own needs for support and assistance (Romito et al, 2013).

Care-giving often adversely affects quality of life (QoL), and psychological distress is commonly experienced by the families and carers of people with cancer, both because of the emotional impact, and because of the stressors of undertaking the caring role (Bauer, et al, 2018). Anxiety, sleeplessness, and fatigue are common problems experienced by FCs (Romito et al, 2013).

High levels of unmet need among FCs have been associated with the information provision domain and in relation to the delivery of information by HCPs, with reports of a lack of compassion and empathy in consultations (McCarthy, 2011).

1.4 The pancreatic cancer workforce

A number of specialist HCPs are likely to be involved in the care of someone with inoperable pancreatic cancer. Within the hospital sector, these would usually include gastroenterologists, oncologists, cancer nurse specialists (CNSs), dieticians, pharmacists, palliative care doctors and nurses and psychologists. Palliative care specialist HCPs may also be involved in providing care within the community, alongside non-specialist HCPs such as district nurses and GPs.

In England, there are 23 specialist hepatopancreatic biliary (HPB) centres to which all patients are usually referred for expert review by a Multi-Disciplinary Team (MDT), and where those people with operable pancreatic cancer receive their surgery. These centres also provide all care for those patients for whom a specialist centre happens to be their local hospital, whether operable, or not. Otherwise, patients who are inoperable would receive their care at their local District General Hospital (DGH). The nursing team within specialist HPB centres, would comprise of specialist HPB CNSs, while in DGHs, CNSs may support patients with any Upper Gastrointestinal (Upper GI) cancer, not just HPB cancers. Occasionally the CNS team may cover all GI cancers. It is also more likely that the workforce within a specialist centre includes specialist HPB dieticians, whereas in DGHs, a dietician may care for people with a range of cancers, or gastrointestinal issues, and not just HPB cancers.

The CNS is pivotal in the care of people with cancer (National Cancer Action Team, 2010). They provide physical and emotional support and provide advice and information to patients on a range of issues, including practical as well as physical issues. A CNS will coordinate services on behalf of the patient, liaising with other

HCPs involved in the individual's care. Access to a CNS does vary however geographically and by cancer site (Macmillan Cancer Support, 2015a).

1.5 Study rationale

Since the publication of Fitch's Framework (1994), many reviews and studies have considered the supportive care needs and unmet needs of cancer patients and their families and informal carers, with a small number considering the needs and unmet needs of people with pancreatic cancer and their FCs (Watson et al., 2019, Scott and Jewel, 2018, Beesley et al., 2016a). These studies have concluded that there are significant unmet needs among this population. In Beesley et al.'s Australian study, 96% of the respondents reported having some supportive care needs, with more than half reporting moderate-to-high unmet physical (54%) or psychological (52%) needs. A UK survey (Watson et al., 2019) found almost half of respondents (49%) reported one or more moderate to high unmet needs within the month prior to them completing the survey, with psychological support and physical support reported as the biggest gaps in care. The UK survey also highlighted that experiences were poorer, and unmet supportive care needs greater, in patients with unresectable disease.

Evidence also suggests that despite the existence of several relevant clinical guidelines (See Chapter 2), not all patients with pancreatic cancer are receiving optimal care when it comes to the management of their symptoms. For example, NICE guidance (2018) recommends that all pancreatic cancer patients are prescribed Pancreatic Enzyme Replacement Therapy (PERT), but a national prospective study demonstrated significant variation in prescription rates between patients with potentially operable disease (74.4%) and those with inoperable disease (45.3%) (Lemanska et al, 2023).

Given the poor prognosis and the inevitable distress caused by a diagnosis of pancreatic cancer, enhancing QoL for people, through equitable, consistent supportive care, is of prime importance. *Improving Supportive and Palliative Care for Adults with Cancer – The Manual* (NICE, 2004) recommends that future research should focus on determining effective solutions for addressing patients' needs, rather than re-assessing them; suggesting that while there is a large body of evidence on need, there is precious little on effective solutions. The guidance goes on to suggest that future research should focus on determining which interventions are most effective (for different patient groups at different stages of disease), alongside longitudinal studies of patient and carer experiences and expectations, in order to describe changes in perspectives over time as the person's illness evolves.

1.6 Research aim, objectives, and research questions

The overall aim of the OPTIMISTIC study is to establish how care and support provided to patients who receive a diagnosis of inoperable pancreatic cancer, and their family carers (FCs), can be optimised. The objectives of the study are as follows:

- To explore the supportive care needs of people recently diagnosed with inoperable pancreatic cancer, and how these change over time,
- To explore the supportive care needs of FCs of patients recently diagnosed with inoperable pancreatic cancer, and how these change over time,

- To explore the extent to which patients and their FCs feel their needs are being met,
- To explore the experience of HCPs who routinely provide care and support to people with inoperable pancreatic cancer to identify the challenges to providing optimal care and support,
- To highlight gaps or areas for improvement in the provision of care or services to address the supportive care needs of patients and their FCs,
- To disseminate findings and recommendations widely within the pancreatic cancer community.

To address the overall research question, 'How can care and support for people with inoperable pancreatic cancer, and their families and carers, be optimised?,' the following sub questions will be considered:

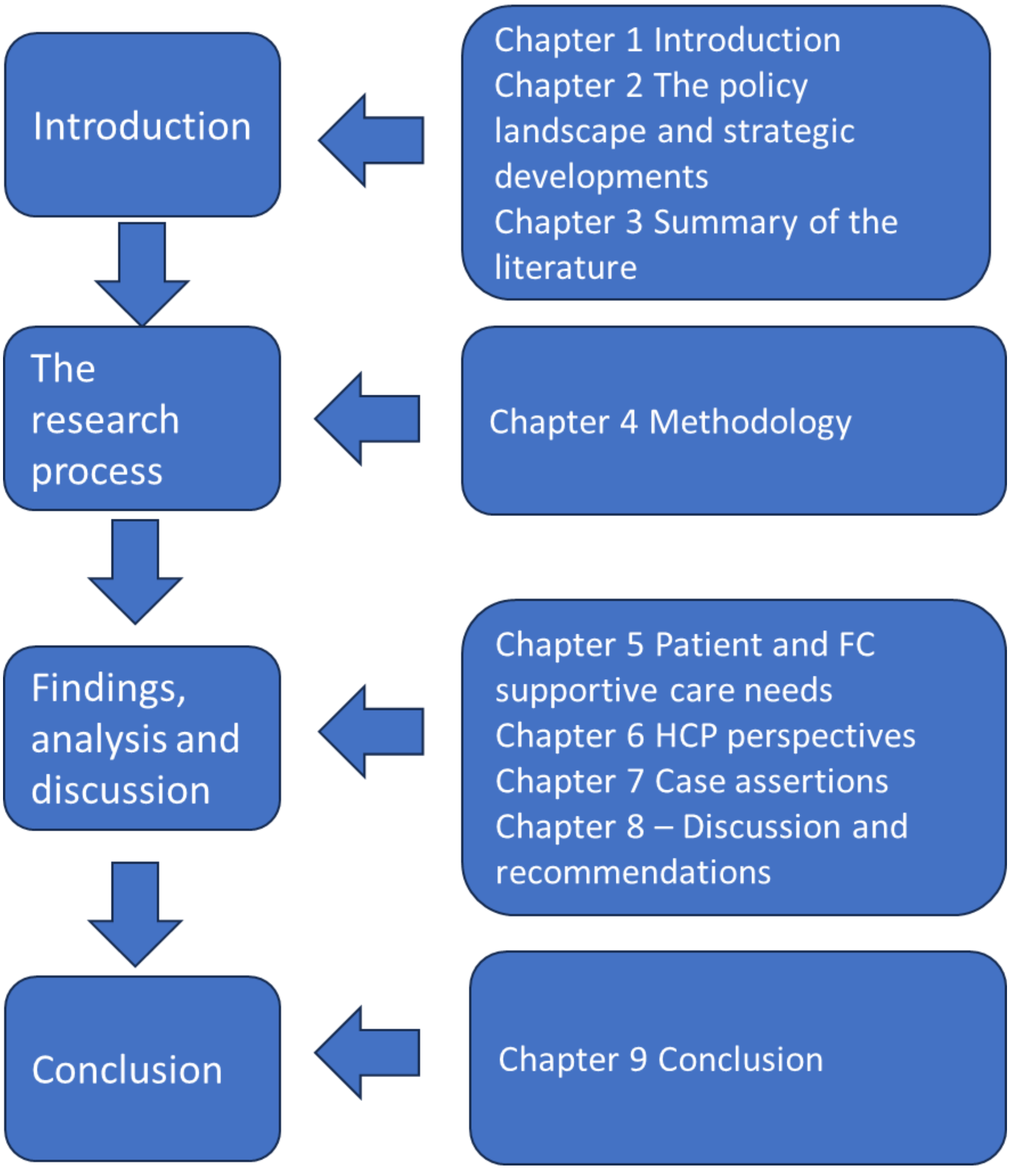
- What gaps in supportive care exist, when do they occur, for whom and in what circumstances?
- What are the challenges in providing optimal supportive care to this cohort of patients and their FCs?
- How can these challenges be addressed to help reduce these gaps?

(For clarity, this thesis is not intended to focus on the efficacy or effectiveness of specific clinical or medical interventions which might be undertaken within the context of providing relief from the symptoms of pancreatic cancer, or the side effects of systemic treatment.)

1.7 Thesis structure and overview

The thesis has nine chapters, as illustrated below.

Figure 2. Diagrammatic representation of thesis structure



Chapter 2 summarises the policies, clinical guidelines, and recent strategic developments relevant to the care of people affected by inoperable pancreatic cancer while Chapter 3 presents a summary of the literature on supportive care.

Chapter 4 describes the research process, summarising the approach and methodology used for the study – an intrinsic case study. This chapter also outlines the underpinning theoretical paradigm which guided the research – the theory of pragmatism. The chapter also describes the preparatory work undertaken to involve patients and their FCs in various aspects of the design and conduct of the study and sets out the ethical challenges encountered during the study.

Chapters 5 and 6 present the empirical findings, offering insights from semi-structured interviews into the experiences of people diagnosed with inoperable pancreatic cancer and their FCs and the experiences of HCPs delivering care and support to this cohort of people. Chapter 7 provides a series of case assertions, or lessons learnt about the provision of supportive care for people affected by inoperable pancreatic cancer, drawn from the findings and supported by the academic literature presented in Chapter 3. Chapter 8 discusses the implications of these case assertions and considers the intersection between optimal supportive cancer care and patient experience before setting out recommendations for practice, education, and research. The chapter also acknowledges the challenges inherent in making changes to practice. Chapter 9 provides a conclusion to the thesis.

1.8 Summary of chapter

Inoperable pancreatic cancer is a complex disease, with a heavy symptom burden and limited treatment options. The provision of high quality supportive care can help to alleviate that symptom burden and improve the overall care experience for patients and their FCs, potentially contributing to an improved QoL for whatever time people have. However, existing evidence suggests that high quality supportive care is not always provided, and people have needs that are not being met. The purpose of this case study therefore is to identify inoperable patients' and FCs' supportive care needs, using Fitch's seven domains of needs (1994), to identify the gaps in provision, and to explore the challenges that exist in meeting these needs appropriately.

The next chapter provides a summary of the main policies, clinical guidelines and strategic developments affecting the delivery of care for people with pancreatic cancer and their FCs.

Chapter 2 - The policy landscape and strategic context

2.1 Introduction

This chapter starts with a summary of the most recent policies, guidelines, and strategic developments relevant to pancreatic cancer, presented in reverse chronological order of the date of publication, or launch, with the most recent first. The chapter then summarises recent policies and guidelines relevant to all people with cancer, and their FCs.

The last two years have seen some significant developments in policy announcements and strategic developments in the UK for the treatment and care of people affected by pancreatic cancer, including the establishment of a national clinical audit on pancreatic cancer, and the launch of an NHS improvement programme called Getting it Right First Time (GIRFT). The specialist charity Pancreatic Cancer UK (PCUK) has also been instrumental in campaigning for improvements in diagnosis, treatment, and care during this period, culminating in the launch of its ‘Optimal Care Pathway’ – ‘Faster, Fairer, Funded’ in October 2023 (PCUK, 2023b). The charity also launched its ‘Demand Survival Now’ campaign in March 2024. These initiatives are the most significant developments since the publication of the NICE guidelines for the treatment of pancreatic cancer (2018).

2.2 National Pancreatic Cancer Clinical Audit (NPaCA)

The Royal College of Surgeons of England, commissioned by the Healthcare Quality Improvement programme, commenced work on the first national clinical audit on pancreatic cancer, in October 2022. The audit uses existing mandated data provided by hospitals to the National Disease Registration Service (NDRS) in NHS England (NHSE) in England, and the Wales Cancer Network in Public Health Wales, in Wales. The NPaCA team held its first Clinical Reference Group in July 2023 to discuss the clinical scope and design of the audit, publishing its data items for collection in December 2023. Data items include the source of a patient's referral, the date the patient was first seen, their imaging procedure date, MDT discussion date, treatment start date, and whether the patient has had access to a CNS. The first quarterly report from the audit published in April 2024 provides an overview of the quality of key data items captured in the standard dataset for people diagnosed in NHS trusts with pancreatic cancer in England between 1st October 2022 and 30th September 2023. The NPaCA published a 'State of the Nation' report in October 2024. The audit team will also support provider units by facilitating the deployment of quality improvement tools.

The audit is a significant development for the pancreatic cancer community, with its potential to drive quality improvement initiatives, as has been the case with other national audits. For example, the most recent report from the lung cancer audit (RCP, 2021) demonstrates areas where significant improvements have been made in people's care and treatment, such as increased number of patients having surgery or systemic treatment.

2.3 Getting it Right First Time Programme (GIRFT) for pancreatic cancer

This NHS England Cancer Programme initiative is reviewing pancreatic cancer services in England as part of an ongoing programme of quality improvement GIRFT projects of different clinical specialities. The review involves visits to all of England’s specialist centres and their referral hospitals to assess progress against the delivery of the Optimal Care Pathway, a PCUK-led initiative, which has developed standards for the time taken from presentation to diagnosis and treatment of people with pancreatic cancer (see below). The data collected will form the basis for a series of reports from each specialist site, with an overarching national report incorporating examples of good practice and recommendations of areas for improvement in service delivery. The national report was due in the autumn of 2024 but has not yet been published.

The Programme is also exploring how the workload of CNSs working with this cohort of patients can be assessed, in order to derive a guide for minimum CNS staffing requirements.

2.4 Pancreatic Cancer UK Optimal Care Pathway

In 2022, PCUK launched a consultation on the development of a UK-wide Optimal Care Pathway (OCP). The pathway was developed by a committee of clinical experts and people with lived experience of pancreatic cancer from across the UK. The OCP, which was launched in October 2023, sets out recommendations to achieve faster diagnoses and faster treatment for patients. The OCP calls for people to have a confirmed diagnosis within 21 days of being sent for tests, and to start treatment within 21 days of receiving a diagnosis – this compares to existing targets of 28 days for diagnosis and 62 days for treatment to commence (NHS, 2019). In their booklet to accompany the launch of the pathway, *‘Faster, Fairer, Funded’* (PCUK, 2023b), the charity calls for everyone to have ‘the best support and care from expert professionals, regardless of where they live, or their chance of survival,’ (p13) and for all UK Governments to ‘provide the sustained funding to make these changes possible,’ (p13). PCUK suggests that if the OCP was implemented, treatment rates could double from 30% to 60% by 2028 (p8).

The detail of the campaign includes calls for investment in the diagnostic and cancer treatment workforce including additional specialist pancreatic cancer roles in every Cancer Alliance and Network across the UK, improved data collection on patients’ experiences, faster roll out of diagnostic routes such as the Suspected Cancer (SCAN) pathway for vague and non-specific symptoms, and a commitment to using a standardised radiology reporting template called PACT UK, to speed up decision-making. The campaign also calls for centralised, digital patient record management to speed up decision-making.

NHS Guidance on implementing a timed HPB cancer diagnostic pathway was published on its website on 25th March 2024 - [NHS England » Implementing a timed HPB cancer diagnostic pathway](). PCUK has developed a strategy to ensure the OCP is implemented by 2028. This includes work at a national level to gain commitment for the long-term funding from government to implement and sustain the pathway.

2.5 Digestive Cancers Europe (DiCE) – call to action (2022)

Digestive Cancers Europe is an umbrella organisation of national members representing patients with digestive cancers, including pancreatic cancer. The organisation, which includes the UK charity, Pancreatic Cancer Action, published a Call to Action paper setting out a 10-point plan which members and representatives believe is necessary to improve overall survival and quality of life (Vitaloni et al, 2022). The 10 points cover the following areas: Diagnosis and raising awareness of red flag symptoms; screening of high-risk populations and reducing referral times; provision of clear, timely information; ensure patients are only treated in high volume Centres of Excellence; ensure continuity of care by HCPs; ensure patients have access to psychological, nutritional and pain relief services, as required; facilitate the development of national patient organisations; increase levels of research funding; and ensure the collection and sharing of high quality data. DiCE is calling for governments and policymakers to act swiftly across all 10 key areas to improve outcomes for people with pancreatic cancer and other digestive cancers.

2.6 Pancreatic Cancer UK five-year strategy (2023-2028)

Before the launch of its OCP, PCUK set out a range of additional actions it would take to drive earlier and faster diagnosis and accelerate treatment breakthroughs (PCUK, 2023c). The document highlights the charity's funding of research which has recently produced a set of potential biomarkers for the disease; a blood test which initial trial results suggest is accurate in more than 95% of cases; and research which is developing a breath test for early diagnosis (PCUK, 2023c). In terms of treatment breakthroughs, the document highlights other work that has already developed the first in-human trials of cancer destroying viruses and early-stage experiments that demonstrate the feasibility of using CART cell therapy[2] to target and destroy pancreatic cancer cells.

The strategy document sets out the charity's commitment to do more to raise public awareness of the symptoms of pancreatic cancer and to work with others to develop screening programmes for high-risk groups, such as those with a family history of pancreatic cancer or early onset diabetes.

2.7 Pancreatic Cancer UK – Patient's Charter

A Patient Charter, produced by PCUK (2021) addresses six key areas of treatment or care, with a standard of treatment people should expect to receive as follows:

1. Review by a specialist MDT at a specialist centre and access to a named cancer nurse specialist, or keyworker.
2. A clear explanation of the individual's diagnosis and treatment options, with information provided in a way that meets the individual's needs.
3. Timely and individualised treatment to include: Involvement in decision-making; fit with NICE guidelines; a second opinion if desired; the offer of a Holistic Needs Assessment (HNA); advice and support regarding diet and nutrition; effective pain management; information on suitable clinical trials; and liaison with the patient's family doctor or GP.

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[2] CAR-T – chimeric antigen receptor T-cell – therapy is specifically developed for each individual patient and involves reprogramming the patient's own immune system cells which are then used to target their cancer – NHS England [NHS England » CAR-T Therapy]

4. To be treated with compassion, dignity and respect which includes HCPs asking about and offering people emotional support, and providing information about what practical support is available for people to access.
5. Information and support for family members and carers, including access to emotional and practical support for family members and the provision of support and symptom management at end of life (EoL); and
6. Access to well-co-ordinated palliative care and advice, if needed – to be provided by specialist professionals.

The Charter, available as a booklet on the charity's website, has no official status as treatment or care guidelines. Official clinical guidelines are produced by NICE - the National Institute for Health and Care Excellence, as below.

2.8 NICE Guideline for diagnosis and management of pancreatic cancer (NG85)

A Guideline for the diagnosis and management of pancreatic cancer in adults was published in 2018 (NICE, 2018). The Guideline, covering all patients with pancreatic cancer, includes diagnostic tests patients should expect to undergo, interventions to manage pain and nutrition, such as the prescription of PERT and recommendations for the ongoing assessment of psychological needs and the provision of information and support to address these needs. NICE is currently seeking the views of the pancreatic cancer clinical community as to whether the existing Guideline requires updating.

A supplementary guideline (NICE, 2021) states that people over 40 and presenting with new jaundice should be referred on a 2 week wait pancreatic cancer pathway, while direct access to CT should be considered for people aged 60 and over with weight loss and any of the following other symptoms; Diarrhoea, back pain, abdominal pain, nausea, vomiting, constipation or new-onset diabetes.

2.9 Quality of Life indicators for pancreatic cancer patients

The results of a qualitative study, undertaken as a precursor to the development of a specific Quality of Life (QoL) questionnaire for patients with pancreatic cancer generated a range of additional issues to the items captured by an existing generic QoL questionnaire for all cancer patients – QLQ-C30 (Fitzsimmons et al., 1999). Symptoms and side effects identified by patients included pain in the abdomen, back, and bony pain, changes in appetite, including the amount and type of food that people could tolerate, indigestion, a swollen abdomen, excessive wind, changes in bowel habit, jaundice, itching and other changes to the condition of the skin, a sore or dry mouth, tingling and/or numbness on hands and feet, feeling drowsy during the day and weight loss and loss of physical strength. Additional QoL issues identified by the patients involved in the study were concerns about the future, and loneliness. Being able to talk to others about their illness, having family support and receiving information about their illness and treatment and maintaining some sense of control of their illness as well as planning future events, were all items that could contribute to a better QoL, as reported by patients (Fitzsimmons et al., 1999).

A project is currently underway by the European Organisation for Research and Treatment of Cancer (EORTC) - the organisation which coordinates and conducts international translational and clinical research to improve cancer treatment for patients, to review the questionnaire to assess whether it still covers the most important QoL issues for people with pancreatic cancer or whether it needs updating. This involves interviews with people diagnosed with pancreatic cancer and HCPs. This phase of the study was due for completion in July 2024 with a report due in October 2024. An updated version of the questionnaire will then be piloted in a future study.

The following sections now summarise the clinical guidelines and policy developments relevant for all cancer patients, and EoL clinical guidelines and policy developments for all conditions. This section also presents the relevant literature in reverse chronological order of publication, or launch, with the most recent first. The section concludes with a summary of the most recent guidance for informal caregivers.

2.10 The NHS Long Term Plan

The NHS Long Term Plan (2019) includes a chapter dedicated to cancer services in general. This document set out the 28 day diagnostic target referred to in Section 2.4 and includes commitments to improve services for some specific cancers, though these do not include pancreatic cancer. Other generic requirements include access to personalised care, including a needs assessment, a care plan and health and wellbeing information and support for every person diagnosed with cancer, and access for every patient to a CNS, or other support worker, for the right expertise and support.

2.11 NICE Guideline for end of life care for adults (NG142)

The Guideline, published in 2019, covers the organisation and delivery of EoL care services for adults with any condition, and includes advice on services for FCs. The Guideline covers the need for HCPs to introduce systems to identify people approaching EoL, in order to start discussions about advance care planning (ACP), and systems to identify the person’s informal carer(s). The Guideline defines ACP as a voluntary process enabling individuals to discuss their future care with their care providers and for care providers to solicit the individual’s understanding about their illness and prognosis. It might include the individual's concerns and wishes, their priorities and values i.e. QoL over length of life and their preferences for certain types of care, treatment, or interventions in the future e.g. resuscitation.

The Guideline also recommends that a Holistic Needs Assessment (HNA) is carried out to ensure the right support is provided to that individual, and notes that FCs should also be offered a carer’s needs assessment, in accordance with the Care Act 2014, and thought given to what practical and emotional support they may require.

The Guideline goes on to recommend that people should be given the information they need to make decisions about their care and are offered the opportunity to take part in discussions about existing treatment plans alongside their FCs, where their involvement has been agreed.

The Guideline also emphasises the importance of communication and information sharing between organisations involved in a person’s care to provide effective care co-ordination and recommends electronic information-sharing systems that are accessible between different services and organisations. Finally, the Guideline states that people should have access to an HCP 24/7, who is able to access the person's health records and make appropriate decisions about their care.

2.12 Enhanced supportive care model for inoperable cancer

The NHS in England launched an enhanced supportive care (ESC) model in 2015 for all patients with a diagnosis of inoperable cancer (NHS England, 2015). This was developed by The Christie Hospital and became the subject of a Commissioning for Quality and Innovation CQUIN[3] for 2016-2019 (NHS England, 2015).

The model was based on evidence that good supportive care provided early to patients with advanced cancer, could improve QoL, potentially increase survival and reduce the need for aggressive treatment near EoL.

In the first phase of the ESC CQUIN, referrals to supportive care were encouraged for patients who had received a diagnosis of inoperable cancer within the preceding six weeks. Though it was initially anticipated that 23 Cancer Centres would sign up to the CQUIN, only 14 centres took part over the three-year period (2016-2019). An interim evaluation of the scheme took place in October 2018 (Berman et al, 2020) which reported that the Programme was associated with a number of positive outcomes, including: timelier referral of patients with supportive care needs, improved symptom control, improved quality of life, reduced 30-day mortality from chemotherapy, improved overall survival and reduced healthcare costs.

The interim evaluation acknowledged that a limitation of the initiative was the extent of variation in service delivery models across the centres involved, such as

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[3] This is an NHS quality improvement initiative providing financial incentives to care providers, when specific target indicators are achieved.

the range of cancer types that organisations could choose to focus on. Hepatobiliary cancers were included within the range of cancers covered by the CQUIN in some organisations, but not enough data was gathered over a long enough time period for meaningful disaggregation for pancreatic cancer patients to understand the impact of the ESC model on their experience and outcomes.

In addition, the CQUIN was only ever intended to be applied to Cancer Centre settings, and while many pancreatic cancer patients are seen within these centres, many will also be seen only in DGHs. The interim evaluation in fact acknowledged that further research was needed to determine ‘the ‘optimal’ approach for delivery of supportive care services within cancer centres, and in other settings.’

2.13 Improving supportive and palliative care for adults with cancer - the Manual

NICE produced a manual for improving supportive and palliative care for adults with cancer in 2004. This manual defined service models to ensure that patients with cancer, and their FCs, would receive the right support and care to help them cope with cancer and its treatment at all stages. One of the key developments set out in the manual was a model of psychological and supportive care for people with cancer. This model outlines various levels of support which may be required by people diagnosed with cancer and it specifies which health and social care professionals should have the competencies to provide support at each level.

The service model set out in the manual involved Cancer Networks as the vehicle for delivery of the NHS Cancer Plan (NHS, 2000) – the most recent policy document at the time. Cancer Networks have since been superseded by Cancer Alliances and the Cancer Plan was updated with the NHS Long Term Plan in 2019 (NHS, 2019).

Readers of the manual are therefore advised to refer to NICE Guidance published in 2019, which relates to end of life care for all adults, regardless of condition (NICE, 2019) – see above.

Though it is now 20 years since its publication, the introduction to the manual makes a number of statements about people's expectations for supportive and palliative care which are likely to still be relevant. These are, firstly that, 'Most patients want detailed information about their condition, possible treatments and services.'(p3); secondly that '…they [patients] expect to be offered optimal symptom control and psychological, social and spiritual support….' and thirdly 'They [patients] want to be assured that their families and carers will receive support during their illness and, if they die, following bereavement,' (p3).

The manual also recognises that patients' needs may not be met for several reasons, including the lack of availability of potentially beneficial services and non-referral to services, either as a result of the patient's own reluctance or as a result of their needs going unrecognised by HCPs. A key recommendation of the guidance is that a HNA should be undertaken at key points within the patient pathway. These observations are still entirely relevant today.

2.14 Cancer care reviews

Cancer care reviews (CCR) were introduced in the UK in 2003. A CCR takes place within primary care and may be conducted by a GP or Practice Nurse. The review is intended to allow patients to talk about their experience of cancer and their concerns, alongside the provision of information on self-management and the support available within their community. An initial CCR is expected to take place within three months of the patient receiving a diagnosis, and a second is expected to take place within 12 months of receiving active treatment. Practices are financially incentivised to undertake CCRs under an incentive scheme known as the Quality and Outcomes Framework (QOF).

2.15 Gold Standards Framework (GSF)

The GSF has been in existence for over 25 years – it was introduced as a training and accreditation standard to facilitate frontline generalist HCPs to provide a ‘gold standard’ of care for people at EoL. The Framework - a series of principles for how people should be cared for and treated - can be applied to any setting where people may be receiving care, including acute settings, care homes and prisons.

The GSF in primary care was incorporated into the QOF in 2004, meaning that GP practices were financially incentivised to provide enhanced care and support for people considered to be in their last year of life. In the most recent QOF Guidance for 2024/25, indicator PC001 – requires practices to maintain a register of people in need of palliative care or support, in order for the practice to earn the points available against this indicator (NHS England, 2024). The 2024/25 guidance notes that while the creation of a register in itself will not improve care, the systematic identification of people approaching the end of life, could allow practices to focus attention on this cohort of patients and their FCs.

In addition to the GSF, The Royal College of GPs, in conjunction with the charity Marie Curie, developed a free, evidence-based framework called The Daffodil

Standards (rcgp.org.uk) to help practices self-assess their current practice with regards to offering the best end-of-life care for patients and bereavement care for FCs. The framework encourages practices to review practice processes, such as coding and data management and to review individual patient cases, to extract learnings. An evaluation is currently underway and early results suggest that while primary care practitioners are motivated to undertake EoL activities, there are challenges relating to a lack of resources and capacity within primary care to do so effectively (Sivell et al., 2024).

2.16 NICE Guideline for carers (NG150)

A NICE Guideline was produced for adult carers in 2020 (NICE, 2020). The Guideline covers support for adults (aged 18 and over) who provide unpaid care for anyone aged 16 or over with any kind of health or social care need. The Guideline is intended to support health and social care practitioners identify people who are caring for someone, in order to provide them with the right kind of information and support, when needed. The Guideline cover carers' assessments, practical, emotional, and social support and training, and support for carers providing EoL care.

2.17 Summary of chapter

The NPaCA and the GIRFT Programme both have the potential to drive quality improvements in care over time. The specialist charity, PCUK, has also made a significant contribution to driving quality improvement through its Patient Charter and Optimal Care Pathway, and continues to be active in this space, working with the clinical community and patient and FC representatives, to encourage the uptake of its best practice recommendations.

As is apparent, there are already clinical guidelines for the management of pancreatic cancer and for the management of people with a terminal disease more generally, and while it is not mandatory to apply NICE recommendations, HCPs are expected to take the guidelines into account, while also considering a patient's individual needs, preferences and values. It is not the purpose of this case study to review or challenge these guidelines in terms of the clinical efficacy of the procedures and interventions recommended but it is appropriate that the study highlights where practices recommended in the guidelines are not always being followed, as noted for example, in Chapter 1 and the highly variable prescription of PERT (Lemanska et al, 2023), and to consider why these recommended practices are not being implemented.

Having considered the relevant policy literature here, the next chapter considers the academic literature relating to the supportive care needs of people with inoperable pancreatic cancer and their FCs.

Chapter 3 Supportive care needs and the provision of supportive care - literature summary

3.1 Introduction

This chapter starts by setting out the choice of approach for the study - a narrative review of the literature, and provides a full account of how this approach evolved from what had originally been intended – a scoping review, during the study.

It describes the process undertaken to retrieve the literature for the narrative review before presenting an overview of the papers included in terms of research approach, methods, sample sizes, and geographical spread and foci of research. The literature is presented using Fitch's Framework as an organising framework, where relevant. The chapter discusses the limitations of a narrative literature review before concluding with an assessment of the gaps or deficits in the literature presented, providing a clear rationale for this study to be undertaken.

3.2 Choice of approach

To contribute to an overall understanding of the topic and to inform the empirical research, it was necessary to interrogate the literature to determine what was known about the supportive care needs of people with inoperable pancreatic cancer and their FCs and the provision of care to address those needs.

It was initially intended that a scoping review entitled 'Best practice in the provision of supportive care for patients with inoperable or advanced pancreatic cancer and their FCs.' would be conducted and a protocol was developed on this basis

(Appendix 1). A scoping review is by its nature exploratory, but systematic (Peters et al, 2020). It maps the available literature on a topic, identifies key concepts and theories, identifies sources of evidence and highlights gaps in the existing research. This was considered the most appropriate type of review to undertake as scoping reviews are broader in interest than a systematic review. A scoping review would therefore normally use the PPC framework (Population, Concept, Context) to determine the aim of the review, rather than the standard PICOT (Population, Intervention, Comparison, Outcome, Time) or similar, used for systematic reviews. Guidance also encourages the inclusion of grey literature in scoping reviews (Peters et al, 2020). A meta-analysis or synthesis of outcomes is not attempted in a scoping review, as the aim is not to come up with an answer or to test a hypothesis but to see what evidence exists (Peters et al, 2020).

Given the broad definition of supportive care adopted in this study (see Chapter 1), the range of domains the term covers (Fitch, 1994), and the extent of potential symptoms and side effects, there were inherent challenges in producing a clearly defined research question and a focused search strategy, employing workable search terms and appropriate inclusion and exclusion criteria. Despite this, a research question was developed and search terms identified. The search strategy was designed to screen out literature relating to the efficacy or effectiveness of specific clinical or medical interventions, which were not relevant to the objectives of the search, while retaining literature relating to the management of supportive care services in a broad sense i.e. how services were organised, delivered, and accessed by patients and their FCs.

Searches were undertaken in January 2022 using four databases – CINAHL, MEDLINE, PsychInfo and Academic Search Complete. The searches returned 4,504 hits and these were uploaded into Rayyan - a reference management system. After removing duplicates and screening titles and abstracts, 4,387 were excluded. (This screening process involved two members of the supervisory team providing a check for consistency of a selection of hits that were excluded). A further 51 articles were excluded after accessing their full texts and scanning for relevance.

This left 66 potential articles to include once their full texts had been reviewed for relevance. Further searches conducted in February 2022 for additional articles through a number of relevant journals, and for grey literature through a number of appropriate organisations (see Appendix 1) yielded a further six articles to consider.

The full texts of the 72 remaining articles were reviewed and further articles were excluded that reported only on the clinical effectiveness of certain treatments or interventions such as those which related to the efficacy of using plastic or metal stents in procedures and those related to Chinese Traditional Medicine (CTM). The remaining articles included a number relating to the provision of palliative care for people with advanced pancreatic cancer, such as a comparison between systematic versus on demand palliative care (Maltoni et al., 2016) and a pilot study of early speciality palliative care for patients with advanced pancreatic cancer (Schenker et al., 2018); articles reporting on guidelines or standards for the overall clinical management of pancreatic cancer patients but which included additional data or discussion points that were relevant to the aims of this study such as Burmeister et al.’s Delphi study (2016) to determine optimal care for patients with pancreatic cancer; an article exploring the symptom experience of people with advanced pancreatic cancer (Tang et al., 2017), and an article exploring patients' preferences for information and decision-making (Ziebland et al., 2015). However, ultimately, no coherence was evident from the studies regarding conceptualisation of supportive care needs.

Given these challenges, and in discussion with the supervisory team, a narrative review of the available literature was determined as the most appropriate means to explore the landscape of supportive care for people affected by inoperable pancreatic cancer within the literature.

Method for retrieving relevant literature

To produce the summary, several sources of literature were considered. Firstly, articles were reviewed that were already known because of the researcher's previous work in the area (e.g. Watson et al., 2019, Scott and Jewel, 2018, NICE, 2018, and Hagenson et al., 2016). Secondly, several relevant articles were identified from the attempt at conducting a scoping review as noted above including those from relevant journals (e.g. Psychoncology) and the websites of relevant organisations (e.g. The Pancreatic Society of Great Britain and Ireland). Finally, more recent articles were either recommended to the author by professional contacts (e.g. Chong et al., 2023) or were retrieved as the result of EBSCO host alert notifications, set up when original attempts were made at searching relevant databases (e.g. Benson et al., 2023 and Chawla et al.,2023). A snowballing technique, also known as citation mining or pearl growing (Cooper et al., 2018), was subsequently employed, using the primary manuscripts or literature identified by the steps described above, to identify additional relevant literature.

The summary uses Fitch's Framework (1994) as the organising basis for the first sections, where the literature considers individual domains of need.

3.3 Overview of the literature

The research summarised in this chapter includes systematic literature reviews (e.g. Chong et al., 2023), quantitative studies (e.g. Pihlak et al., 2023) and qualitative research (e.g. Chapple et al., 2012). The quantitative research includes the administration of QoL type questionnaires to patients and/or their FCs with samples drawn from single sites or a limited geographical area (e.g. Beesley et al., 2016b), or audits of patient records, either from single sites (e.g. Gonzalez et al., 2023) or population-based studies (e.g. Lemanska et al, 2023). The qualitative research, usually employing semi-structured interviews with patients and FCs, is based on small samples, often drawn from a single site (e.g. Dengsø et al., 2024). Studies reported by the literature represent a wide geographical base, including the US (e.g. Engebretson et al., 2015), Canada (e.g. Papadakos et al., 2015), Australia (e.g. Gibson et al., 2016), New Zealand (Landers et al., 2023), the UK (e.g. McCallum et al., 2016), Finland (Miinalainen et al., 2022), the Netherlands (Pijnappel et al., 2022), Germany (e.g. Schildmann et al., 2013) and Italy (Maltoni et al., 2016).
A number of studies include participants with a range of cancers including pancreatic cancer (e.g. Khan et al, 2022). In some instances, the studies distinguish between participants with different cancers in the reporting of results (e.g. Dose et al., 2017), while in others, the findings are generic across the cancer groups (e.g.

Papadakos et al., 2015). Other studies that focus on pancreatic cancer patients only, include all pancreatic cancer patients, not just inoperable patients (or those with advanced disease) (e.g. Johnson et al., 2023). In these studies, distinctions are not always made in the resulting data between participants who are operable or inoperable (e.g. Ristau et al, 2023a), though the numbers in each category are usually provided. There are however a few studies which do focus on people with inoperable or advanced pancreatic cancer only (Landers et al., 2023, Clelland et al., 2023, Pihlak et al., 2023, Benson et al., 2023, Brugel et al., 2023, Jang et al., 2015, Maltoni et al., 2016, and Gonzalez et al., 2023).

The studies reported in the literature include those which consider the general supportive care needs of people with pancreatic cancer (e.g. Beesley et al., 2016a), and those which consider specific domains of need such as psychological needs (e.g. Ristau et al., 2024), information or communication needs (e.g. Ziebland et al., 2015), or physical needs such as nutritional support (e.g. McCallum et al., 2016). There are also studies relating to the needs and experiences of FCs of people with pancreatic cancer (e.g. Petrin et al., 2009).

There has been a significant addition to the corpus of literature since the original summary of the literature was undertaken in early 2022, with several studies published between 2022-2024, including a number relating to aspects of palliative and EoL care alone (Johnson et al., 2023, Clelland et al., 2023, Benson et al., 2023, Brugel et al., 2023, Chawla et al., 2023, Gonzalez et al., 2023 and Miinalainen et al., 2022). These latter studies have been included in the summary below.

3.4 Identifying the unmet supportive care needs of patients

Several studies have considered the totality of supportive care needs of people with pancreatic cancer and have sought to determine which of these needs were not being met (Beesley et al., 2016a and 2016b and Watson et al., 2019). As reported in Chapter 1, studies by Beesley et al. (2016a) and Watson et al. (2019) both report patients having unmet needs, with physical and psychological needs reported as the most prevalent. Both operable and inoperable pancreatic cancer patients were included in the two studies and both studies conclude that unmet supportive care needs are greater among those with inoperable disease.

A second study by Beesley et al. (2016b) indicated that the needs of people with advanced or metastatic disease increase over time, particularly in relation to pain and psychological distress and the authors call for ongoing assessment of needs for this cohort of patients, and timely referral to palliative care.

3.5 Physical needs

(Need for physical comfort, freedom from pain, optimum nutrition, ability to carry out day-to-day functions) – from Fitch, 2008, p9

The literature addressing patients' physical needs is largely focused on managing gastrointestinal function with PERT. As noted in Chapter 1, PEI is prevalent among people with pancreatic cancer and managing this with PERT is an essential element of supportive care.

An Australian qualitative study found that the management of PEI was an area of unmet need that severely impacted on participants' QoL (Gooden and White, 2013). The study also found that this had a knock on effect on increasing the carer burden, with significant levels of distress reported by FCs who experienced feelings of frustration and powerlessness as they struggled to support their family member with their nutrition. The researchers noted that these issues were related to patients and family carers lacking information about the condition and having a poor understanding of dosing guidelines. This, they suggest, was compounded by patients having limited access to specialist HPB dieticians, and patients' perceptions that clinicians were reluctant to prescribe enzyme supplements (Gooden and White, 2013).

A later, single-centre, retrospective analysis of patients diagnosed with pancreatic cancer (both pancreatic ductal adenocarcinoma and neuroendocrine tumours) between Jan 2013 and Jan 2014 found that patients were not routinely screened or assessed for PEI. The researchers suggested that a focus by specialists on anti-tumour therapy i.e. oncologists on chemotherapy and surgeons on surgery, may take attention away from the diagnosis and treatment of PEI. While access to a specialist dietician was likely to be important in addressing this, the study found that this service was not always routinely available to patients (McCallum et al, 2016).

A UK-wide prospective audit of 1350 patients from 59 secondary care units and 25 tertiary care units, reported that just over half the patients included in the audit 736 (54.5%) were prescribed PERT. Factors associated with higher PERT prescribing rates were age – with younger patients more likely to receive PERT, a good performance score, being on a curative pathway, being treated in a tertiary care centre, seeing a CNS and a dietician, and having acid suppression medication co-prescribed (Lemanska et al, 2023).

The impact of having access to a dietician to support patients was explored in a qualitative study of 12 patients with advanced pancreatic cancer, accessing palliative care services in New Zealand (Landers et al., 2023). The study, which involved embedding a dietician in a specialist community palliative care team, explored participants’ engagement with PERT and how the medication was taken and tolerated. The dietician prescribed patients with PERT for malabsorption within 2-3 days of referral from their oncology team and provided them with information about dosing. The dietician reassessed the patients at one and two weeks after medication had commenced.

All participants reported having a good level of understanding of how PERT worked, and were highly engaged with their medication, with high levels of compliance and effective dosing. Participants felt encouraged by an increased sense of control and mastery, and a sense of re-normalisation to eating along with effective symptom control (Landers et al., 2023).

A limited awareness among oncologists of the impact of nutritional status on patients with pancreatic cancer has been suggested as a contributory factor to poor PEI management in some instances. For example, Taieb et al. noted that despite French guidelines recommending regular screening for all patients for malnutrition and personalised dietary consultations, integrating nutritional support into practice in the country remained challenging. Recommendations proposed to address the situation included standardizing nutritional assessments into clinical practice, ensuring MDT meetings incorporated discussions of nutritional assessments and nutritional support, as well as discussions of systemic treatment, and training to improve awareness of the importance of optimal nutrition (Taieb et al., 2023).

As noted in Chapter 1, pain is the third most common symptom for people with pancreatic cancer, after weight loss and jaundice, and should be assessed at diagnosis, and regularly reviewed thereafter for its effective management (Koulouris et al., 2018). A trial comparing the effects of endoscopic ultrasound-guided celiac plexus neurolysis (EUS-CPN) at diagnosis versus conventional drug therapy found that the pain relieving qualities of EUS-CPN were superior to conventional drug therapy (though patients' overall survival and QoL were not significantly different between the two cohorts) (Wyse et al., 2011). NICE guidance however only recommends that EUS-CPN is considered for people with uncontrolled pancreatic pain or who are experiencing severe opioid adverse effects (NICE, 2018).

In addition to medication and EUS-CPN, evidence presented in Koulouris et al.'s literature review shows that pancreatic duct stenting and chemotherapy can also be effective pain relieving interventions (Koulouris et al., 2018). However, as noted in Chapter 1, rates of chemotherapy are consistently low internationally, and particularly so in the UK (PCUK, 2023a).

Apart from nutrition and pain relief, the importance of an adapted physical activity programme, even for those with advanced disease, is also considered to be an important means by which to improve QoL. Physical activity can help address and minimise other physical issues such as cancer-related fatigue, decline in cardiorespiratory fitness, muscle strength reduction, and treatment-related side effects (Taieb et al., 2023 and Védie and Neuzilletet, 2019).

The papers summarised above emphasise the importance of the systematic and ongoing assessment of symptoms, the provision of clear information, and specialist support to address physical needs in order to maintain or improve the patient's QoL. In addition, the literature also makes the case for ensuring that nutritional support is recognised as an equally important element of a patient's care, alongside other treatments, and interventions, and that this requires a greater sensitisation to these needs from HCPs.

3.6 Psychological, emotional, and social needs

(Ability to cope, need for optimal personal control and positive self-esteem; need for comfort, understanding and reassurance; and needs related to relationships) - from Fitch, 2008, p9)

Patients with pancreatic cancer are recognised as a group at high risk of experiencing psychological stress (Mazzella Ebstein et al., 2020). Studies have shown that patients with pancreatic cancer are at an increased risk of depression, anxiety, and suicide (Clark et al., 2010, Turaga et al., 2011 and Geukens and Verheezen, 2017). A population-based study using data of people diagnosed with cancer between January 1, 1995, to December 31, 2015, from the National Cancer Registration and Analysis Service in England, showed that the risk of suicide was highest among patients with mesothelioma, followed by those with pancreatic cancer and that suicide risk was highest in the first six months following cancer diagnosis (Henson et al., 2019).

The traumatic transition at diagnosis from ‘healthy to ill’ was identified in an Australian study of how people with pancreatic cancer negotiate and respond to the identity transitions resulting from their diagnosis (Gibson et al., 2016). People, who have previously been, or considered themselves to have been, fit and healthy before their diagnosis, and who have made ‘good choices’ in their lifestyle may be affronted by their diagnosis, the implication being that illness should happen to others who have not made healthy choices in their lives. Gibson et al.’s study of 19 patients (8 of whom were inoperable), also reported the ‘upending’ for people of previous habits and pleasures, such as the enjoyment of food or physical activity, and the changes to identities previously held i.e. the ‘breadwinner’, the ‘matriarch’. These changes required challenging identity ‘negotiations’ by the patient and those closest to them within very short timescales (Gibson et al., 2016).

The study found that people also tended to talk in binary terms about either ‘being positive’ or ‘being pragmatic’ in response to their diagnosis. The authors suggest that those patients who talked about ‘being positive’ did so to retain a sense of control over their situation by assuming personal responsibility for tackling the disease and not ‘giving up.’ Those who talked about being pragmatic, talked about preferencing QoL and working towards a ‘good death,’ prioritising tasks or activities of personal importance to them.

The authors concluded that people often respond to their diagnosis in terms of the prevailing social discourse, whether that is to feel cheated that they have done everything ‘right’ in their lives and don’t ‘deserve’ cancer, or whether that is to ‘fight’ or ‘battle’ their cancer. They argue that the way in which patients respond, determines how HCPs can respond, so that if a patient’s approach is to ‘be positive,’ this may actually limit opportunities for discussions about disease progression. In this way, conversations about palliative care and activities such as ACP may be compromised (Gibson et al., 2016).

A quantitative study in the US, exploring patients’ and FCs’ perceptions of diagnosis, the psychological impact of the disease, and the importance of support services, reported that people most commonly felt either devastated or heartbroken (31.7%), shocked (29.7%), or scared or anxious (23.7%) following diagnosis. While almost twice as many patients felt scared or anxious compared to FCs (26.6% compared to 12.2% respectively), the ratio was reversed when it came to feelings of sadness or depression (9.8% and 17.4% respectively). And while a fifth of patients (20.1%) reported having a determined or positive outlook following diagnosis, only 5.2% of FCs reported the same. When asked which emotions they were experiencing ‘very often,’ FCs reported experiencing negative feelings, such as worry, sadness, and fear, more often than patients (Engebretson et al., 2015).

A recent study exploring the experience of diagnosis among 20 patients (13 with operable disease and 7 with inoperable disease), found that the nature of the communication of the diagnosis was central to patients’ perception of their situation (Ristau et al., 2024). Two competing responses emerged - non-handling (the inability to process the information) or acceptance of the diagnosis on one side, with the questioning or rejection of the diagnosis on the other. Those patients accepting the diagnosis, or unable cognitively to process it, tended to start their treatment earlier than those rejecting or questioning the diagnosis, where second opinions were sought (Ristau et al., 2024). The study indicates that the psychological and emotional response to the diagnosis can impact the speed at which treatment starts, potentially affecting the patient's prognosis.

A scoping review of the literature on coping among all patients with pancreatic cancer identified the coping tasks which patients face (Ristau et al., 2023a). These included several that were generalisable across other cancer types such as experiencing grief and loss, experiencing pain, adapting to change, and facing fears; as well as tasks that the authors suggested were specific to pancreatic cancer including managing hopelessness and managing digestive issues. The authors noted that though the coping strategies of people with pancreatic cancer may be similar to those of others with serious illnesses, the former face a triad of specific contextual factors i.e. receiving a diagnosis at an advanced stage, short or non-existent periods of disease stability, and a poor prognosis, which increases the need for professional mental health support (Ristau et al., 2023a).

Ristau et al. went on to develop a model of coping, specific to pancreatic cancer patients. The model, developed through a grounded theory study with 26 patients, comprises an acute phase immediately after diagnosis, when the focus is on survival, overcoming short-term effects of the disease, and the search for information; and a later circular phase, when the focus is on 'living on' and adapting to longer-term consequences (Ristau et al., 2023b). In the second, circular phase, there are repeated episodes of anticipatory anxiety at follow-up appointments, caused by a fear that disease progression will be disclosed. The authors suggest the model may allow HCPs to develop a better understanding of the psychological challenges and needs of these patients (Ristau et al., 2023b).

The findings from the studies summarised above underline the importance of providing professional psychological support for both patients and FCs at the point of diagnosis, or soon after. Other studies also make the case for psychological and emotional support to be available to patients and FCs throughout the cancer trajectory. Such support can help people to address ongoing issues such as changes in roles and identity, managing weight loss and gastrointestinal problems, fear of disease progression, and the importance of maintaining a sense of personal worth or meaning in life (Wong et al., 2019 and Pijnappel et al., 2022, Dose et al., 2017).

3.7 Information needs

(Information to reduce confusion, anxiety, and fear; to inform decision-making and to assist in skill acquisition) - from Fitch, 2008, p9

A study of German patients' perceptions and views on information provision and shared decision-making at different stages in the cancer trajectory, found that in the initial stage following diagnosis with pancreatic cancer, participants felt they had no choice but to trust their physician and follow their advice (Schildmann et al., 2013). In time, however, with increased knowledge and understanding of their disease and treatment, participants were found to be more proactive - seeking information, asking questions during their consultations, and taking a greater part in decision-making (Schildmann et al., 2013).

However, participants in the study expressed difficulties about knowing when the right time might be to cease treatment. Participants were split between those who believed only they could weigh up the pros and cons of continuing with treatment and those who believed this responsibility should lie with their doctor (Schildmann et al., 2013).

The provision of clear, honest, unbiased information on a patient’s prognosis and the pros and cons of treatment is critical in the context of decision-making. Indeed, a Canadian survey of the information needs of people with gastrointestinal cancers (n=82), including pancreatic cancer (n=10), reported that the provision of information on the different types of treatment available, along with their advantages and disadvantages, was of most importance to participants (Papadakos et al., 2015).

However, the provision of such information may not always be forthcoming. A UK qualitative study found that the patient participants were sometimes provided with quite vague information about the risks and benefits of treatment, with participants suggesting that HCPs might sometimes downplay the side effects of chemotherapy or present it as ‘the only sensible option’ (Ziebland et al., 2015). The study authors note that shared decision-making in the context of pancreatic cancer is challenging for all parties, as people’s preferences are highly individualised, particularly at EoL. The authors suggest that to assist shared decision-making, HCPs should follow a process of ‘option listing’ for patients rather than make recommendations (Ziebland et al., 2015).

The challenge of shared decision-making was highlighted in a recent study which found that there were notable differences between the views of patients with advanced pancreatic cancer and their clinicians, regarding preferences for systemic treatment and optimism regarding the effectiveness of chemotherapy. Most patients expected their life would be extended by 1–5 or >5 years with chemotherapy, while clinicians expected the extension of life to be less than a year. Such expectations were evident even among those patients who had prognosis discussions documented in their records (Pihlak et al., 2023).

The study raises interesting questions about why patients might hold such unrealistic expectations about the benefits of treatment and to what extent this is related to the effectiveness of the communication between patient and clinician. It is recognised that these discussions are challenging for all parties (Burmeister et al, 2016), in part because clinicians may be hesitant to provide an estimate of likely survival and may be unsure as to whether the patient wants to know this information or not (Johnson et al, 2023).

A recent single site study in a UK tertiary unit reported that a prognosis discussion was recorded in the medical notes for only approximately 60% of new patients with advanced pancreatic cancer, at their first new patient consultation, with patient preference recorded as the most common reason for this discussion not happening (Clelland et al, 2023). However, the study also found that the likelihood of a prognosis discussion occurring was higher when a patient was seen by a nurse clinician (advanced nurse practitioner) at their first consultation, than if they were seen by a consultant or registrar. Patients seen by nurse clinicians were also more likely to be referred to community palliative care services, than those that were not. The authors suggest that the higher instances of prognostic discussions and referral rates to community palliative care services, may be due to nurse clinicians having more time to spend with patients, and/or patients finding it easier to discuss their prognosis with a nurse clinician than a doctor (Clelland et al, 2023).

Communication style is clearly important within these kinds of conversations. Indeed, the first study of its kind to explore the research priorities of both patients and FCs, identified clinician communication as one of the three topics achieving greatest consensus among the 11 participants (Saunders et al., 2009). Though a small sample, all participants talked about their experiences of insensitive conversations with clinicians, either in the provision of a diagnosis, or in discussions of treatment or management options.

The literature summarised above demonstrates the complexity of information provision and decision-making for patients and HCPs. The nature of conversations about prognosis and treatment options for people with inoperable pancreatic cancer are inherently difficult, given the limitations of treatment to extend life. The literature suggests that patients and FCs have an appetite for unbiased, realistic information but require this to be given sensitively and in an environment that is conducive to meaningful discussion.

3.8 Provision of palliative and end of life care

The literature on palliative care and EoL care makes an important contribution to the overall body of literature on the provision of supportive care to patients with inoperable pancreatic cancer and their FCs.

The integration of specialist palliative care into the oncological care of people with any advanced cancer has long been recognised as important in order to improve symptom management, increase QoL (Hearn and Higginson, 1998) and to improve illness understanding and expectations of treatment (Temel et al., 2010). The intervention of palliative care is also a contributing factor to the provision of timely and high quality ACP. ACP is critical to eliciting the patient's goals and wishes, including the views of the patient towards aggressive treatment at the end of life such as cardiopulmonary resuscitation and mechanical ventilation (Agarwal and Epstein, 2017). The absence of aggressive care is considered an EoL quality measure, as aggressive care is linked to poorer QoL for the patient and worse bereavement adjustment for caregivers (Jang et al., 2015).

A number of studies specific to pancreatic cancer have all concluded that a palliative care referral (PCR) makes a positive difference to the patient's QoL, though they are inconclusive about the optimal timing of a PCR and its effect on subsequent healthcare service usage by the patient (Gonzalez et al., 2023, Lees et al., 2019 and Schenker et al., 2018). These studies have been undertaken in a range of international settings including the US, Canada, Australia, Finland, and Italy, suggesting that this effect is not restricted by healthcare system, nor national or cultural norms.

Jang et al.'s Canadian study found a positive association between a patient with advanced pancreatic cancer receiving a palliative care consultation, and a reduction in the patient subsequently receiving aggressive care (determined in their study as chemotherapy within 14 days of death alongside hospital admissions). An increase in the frequency of palliative care interventions further reduced the level of aggressive care received. Patients who received palliative care also had longer survival times than those who did not (Jang et al., 2015).

Other studies have shown higher use of hospice services, improved QoL, and reduced EoL treatment aggressiveness among patients with advanced pancreatic cancer, where a palliative care referral has either been 'systematic' (Maltoni et al., 2016), defined as a planned part of the clinical pathway, rather than at the point a need is identified, or 'early' (Miinalainen et al., 2022) defined as happening a minimum of 30 days before death[4].

An international Delphi study on referral criteria for outpatient palliative care, determined that any patient with an advanced cancer diagnosis and with a median survival of one year or less, should be referred to palliative care services within three months of diagnosis (Hui et al., 2016). However, evidence shows that

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[4] The definition of an 'early' PCR varies between studies of different cancer types, and it is has been variously defined as a referral occurring within 30 days of diagnosis (Bevins et al, 2021) or occurring more than 30 days before death, (Nevadunsky et al., 2014).

palliative care referrals often happen later in the cancer trajectory for patients with inoperable pancreatic cancer, if at all (Brugel et al., 2023, Chawla et al., 2023 and Beesley et al., 2016a).

An audit of 3,138 patient records from 2016-1019 in the state of Victoria, Australia reported that only 52% of all patients were referred to, or received palliative care post diagnosis, representing 73% of metastatic patients and 51% of locally advanced patients. Timely palliative care, defined by the authors as in-patient palliative care at least three months prior to death, occurred for just 11.6% of all patients (Pilgrim et al, 2023).

Barriers to patients accessing palliative care include HCPs' uncertainty over the 'right time' for a referral, often affected by concerns about destroying patient hope; patient perceptions of palliative care – associated with misunderstandings of palliative care being synonymous with EoL care; and logistical difficulties in making referrals because of organizational and resource issues (Pilgrim et al., 2023).

The availability of palliative care specialists is of course a pre-requisite for the provision of an effective service, and the workforce as a limiting factor is noted elsewhere in the literature. In the US, a major shortage of the palliative care workforce has been predicted by 2030 (Kamal et al., 2017).

Shortages in the palliative care workforce may not be the only limiting factor in the provision of high quality palliative care services however, as a recent study in the UK indicates. The UK study, exploring a model of a nurse-led integrated 'Early Supportive Care' service co-located with an HPB oncology clinic (Benson et al., 2023), reported a reduction in the prevalence of certain symptoms and an increase in referrals to other services, such as dietetics and physiotherapy. The authors note that while the service demonstrated patient benefit, there were clear resource implications for the wider clinical team (Benson et al., 2023).

The literature summarised above makes the case for timely PCRs for patients with inoperable pancreatic cancer but notes that this is often not happening. The literature also indicates workforce capacity issues will require attention.

3.9 Experience of supportive care and care co-ordination

Studies have reported inadequate support for symptoms and issues across the cancer journey (Khan et al., 2022), a need for improved care co-ordination, and better support and information for FCs (Khan et al., 2022 and Hagensen et al., 2016), and improved identification and documentation of patient goals and values (Hagensen et al., 2016).

The Australian audit of patient records referred to previously found that only 36% of all patients with pancreatic cancer had received screening for their supportive care needs, against a target of 80% (Pilgrim et al, 2023). The audit informs discussions at a state-wide Pancreas Cancer Summit, to which ‘consumers’ (people affected by pancreatic cancer) contribute. The paper’s authors note that consumers prioritised care co-ordination and supportive care screening as issues of concern at the summit. The same audit also reported that only 73% of patients were presented at MDMs (the Australian equivalent of an MDT meeting), against a target of 80%, with metastatic patients less likely to be discussed in these fora. Pilgrim et al.

suggest this is unsurprising given that MDMs are primarily surgeon-led with minimal attendance of palliative care specialists and other Allied HCPs. They suggest the establishment of metastatic specific MDMs to ensure metastatic patients’ needs are discussed (Pilgrim et al., 2023).

An earlier Australian study exploring perceptions of care co-ordination among patients (Beesley et al., 2018), found that participants were satisfied that they knew who was co-ordinating their assessment and treatments, that HCPs were fully informed about their medical history, and that they weren’t waiting too long for appointments and treatment. However, participants did not feel satisfied that they knew the warning signs and symptoms to look out for, or that they had sufficient support with the emotional impact of their disease, or adequate access to additional services such as counselling and nutritional support. Nor were they satisfied that they were being asked often enough about how well appointments with other HCPs were going, or how well they and their family were coping. The authors suggest that their findings demonstrate the priority that should be accorded to employing care co-ordinators, nurse navigators, or other HCPs who assume the responsibility for care co-ordination (Beesley et al., 2018).

In the NHS, the role of the CNS has long been recognised as a crucial element in the effective co-ordination of care for oncology patients across all cancer types (National Cancer Action Team, 2010; Kerr et al., 2021; and Alessy et al., 2022). However, the only study relating to the role of the CNS in the care of pancreatic cancer patients is Pollard et al.’s audit of the CNS service (2010). The audit found that most patients were positive about the CNS service, finding it useful, particularly for the provision of information and for help in explaining their diagnosis. The audit also found that almost half (46%) of telephone contacts between the CNS and the patient, directly impacted on their clinical care i.e. organising admissions, expediting outpatient clinic appointments, streamlining investigations, and advising on medication (Pollard et al., 2010).

3.10 The needs of informal caregivers (FCs)

It is suggested that though there are likely to be broad similarities between the issues raised by FCs of people with pancreatic cancer with FCs of people with other cancers, direct comparisons are difficult because of the limited evidence base (Brown and Bliss, 2023). It is plausible that a distinctness exists in the FC experience for this cohort, given the rapid speed of transition of an individual's status from their usual role (Chong et al., 2023) along with the attendant shock of the patient's diagnosis (Sherman et al., 2014), the existence of limited viable treatment options for them, and a high mortality rate (Petrin et al., 2009).

The literature suggests the FC burden is dominated by symptom management (Chong et al., 2023 and Gooden and White, 2013) and FCs frequently experience anxiety and depression (Janda et al., 2017; Dengsø et al., 2021; Chong et al., 2023 and Huynh et al., 2023). FCs may also be forced to give up their jobs to care for their family member (Engebretson et al., 2015).

In a recent study of unmet needs among FCs in Australia, almost two-thirds of respondents (63%) reported at least one moderate to high unmet need and there were significant associations between those respondents reporting moderate to high needs and those assessed as having subclinical or clinical anxiety and depression (Huynh et al., 2023). The most prevalent unmet needs included FC's requirement for information on the patient's physical issues, opportunities for FCs to discuss their concerns with the patient's doctor, and information for FCs on the benefits and side effects of treatment (Huynh et al., 2023) – findings in strong accord with a recent literature review which identified FCs' needs for better clinical communication, better support and briefings from HCPs, and help with navigating the healthcare system (Chong et al., 2023).

A second recent literature review aiming to highlight the challenges faced by FCs, suggests that community nurses in the NHS may be well placed to play a key role in supporting them (Brown and Bliss, 2023). The authors suggest that community nurses are well placed to observe carer distress and can make onward referrals for support, or signpost FCs to relevant resources or agencies. It is suggested that the community nursing team can also play a key role in educating carers about what to expect during the cancer trajectory and how to manage symptoms and medication (Brown and Bliss, 2023).

Given the symptom burden for inoperable pancreatic cancer is high, and the speed of disease progression is rapid, symptoms may be managed for short periods only before they worsen again, requiring further and more intense support. The relentless nature of symptom management is likely therefore to be particularly distressing and exhausting for FCs. Indeed Petrin et al. (2009) suggest the need for the development of a specific model of adjustment for the FCs of those with pancreatic cancer, because of these unique factors.

There is a persuasive case for providing tailored support to FCs both as a means of preventing carer burnout and minimising the impact of further health issues among the carer population (Dengsø et al., 2021 and Kim and Baek, 2022).

3.11 Strengths and limitations of a narrative review

A narrative review of the literature is considered by many to be a sub-optimal strategy for a literature review, as unlike a systematic review there is 'no focused research question, no focused search strategy, no clear method of appraisal or synthesis of the literature, and it is not easily repeatable', (Aveyard, 2007, p15). It is suggested that this lack of rigour risks researcher bias in terms of the selection of the material which is included, as there are no explicit inclusion and exclusion criteria (Aveyard, 2007). Narrative reviews may also not be comprehensive in terms of including all the potentially available literature. The researcher may therefore miss important papers which may lead the narrative review to arrive at potentially inaccurate conclusions.

There were strengths however in handling the literature in this way. For example, the citation mining or pearl growing technique (Cooper et al., 2018) continued until no new relevant literature was identified. The methods used for the retrieval of literature therefore allows the researcher a level of confidence that all relevant literature was identified and included within the summary. In addition, the researcher was able to focus on literature which considered aspects of service delivery specifically, an important factor in terms of meeting the objectives of the study overall.

3.12 Summary of chapter

The literature summarised here reports on a range of significant unmet needs for both patients and FCs. These include physical needs, particularly in relation to PEI and associated gastrointestinal issues and weight loss, and psychological and emotional needs. The latter are particularly acute at the point of diagnosis but in evidence throughout the cancer trajectory. Such needs are likely to be distinct from the needs of other cancer patents and FCs given the advanced stage at which the disease is detected, its poor prognosis, people's rapid decline and limited treatment options. Significant unmet needs were also identified in relation to the provision of information to patients and FCs and how this information is communicated. Information on the benefits and risks of treatments is sub-optimal and hampers effective decision-making by patients. Linked to this, information on an individual's prognosis is not always provided and ACP is therefore compromised, leaving some patients and FCs with unrealistic expectations for the future, with the attendant risk of a compromised QoL due to inappropriate aggressive care and treatment at EoL.

The literature also indicates some of the causes of unmet needs. These include limited assessments of supportive care needs and limited screening for symptoms such as PEI and psychological needs. A few papers also report a lack of referrals to specialists such as dieticians, mental health professionals and palliative care specialists, though the reasons for non-referral are not necessarily clear from the literature. Care co-ordination is another factor which is likely to affect whether an individual's supportive care needs are met or not. Several papers comment on the barriers to effective care co-ordination, including the absence of the full range of specialists at MDT meetings, and the inability of organisations to integrate services such as psychology, dietetics and palliative care into routine oncological pathways and settings. Inadequate information provision to patients and FCs, and their subsequent attitudes to, and misconceptions of prognosis and treatment effects, are also likely to be barriers to the provision of optimal supportive care.

While the literature enables the reader to develop a sound understanding of the issues relating to the provision of supportive care to patients and FCs, it is lacking in several respects. Firstly, much of the literature relates to all patients with pancreatic cancer and not just those with inoperable pancreatic cancer. The order of magnitude of need as assessed across the body of literature is therefore likely to be under-reported for people affected by inoperable pancreatic cancer. Secondly, much of the literature comes from non-UK settings and while the supportive care needs of patients and FCs are unlikely to differ significantly between countries, the balance of unmet needs, the causes of these and potential solutions will differ across healthcare systems. Thirdly, the qualitative studies are largely single-site studies, meaning that their transferability may be limited due to specific contextual factors which might affect a single site. Fourthly, there is little literature regarding the provision of supportive care, or indeed any care to patients and FCs, which occurs outside of the acute or hospital setting.

Lastly, some of the literature is over 10 years old and may not be representative of current issues and practices. For example, Pollard et al.’s UK audit (2010) which reinforced the centrality of the CNS role in the organisation and co-ordination of care, is now 14 years old.

This case study therefore addresses a clear gap in the literature by focusing on the experiences of patients with inoperable pancreatic cancer and their FCs in the English NHS, across multiple sites, including both specialist and non-specialist units serving both urban and rural/urban populations. By focusing on the patient and FC perspective, rather than a service perspective, it also considers the totality of supportive care provision across the continuum from primary and community care to hospital-based care (both outpatient and in-patient) and hospice care, where applicable. In addition, the inclusion of the experience of HCPs within the study allows for a comprehensive understanding of the context within which supportive care is delivered.

4 Methodology and methods

4.1 Introduction

The chapter begins by positioning the research study within an ontological and epistemological framework, providing a justification for the chosen philosophical paradigm of pragmatism. The chapter then provides a rationale for employing an intrinsic case study design with data collected from semi-structured interviews. Further details on the research methods and processes are outlined including participant eligibility and recruitment processes, the methods used for data analysis, and the process of mapping and theorising from the data - this section also includes a justification for the theoretical framework chosen for the study.

The patient and public involvement and engagement (PPIE) and clinical engagement activity undertaken during the study are also described along with the ethical and governance issues that arose during the study. The chapter concludes with a discussion on rigour within qualitative studies and how rigour has been demonstrated within this study.

4.2 Philosophical paradigms

Researchers take a particular philosophical position in their research based on their ontological and epistemological beliefs or assumptions about the way the world is (Burrell and Morgan, 2016). Ontology is the branch of philosophy that studies concepts such as existence and reality, while epistemology is the branch of philosophy that studies concepts such as the nature, origin, and scope of knowledge (Oxford English Dictionary). A researcher’s values or axiological assumptions also affect the research endeavour as the researcher will have a ’positionality’ in relation to the context and setting of the research (Creswell and Poth, 2018) i.e. they may feel a strong moral imperative for conducting the research. The choice of philosophical position or paradigm dictates the approach that is used throughout the research endeavour, determining the decisions the researcher takes as regards theory development, methodological choice and strategies, the time horizons used, and the specific techniques and procedures used for data collection and analysis (Saunders, Lewis and Thornhill, 2011).

For example, a researcher who wished to understand people’s social world and to gain insights into the meanings people give to their world might align themselves to the philosophical paradigm of interpretivism - a study of social phenomena in their natural environment (Saunders and Tosey, 2012). This desire to understand people’s social worlds may lead a researcher to undertake an ethnographic study of a particular group of people such as cancer nurses (Farrell et al, 2017), for example, or a phenomenological study examining the lived experience of people with terminal cancer (Kyota and Kanda, 2021).

Alternatively, a researcher concerned with observing and predicting outcomes in order to determine cause and effect might align themselves with the philosophy of positivism – adopting a ‘scientific method’ to propose and test a hypothesis or theory (though they are perhaps less likely to express their positionality than researchers adopting other orientations.) A positivist informed researcher might therefore conduct a clinical trial of neoadjuvant chemotherapy for pancreatic cancer patients to determine the effect of administering chemotherapy on the tumour and the impact this may have on surgical outcomes (Müller et al, 2021).

Given the poor prognosis for people with inoperable pancreatic cancer, biomedical knowledge has its limitations for people whose condition cannot be 'cured.' In positivist informed health research, specific health outcomes or measures such as a reduction in the size of a tumour, or the prevention of cancer recurrence, are the goal, or end point, but for people with inoperable pancreatic cancer, other goals or end points, that require different ways of measuring or examining outcomes, may become more significant, such as a good care experience.

The OPTIMISTIC study did not set out to test a particular hypothesis about the provision of supportive care, which might have led the researcher to adopt a positivist approach. Instead, the aim was to explore patient and FC experiences of supportive care and to explore their preferences for how such care should be delivered, in order to translate these experiences into practical recommendations for improvements to supportive care delivery.

Qualitative methods were therefore determined most appropriate for this study as the fundamental aim of qualitative research is to: 'provide an in-depth understanding of people's experiences, perspectives and histories in the context of their personal circumstances or settings,' (Spencer et al., 2003, p.3). 'Among many distinctive features, it [qualitative research] is characterized by a concern with exploring phenomena from the perspective of those being studied,' (Spencer et al., 2003, p.3), as is the case within this study. Moreover, while qualitative research methods have their roots in social science and humanities, they have been advocated for in health research for over three decades, ‘as a way to investigate peoples' attitudes, beliefs and preferences,’ (Bradbury-Jones et al 2014, p135).

A mono method approach, using qualitative methods only rather than mixed methods (integrating quantitative and qualitative methods and data), was considered most appropriate for the study because of the nature of the subject matter under exploration being not well understood (as demonstrated by the lack of available literature exploring patient and FC experiences), and complex and multi-faceted (an inherent feature of supportive care) (Ritchie et al, 2014).

There are a range of philosophical paradigms that may sit within the interpretative frameworks used in qualitative research. Such paradigms include postpositivism, social constructivism or interpretivism, postmodernism and pragmatism (Creswell and Poth, 2018). This is complex and contested territory however as the relationship between qualitative research and theory is confused by varying definitions among researchers who may use the same words to mean different things (Bradbury-Jones et al, 2014). In spite of these challenges, the suitability of alternative paradigms in relation to the OPTIMISTIC study is considered below and their alignment to the study’s research question appraised.

Postpositivism

Postpositive qualitative researchers take a ‘scientific’ approach to research, which is logical and empirical and cause and effect orientated (Creswell and Poth, 2018). Postpositivist studies may incorporate mixed quantitative and qualitative methods, adhering to a series of steps or stages of enquiry, which are related and may build on each other. Multiple levels of data analysis are incorporated for rigour. It is suggested that the systematic procedures of grounded theory, as described by Strauss and Corbin (1990), illustrate a postpositivist paradigm (Creswell and Poth, 2018) as do researchers who undertake realistic evaluation study designs (Pawson and Tilley, 1997).

A postpositivist approach was discounted for this study for two reasons. Firstly, the aim of the study was not to generate or prove a theory but to explore peoples' experiences of care over time and the challenges of care delivery. Secondly, as noted above, a mono method approach was considered most appropriate for the study, rather than mixed methods.

Social constructivism/interpretivism

The research undertaken by those adopting a social constructivist stance generates meaning from participant accounts of their subjective experiences of the world which they inhabit. The full complexity and range of experiences is sought within such research, rather than a distillation into categories (Creswell and Poth, 2018). The questions asked of participants are broad, general and open-ended, allowing the participant the freedom to articulate the meaning they make of their world on their own terms. Social constructivists subsequently 'interpret' what they have heard to make sense of the meanings people have about their world.

While social constructivism or interpretivism is popular as an approach within healthcare research, it was rejected as being unsuitable for the aim of this study.

Had this study sought to illuminate the lived experience of people diagnosed with inoperable pancreatic cancer as they face the implications of a terminal illness and what this means to them in terms of how they come to terms with their mortality, or how they renegotiate their identity in the final stages of life, then a social constructivist or interpretative methodology, such as a phenomenological study might have been a suitable approach to adopt. A phenomenological approach would have provided a rich and no doubt fascinating account of the lived experience of someone with a terminal illness but it would not have suited the intention of the OPTIMISTIC study – which was to explore the experience of people receiving and delivering supportive care, specifically in order to determine gaps in care, and areas where improvements could be made.

Postmodernism

Postmodernists concern themselves with changing how people think about the world rather than necessarily taking action to change aspects of people's lives. The subjects of interest to postmodernists are the structures of society and issues of hierarchies, power and control (Creswell and Poth, 2018). Postmodernists recognise the unequal nature of society and may research marginalised groups and different discourses – such as Foucault's work on madness and the mental health discourses of the time (*Madness and Civilization: A History of Insanity in the Age of Reason, 1961*), and his alignment with the anti-psychiatry movement (Cornish and Gillespie, 2009).

While there is an argument that postmodernist research into the experiences of people affected by inoperable pancreatic cancer might well have brought to light inequalities in care, and highlighted issues of professional power and marginalisation, the aim of the OPTIMISTIC study was not to change how people think about supportive care for this cohort of people but to arrive at tangible suggestions for change and improvement.

Pragmatism

Pragmatists argue that knowledge is ‘a tool for action’ and should be ‘judged according to its consequences in action.’ The question pragmatists ask about knowledge is ‘does it serve our purposes?’ (Cornish and Gillespie, 2009, p802). Pragmatism therefore gives priority to people’s everyday experience and strives to make a difference to people’s problems in practice (Cornish and Gillespie, 2009).

Pragmatism as a philosophy is considered an American product and proponents of the paradigm include a first wave of academics considered ‘classic pragmatists’ (i.e. Charles Pierce, George Mead and John Dewey) and those considered ‘second wave’ such as Richard Rorty (Baert, 2005). Rorty’s seminal work ‘Philosophy and the Mirror of Nature’ and his later ‘Consequences of Pragmatism’, both published in the early 1980s, develop a line of reasoning that it is pointless to have philosophical arguments about the nature of ‘truth’, and that what really matters is that the pursuit of a ‘truth’ is meaningful if it leads to ‘successful consequences,’ (Baert, 2005); or to put another way - we should treat knowledge as a means of achieving our desires, rather than knowledge for the sake of knowledge.

It is suggested that researchers adopting a pragmatist interpretive framework are concerned with the ‘problem’ being explored, and the outcomes and consequences of the research i.e. solutions to problems (Patton, 1990). It is argued that pragmatism is not fixed on any one philosophical system or notion of reality but that the ‘truth’ is what works at the time (Creswell and Poth, 2018). Researchers adopting a Pragmatist viewpoint determine their methods, techniques and research procedures as they see fit, in order to meet the intended consequences of their research, which they acknowledge exists in a heavily contextualised world (Creswell and Poth, 2018). The pragmatist researcher is therefore likely to use multiple methods of data collection and/or multiple sources of data or knowledge in order to best address the research problem. In this case, although only one method of data collection was used, this was applied to different types of participants (patients, FCs and HCPs).

Critics of pragmatism consider it to be relativistic (nothing can be true or right in all situations), uncritical (Gillespie et al, 2024) and too narrowly focused on utilitarianism rather than the pursuit of a ‘truth’ (Cornish and Gillespie, 2009). It has been criticised as a ‘paradigm of convenience’ which lacks a cohesive set of defining beliefs and which prioritises flexibility and outcomes, and an attitude that suggests the end justifies the means, over established principles of good research. It is criticised as providing a justification to researchers for taking a ‘middle position’ between the ‘purist’ positions of constructivism and post positivism and as an easy answer to the challenge of working with methods derived from different traditions as seen in mixed methods studies (Hampson and McKinley, 2023).

Regardless of these criticisms, or indeed in truth, partly because of them, pragmatism was determined as an appropriate position for this research study. It appears well suited to ‘healthcare’ research, where the subject under study is likely to be heavily contextually dependent. For example, in this study, the subject under study is contextually dependent on temporal aspects of care delivery, given the rapid progression of pancreatic cancer and the setting of care delivery with multiple service providers and multiple transitions between care settings.

The acceptance of plural forms of knowledge, as a basic tenet of pragmatism, is also suited to research in a healthcare arena which has explicitly recognised different forms of knowledge such as that held by service users or patients, or communities of people, for several decades now (Mockford et al, 2012). This recognition of ‘expert experience’ or knowledge is seen particularly with regards to endeavours whereby people are asked about their subjective experiences of care in order to assess what is working well and what is not, so that action can be taken to improve care experiences (Coulter et al., 2014).

Pragmatism has therefore been chosen as a consequence of the priority given ‘to people’s everyday experience (that) should be taken at face value in terms of their relevance and validity as problems requiring solutions,’ (Cornish and Gillespie, 2009), rather than its perceived flexibility and ‘convenience’. It was not an easy option, for as Cornish and Gillespie note, a researcher following a pragmatist philosophy, ‘’…faces the most stringent pragmatist criterion: whether it makes a difference to those problems in practice?’’.

4.3 Choice of approach and methodology

It was originally intended that the study would take the form of a collective case study, whereby one issue or concern is selected (i.e. the provision of supportive care to people affected by inoperable pancreatic cancer) but multiple case studies (i.e. provider sites) are selected to illustrate the issue. The selection of case study sites is important within case study research in order to show different perspectives on the issue while ensuring representative cases (Creswell and Poth, 2018).

Four NHS sites were initially approached as case study sites for recruitment of all three groups of participants. These sites were chosen as they represented both specialist centres (i.e. those providing surgery for patients considered operable as well as providing all-round care for all local patients) and non-specialist provider units (i.e. those that do not provide curative surgery but provide chemotherapy and other supportive care services to local patients). Sites A and B were selected as specialist centres, while sites C and D were selected as non-specialist centres. In selecting the case study sites, consideration was also given to other factors which might contribute to variation i.e. the ethnic diversity of the population served by the sites and the mix of urban and rural areas within the catchment area of the site.

It became apparent however during the study that additional and alternative means of recruiting patient and FC participants would have to be adopted as the rate of patients with inoperable pancreatic cancer presenting at the four selected sites, and who wished to participate in the study, was not adequate to meet the study's recruitment targets. This resulted in the inclusion of a fifth NHS site and the recruitment of participants through PCUK and through social media.

This affected the integrity of a collective case study approach but allowed for the study to evolve as an intrinsic case study, (Creswell and Poth, 2018) where the 'case' being studied was the provision of supportive care to people affected by inoperable pancreatic cancer within the English NHS.

The choice of 'case' was made on the basis that as most people with pancreatic cancer are diagnosed when their cancer is at an advanced stage and curative treatment is not an option (NHS Digital, 2024a), supportive care is the means by which people's symptoms are managed, holistic needs are met and people are kept as comfortable as possible for as long as possible. Optimal supportive care is in effect all that the health service can offer to people affected by inoperable pancreatic cancer.

Yin suggests the possibility of collecting six types of information for case study research: documents, archival records, interviews, direct observations, participant observation, and physical artefacts (Yin, 2009). Two types of information are essentially used in this study, namely documents (policy and strategy documents – see Chapter 2 for the provision of background and contextual data) and interviews. Patients' medical records could have been accessed as a source of information (Yin's archival records) but as the researcher is not a clinician, the interpretation of these records would have been problematic. Observations as a source of information were also discounted as both logistically problematic (given that only scheduled clinical consultations would be feasible to observe) and ethically challenging (given the ‘case’ under study).

4.4 Qualitative methods

In addition to exploring what is known about the provision of supportive care from the literature and what policy and strategies are in place within the NHS to inform the delivery of such care, the study employed semi-structured interviews with three groups of participants - people with newly diagnosed inoperable pancreatic cancer (hereafter referred to as patients for brevity), their nominated FCs[5] and healthcare professionals (HCPs). Participants were recruited from multiple sites representing a range of contexts (see section 4.4 above). The range of participants and the range of sites provided multiple sources of data – a defining feature of a case study (Creswell and Poth, 2018).

While Yin refers specifically to interviews as a source of information for case study research (Yin, 2009), they were considered most appropriate by the researcher to other qualitative methods as the method of data collection for several reasons. For example, focus group interviews are commonly used for data collection but this method was discounted for a number of reasons. Firstly, focus groups or group conversations, are generally considered less helpful for the ‘detailed generation of individual accounts’ and more useful when the group process or interaction

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[5] An FC was defined as the person the patient considered they got the most informal support from. This individual could have been a spouse or partner, an adult child, another family member or relative or a friend.

between participants ‘will illuminate the research issue’, (Ritchie et al, 2014, p56). Focus groups are therefore helpful in research into people’s attitudes but less helpful when exploring complex or sensitive experiences. The researcher therefore felt that focus groups would be too intrusive given the participant cohort and the nature of the subject under discussion. The researcher also felt they would be too inflexible logistically i.e. geographically dispersed participants, and participants who may also be unwell and unable to participate on the day.

Alternatively participant diaries were considered as a means of data collection but again discounted as being too burdensome on patient and FCs time, when their time was already subject to the significant demands of their illness.

Semi-structured interviews were therefore considered the most appropriate means of data collection as they allowed for an in-depth exploration of the topic and while the interviews were based around and guided by a topic guide, they were also ‘conversations with a purpose,’ (Ritchie et al, 2014), allowing the interviewee the opportunity to focus on aspects of most importance or significance to the interviewee.

Longitudinal element

Where possible, more than one interview was undertaken with patients and their nominated FCs, over a six month period. These multiple interviews took place at approximately one month, three months and six months post diagnosis. This longitudinal element was incorporated in order to explore how supportive care needs might change over time with disease progression. Given the nature of the patient cohort and the contingent nature of qualitative longitudinal research on the data subjects' availability over time, the longitudinal aspect is a design element rather than a methodological approach in its own right (Audulv et al. 2022).

In contrast, HCPs were interviewed once only, as the temporal aspect of their experience of providing care was not necessary for this study.

4.5 Clinical engagement and Clinical Advisory Group

Extensive clinical engagement took place with all NHS sites involved in the study. This involved a series of meetings with the relevant clinical leads and other relevant health professionals i.e., oncologists and CNSs, to introduce the study and to discuss specific aspects such as the logistics of recruitment. Clinicians at all sites were fully supportive of the study from the outset and were fully committed to working with the researcher to ensure its success.

A Clinical Advisory Group (CAG) was established at the outset of the study to provide clinical oversight to the study. Members included the Clinical Leads for the HPB service from Sites A and B, and an oncologist and CNS from Sites A and B. Regular meetings were held with the CAG during the study.

Early discussions with members of the CAG led to refinements in the sampling strategy and in the recruitment process of participants. This led to the inclusion of patients who might be considered borderline resectable at diagnosis as they were assessed as being inoperable at this point. The advice of the CAG also meant that the study's lead oncologist at each site could identify suitable patients themselves, without the need for potential patient participants to be identified via the HPB Specialist MDT meetings at Sites A and B. The CAG also provided helpful advice and support throughout the recruitment period and in later stages of the study, it provided a sounding board for the testing out of early findings. The CAG also played a key role in providing comments and feedback on the study's recommendations – see Chapter 8.

4.6 Patient and public involvement and engagement activity

Extensive PPIE activity took place prior to the start of the study in order to ensure that people affected by pancreatic cancer felt the underlying rationale for the study was valid i.e. that the care of this cohort of people was sub-optimal and was amenable to improvement. This involved discussing the rationale for the study with contacts from previous work undertaken. These contacts included both pancreatic patients and FCs, who were asked for their thoughts on the study's aims, its relevance and feasibility. Feedback from these conversations reinforced the relevance of the study and its importance, and confirmed some of the researcher's early thoughts about the nature of supportive care in relation to this cohort of people.

To ensure that the study was completely sensitive to the needs of patient and FC participants, a robust process for Patient and Public Involvement and Engagement (PPIE) was established in conjunction with the specialist charity Pancreatic Cancer UK (PCUK). In the first instance, this involved the facilitation of a discussion group involving members of PCUK's established Research Involvement Network (RIN) and the distribution of a brief survey via the RIN, both of which occurred in April 2021.

PPIE Discussion group

Membership consisted of six participants – two people (both male) whose cancer had been operable, the wife of one of the male participants, a woman whose sister had died from inoperable pancreatic cancer, and the wives of two men who had also died from the disease. A brief presentation was provided on the aims of the study, and an outline of the proposed methods, before the group was asked to consider several questions regarding the relevance of the study, and the optimum means to recruit participants.

The group firstly discussed the gaps or limitations they had experienced in their own care or that of their family members, demonstrating the relevance of the study. These gaps, or limitations in care included poor to non-existent nutritional advice, including a lack of advice on taking PERT; a lack of co-ordination of care with poor and delayed communication; the overwhelming provision of information that was not always perceived as helpful; and a lack of support for carers, whose needs they believed were often overlooked.

When answering questions about the timing of recruitment of participants, the group suggested the sooner the better due to the poor prognosis for most people but noted that this should not happen at the point of diagnosis, as this is when people are experiencing shock and confusion and there is already a flurry of activity and a lot of information to take in.

The group felt that people would be interested in taking part despite their diagnosis, as they were likely to want to help, and could frame their participation as something positive for them to focus on. The group also felt that involvement in the study might have a therapeutic benefit for some participants as they might find it helpful to simply talk to someone about their experience.

The consensus of the group was that the CNS would be best placed to introduce the study and ascertain if patients and FCs would wish to consider taking part. Participants had varying experiences with their oncologist and not all were positive. Participants felt the nurse had the time to listen and explain and was more approachable.

The amount of information given to people at the time of diagnosis was felt by all members of the group to have been overwhelming. It was suggested therefore that the initial research information needed to be succinct - a brief summary introducing the idea of the research was considered preferable with further information available if someone expressed an interest in taking part. Group members also thought it would be helpful to have a photo and a short bio of the researcher within the information pack.

The general view of the group was that having the researcher in the clinic to undertake recruitment would not be helpful, as it would just be ‘another face’ among many, at a time when so much was already going on for them. It was suggested that the researcher’s presence may therefore feel like an intrusion, and speaking to the researcher at that point would be an additional time burden when people might already have spent a long time at the hospital for their clinic appointment. Participants therefore doubted whether patients and their FCs would be very receptive to being recruited into a study in this way.

In order to conduct the interviews, the group felt home visits or telephone or video calls in the participants' home environment would be preferable to interviews undertaken within the hospital environment. The time commitment required for the interviews (60 mins *3 over 6 months) seemed reasonable to group members but the need for flexibility was noted in case participants needed to rearrange interviews at short notice if they weren't feeling up to it at the time.

PPIE Survey responses

Eleven survey responses were received - one from a patient and 10 from FCs. All respondents answered positively regarding the relevance and importance of the study. Ten of the respondents, including the patient, felt people would definitely be inclined to take part in the study, while one FC wasn't sure but hoped that people would.

Most respondents were in favour of potential participants being approached about taking part, at the time of their first post-diagnosis appointment with an HCP. As with discussion group members, most respondents also felt the CNS would be the most appropriate person to introduce the study. Respondents also felt that a brief summary of the project should be provided initially, with a follow up phone call sometime later to assess the patient's interest in taking part. A photo and bio of the researcher were also felt to be useful to include in the information pack.

There were mixed views in relation to the timing of the three interviews, with several respondents noting that interviewing patients over the timescale proposed was probably ambitious, given the potential for rapid disease progression. As regards the ordering of interviews between patient and FC, respondents felt there should be no fixed rule but that this should be based on personal preference.

Finally, people were asked whether including a diary or log sheet in the study information pack, to record appointments and interactions with HCPs, would be useful as a memory aid in interviews. The consensus was that this would be very useful for those that wanted to use it but that it should not be mandatory.

PPIE Feedback on patient and FC facing documentation

Members of PCUK's RIN were subsequently invited to provide comments and feedback on the study documentation in late September 2021. Nine members came forward, all of whom were FCs. The documentation which included participant information sheets, consent forms, topic guides and the diary/log sheet, was sent out by email, with a series of questions to guide the reviewers' comments.

A series of amendments were made to the documentation based on these comments including changes to certain wording and the simplification of wording, the visual presentation of documents; clarifying explanations for certain words or phrases; the inclusion of additional questions in the topic guide; and the inclusion of an additional contact for advice and support.

In summary, 26 people took part in formal PPIE activities. Their comments and feedback were thoughtful and comprehensive. The PPIE activity informed the development of the research protocol and led to a series of changes in study documentation.

PPIE Feedback on findings

As detailed in Chapter 8, a summary of the findings was produced to ‘sense test’ with various stakeholders, including people affected by pancreatic cancer. The summary was published in PCUK’s RIN newsletter in late February 2024 and was also sent separately to a number of FCs, including one who had taken part in the study and three who had not taken part in the study. Feedback on the findings was subsequently received from three FCs. Their comments indicated that the findings resonated well with their experiences and that they felt all the key issues and concerns had been captured well and presented sensitively.

Participant feedback on study summary including recommendations

At the end of the study, when a final summary had been produced, the researcher contacted patient and FC participants (after checking the status of patient participants with their healthcare team first) to enquire whether they wished to receive a copy of the summary. This approach was undertaken in order to avoid upsetting people by sending an unsolicited summary. Of the 13 patients who had taken part in the study, only four had survived to its completion, of which one was in receipt of EoL care. An email was therefore not sent out to this individual to enquire whether they wished to receive a copy of the report but each of the surviving three patients, along with their FC were contacted and all requested a copy of the report. The FCs of those patients who had died since the end of the data gathering period were contacted and the researcher's condolences were offered. Of these individuals, 3 requested a copy of the summary. A further two summaries were sent out to FCs whose family member had died during the course of the study, and whose death was already known to the researcher. Four FCs did not respond to the invitation to receive a summary and no further action was taken.

PPIE throughout the study

Given the disease burden affecting patients with inoperable pancreatic cancer and the caring burden faced by their FCs, a decision was made not to establish a bespoke patient advisory group for the purpose of the study. Instead, the researcher endeavoured to ensure the study remained person-centred and focused on patient experience throughout through regular contact and discussion with the specialist charity PCUK and its RIN members (patients and FCs) as noted above, and through regular contact and discussion with an existing personal contact of the researcher whose husband had previously died from pancreatic cancer.

4.7 Participant eligibility and recruitment process

Patients were considered eligible for inclusion in the study if they were 18 or over (with no upper age limit) with either a new diagnosis of pancreatic cancer or a new diagnosis of metastatic pancreatic cancer, and who were assessed by their clinical care team to be inoperable at the time of diagnosis. Patients who were likely to die within six months, as assessed by their clinical care team were excluded from the study. Patients were also only eligible if the clinical care team judged them to have the capacity to give informed consent.

Patients were provided with the recruitment information pack, including a summary of the study (Appendix 2), by either their oncologist or CNS at their first oncology clinic appointment. Patients were invited to contact the researcher directly if they were interested in taking part, for a further discussion about participation (this process changed slightly during the study to help increase recruitment rates – see section 4.8 below). This involved talking through the participant information sheet (Appendix 3) and consent form (Appendix 4). Consent was also taken verbally and audio recorded at the start of each interview. Participants were reconsented, prior to the interview, when multiple interviews took place.

The patient was also asked who they wished to nominate as their FC for the purpose of participation. The decision to include dyads of patients and FCs was made for two reasons; firstly, because the views of FCs were integral to the study and this was viewed as an appropriate means of recruiting FCs, as the researcher believed that FCs may feel more inclined to participate if their family member was also participating. Secondly, the experience of cancer can be considered a ‘shared experience’ between patient and FC, with the FC ‘embedded’ in the situation (Morris, 2001).

Individuals were considered eligible for inclusion as a FC if they were over 18 years of age (with no upper age limit) and were nominated as an informal carer (person they get most support from) by a patient who had been invited to participate.

When a patient nominated a FC, they were also contacted to go through a participant information sheet (Appendix 5) and consent form (Appendix 6). Consent was also taken verbally and audio recorded at the start of each interview. As with patient interviews, FC participants were reconsented where multiple interviews took place. (When joint interviews took place, both participants gave their consent verbally.)

The log sheet included in the participant pack (Appendix 7) was also drawn to the participant's attention at this point. The diary or log sheet was intended for participants to record appointments and interactions with HCPs if they wished to do so, so it could act as a memory aid in interviews.

A suitable time was arranged to interview both participants, either separately or jointly, depending on preference. Participants were offered the opportunity to participate according to their preference as this was felt to be the most ethically appropriate option as it would address issues of 'intrusion and choice' – the intrusion of the interviewee disrupting the FC's day-to-day life and potential for feelings of exclusion to occur if they were not interviewed jointly, and the opportunity to provide some degree of empowerment to participants by providing some choice within the process (Morris, 2001).

When joint interviews were undertaken, both patient and FC topic guides were open in front of the researcher to ensure that no topics were overlooked. The opening questions were the same on both topic guides and the researcher therefore addressed these questions to both participants. Depending on who answered the question, the researcher would then ask the other participant if they had anything to add. This pattern continued throughout the interview depending on who answered the question, except where questions were relevant for just one of the participants i.e. whether the FC felt their needs were being addressed.

Both joint and separate interviews have advantages and disadvantages. For example, joint interviews with dyads might be considered problematic in case one person dominates the conversation, or friction is created between the dyad, while separate interviews might be logistically difficult to arrange or foster an unwarranted sense of secrecy between dyads (Morris, 2001). In practice, both types of interview revealed benefits - joint interviews proved beneficial in allowing participants to remind each other about certain events or experiences, which might not have been recalled otherwise, while separate interviews yielded a qualitatively different kind of data is some cases – see Chapter 5.

When separate interviews were conducted, their ordering between the patient and FC was based on individual preference.

It was possible for patients to take part without nominating a FC, if that was their preference but it was not possible, initially, for an FC to take part without the patient participating. This limitation was subsequently changed through an ethical amendment – see Section 4.8 below.

HCPs were identified as potential participants by the Lead Clinician at each site and invited to contact the researcher. Eligibility for participation as a HCP required someone to be providing care to patients with pancreatic cancer. This included nurses, oncologists, supportive care specialists, allied health professionals and third sector professionals such as HCPs providing hospice based, or community-based palliative care and those providing specialist support through UK helplines.

When contact was made, the researcher talked through the HCP participant information sheet (Appendix 8) and took consent (Appendix 9). Further HCP interviewees were identified through the snowballing technique - whereby individual participants suggested other colleagues who might make a valuable contribution to the project and passed the researcher their email address.

All participants were provided with an interview topic guide (Appendices 10-16) in advance of the interviews so they could prepare for the interview if they choose to do so. This ensured that participants could cover all the information they wanted to share, without the cognitive demands of having to ‘think in the moment.’ The development of the topic guides for all three groups of participants resulted from the orientation conversations the researcher had with her existing contacts in the pancreatic community before the study started, a reading of the literature identified during the first year of the PhD, some of which is summarised in Chapter 3 and through the PPIE process detailed in section 4.6 above. The researcher made a conscious decision not to use Fitch's Framework and her domains of need as the basis for the topic guides. It was considered unlikely that people would think naturally in these categories of needs and therefore structuring the topic guides in this way may have affected the participants' understanding of the questions and the subsequent flow of conversation.

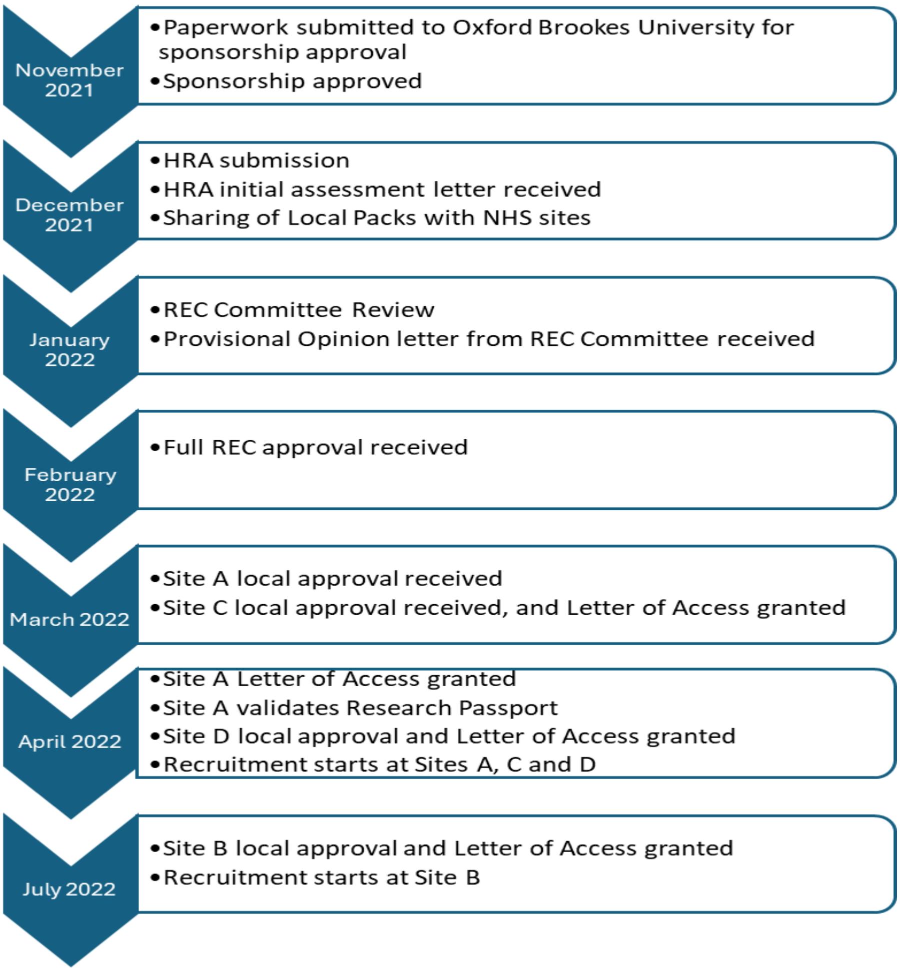
Instead, patient and FC topic guides covered issues such as their experience of diagnosis, the treatment the patient had received, the HCPs they had seen or been referred to, and whether their physical, emotional, and practical needs were being addressed. HCP topic guides covered the individual's experience of the issues and concerns patients and FCs would be likely to have, their ability to respond to patient and FC needs and where they felt there might be gaps in care or areas for improvement.

All interviews took place either by telephone or via Zoom© and were audio recorded if taking place via telephone, and either audio-visually recorded if taking place via Zoom, or audio recorded only, depending on the participants' preference. Audio files were transcribed by the researcher initially. However, the use of a third party transcription service was also used when the volume of interviews increased.

4.8 Ethics and research governance

The process to gain ethical and research governance approval for this study is set out in Figure 3. below. The process commenced in November 2021 and the application was reviewed by the Oxford B Research Ethics Committee (REC) on 11th January 2022. A Provisional Opinion letter was received indicating a number of changes to be made and clarifications sought. Having satisfied the REC that the appropriate changes had been made, full REC and Health Research Authority (HRA) approval were subsequently received on 24th February 2022. Recruitment started at three of the sites in April 2022, and the fourth site in July 2022.

Figure 3. Ethics and governance timeline



Further ethical issues raised by the research

Further ethical issues arising from the research were assessed as managing any potential distress in participants (patients and FCs specifically but all participants to an extent) and taking steps to prevent the potential development of an emotionally dependent attachment between the participants (patients and FCs specifically) and the researcher.

A Distress Protocol (Appendix 17) was therefore produced which set out the steps the researcher would take if the participants became distressed during interviews. A second Distress Protocol (Appendix 18) was produced to cover the researcher and the supervisory team. The protocol ensured that the researcher had access to a member of the supervisory team when undertaking field work, in order to accommodate an immediate debrief after interviews, if required. In addition, informal weekly debriefs were scheduled with a member of the supervisory team during the data collection period. The protocol determined that in the first instance, supervisory team members would provide peer support to each other, while the University's full range of wellbeing services for staff would be available should these be required.

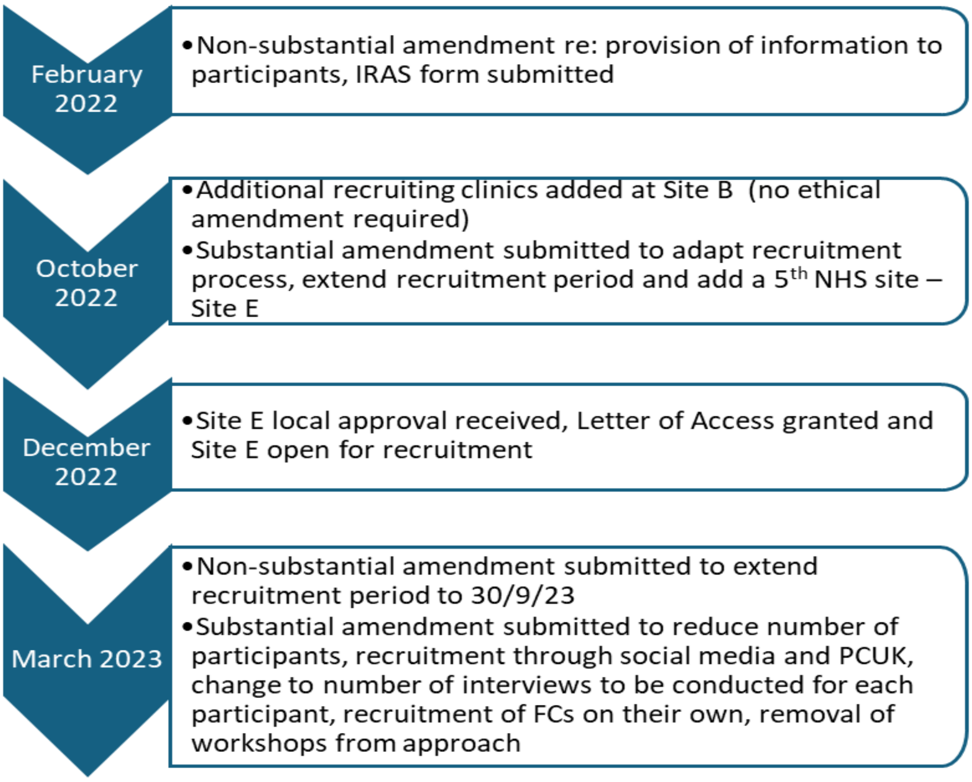
Given the longitudinal element of the research study, it was also considered possible that patients and FCs could develop an emotionally dependent attachment to the researcher (Calman et al, 2013). This was considered a particular risk for this study given the context of the research and the possibility that the researcher might be the only person that the patient and/or FC were able to talk with freely about their experiences of the disease, and the care they or their family member had received.

A Discontinuation Protocol (Appendix 19) was therefore produced which set out the steps that would be taken to mitigate for these circumstances, if deemed necessary. The protocol determined that at the conclusion of the third and final interview, participants would be provided with a thank you card and a 'Goodbye Letter.' The 'Goodbye Letter' made an explicit statement about the nature of the relationship between the researcher and participants and set out the next steps for the study. The letter concluded by reiterating the support available to participants through PCUK and other charitable organisations.

Ethical amendments

Several changes were made during the study, most of which required amendments to be submitted to the HRA for approval - see Figure 4. below.

Figure 4. Timeline of protocol changes and associated ethical amendments



February 2022

- Non-substantial amendment re: provision of information to participants, IRAS form submitted

October 2022

- Additional recruiting clinics added at Site B (no ethical amendment required)
- Substantial amendment submitted to adapt recruitment process, extend recruitment period and add a 5th NHS site – Site E

December 2022

- Site E local approval received, Letter of Access granted and Site E open for recruitment

March 2023

- Non-substantial amendment submitted to extend recruitment period to 30/9/23
- Substantial amendment submitted to reduce number of participants, recruitment through social media and PCUK, change to number of interviews to be conducted for each participant, recruitment of FCs on their own, removal of workshops from approach

These changes were the result of the challenges experienced in recruiting patient and FC participants. The first main change was to the recruitment process, so that rather than patient and FC participants being expected to contact the researcher directly, they were asked by an HCP for their permission to have their contact details passed to the researcher. The researcher would then make contact to discuss their participation. Further amendments included extensions to the recruitment period, the addition of more clinics at existing NHS sites and the addition of a fifth NHS site – Site E, a change to allow FCs to be recruited without the patient participating, and the introduction of recruitment through non-NHS routes. In addition, an amendment revised the maximum number of patients and FCs to be recruited from 25 to 15 for each cohort.

Given the extended recruitment period, an amendment also allowed for patients and FCs recruited after March 2023 to be interviewed at just two time points – the first interview taking place within three months of diagnosis and the second within six months of diagnosis. The extended recruitment period also meant that the original intention to test findings and recommendations out with participants through a series of workshops had to be revised. Recognising the importance of ensuring that any practical suggestions for improving people’s care and support were acceptable to stakeholders and feasible to implement, the amendment allowed for the findings from the study to be shared with PCUK’s RIN and a representative of a national network of hepatobiliary nurses.

4.9 Data analysis

It is accepted that the analysis process for qualitative research does not wait to start until all data has been collected but is instead ‘ongoing’ and ‘an inherent part of the whole process of qualitative research’, (Ritchie et al, 2014, p275). The analysis process in this study began with the production of interview summaries after each interview had been completed. This process allowed the researcher to begin to identify common issues with people’s care and support from an early stage which the researcher was then alert to in subsequent interviews (Harding, 2013).

The ordering of interviews was also helpful in this regard in that three of the first four interviews were with specialist nurses from a charity helpline. Given the nature of their role - speaking to patients and FCs on a daily basis, their combined years of experience, and their geographical reach, these interviewees were able to provide a good overview of the supportive care issues patients and FCs were likely to face. These were therefore interviews that orientated the researcher to the topic and raised issues in the provision of care that were not evident in the literature or previously on the researcher’s radar from earlier PPIE discussions. For example, particular issues regarding patients’ access to GPs were highlighted by these interviewees along with the difficulties patients might experience in the co-ordination of their care outside of the acute sector.

The common themes in these three interviews therefore informed subsequent interview data collection with patients and FCs, who were asked specific questions about their contact with primary care. And while it had been the intention from the outset to interview GPs if possible, their importance as participants became increasingly clear during these interviews with patients and FCs, as many comments were made about perceived deficiencies in the support received from primary care. It was therefore critical to understand GP's perspectives, and to explore the challenges they faced caring for this cohort of people. Consequently, three GPs were recruited and interviewed.

The ongoing use of summaries after interviews also assisted in identifying additional issues or concerns that were then incorporated into interview questions and probes, such as the emotional effect on HCPs of working with this cohort of patients and FCs and the experience of patients when hospital inpatients.

Hence the process between data collection and analysis was iterative - a fundamental feature of qualitative research (Ritchie et al. 2014).

The Framework Approach

Data from the interviews were formally analysed using the Framework Approach (Ritchie and Lewis, 2003). This is a means by which qualitative data can be reduced systematically into a manageable format for analysis. The Framework Approach is not aligned with any particular epistemological, philosophical, or theoretical approach and is not limited in its application to either an inductive or deductive thematic analysis (Gale et al, 2013). It is commonly used in the thematic analysis of semi-structured interview transcripts and when the data are homogeneous i.e. covering similar topics or issues (Gale et al, 2013).

How the Framework Approach was applied in this study is summarised in Table 3 below and described in full in the subsequent text.

Table 3: The Stages of the Framework Approach (adapted from Gale et al, 2013)

Stage	Process	Description	Application to the study
1	Transcription	The process starts with the transcription of interview audio files by the researcher.	A combination of researcher-transcribed (35%) and professionally transcribed (65%) audio files was employed to manage the amount of data collected.
2	Data familiarization	This occurs through listening to the interview audio files and reading and re-reading the transcripts.	Once transcribed, hard copies of all transcripts were printed and read through a minimum of three times - notes were made in the margins of initial thoughts and impressions.
3	Coding	In this stage of the process, the transcript is read line by line with a descriptive label or code applied to sections of the text. A combination of deductive and inductive approaches can be used to generate codes.	A combination of deductive and inductive approaches was used to generate codes. Codes such as symptom control and care co-ordination were pre-selected (deductive) as the literature highlighted the importance of these. In other cases, labels were generated from the data through open (unrestricted) coding i.e. the importance of peer support among HCPs.
4	Developing an analytical framework	It is usual practice for a researcher to code a few initial transcripts to discuss with other members of the research team. Codes are grouped together into categories and a tree diagram is used to represent sub-categories. Additional codes may be added as further transcripts are analysed.	Due to the PhD nature of the research, most of the coding was conducted by the researcher. The supervisory team were involved in testing the analytic framework and codes by joint coding two transcripts each. This resulted in a small number of additional codes being suggested. Coding began on the HCP transcripts initially to develop a framework. The first six transcripts were read and coded before the framework was developed. The framework used several categories and sub-categories, and a tree diagram was used to represent these codes.
5	Applying the analytical framework	Categories and codes are marked as they appear, on each transcript.	Single words or short labels were used in the application of the analytical framework e.g. Communication, delays, GP access, navigating the system, decision-making.
6	Charting data into the framework matrix	A matrix output is produced with rows representing cases (each interviewee) and columns representing codes (themes identified). The cells of the matrix contain summarised data from each interviewee for that code.	A first draft of the matrix was produced after the charting of 22 HCP interviews. The matrix was subsequently added to and amended as the analysis of two additional transcripts was included.
7	Interpreting the data	This final stage seeks to explain the data through theoretical concepts, connections, and causality	In this study the emotions and feelings HCPs expressed about working with this cohort of patients could be interpreted through the concept of emotional labour.

The coding process began with the reading and notation of the first six HCP transcripts. Manual coding was used as the researcher's personal preference for speed and ease of use. This involved the use of highlighters and making notes in the margins of paper transcripts to identify codes. (See Appendix 20 for an illustrative extract of a coded transcript). Single words or short labels were initially used to describe the issue or topic being discussed. This was both deductive, using themes identified from the literature i.e. a priori codes e.g. PEI and PERT, palliative care, communication etc., and inductive i.e. being open to new themes and ideas e.g. GP access, emotional labour etc. (Saldana, 2021). The codes were grouped into broad categories sharing patterns or characteristics (Saldana, 2021), to develop the framework. This categorisation was based initially on the seven domains of need, and the time points along the cancer trajectory i.e. diagnosis phase, treatment phase and palliative/EoL phase, in Fitch's framework (1994). Additional categories were added as codes were added with similar characteristics that did not relate to Fitch's framework i.e. organisation of services.

The remaining HCP transcripts were then re-read, and these categories and codes were applied, with additional codes added and refined during the process, until all 22 HCP interviews, undertaken up to that point, had been analysed and coded. The process then began of charting the data from the HCP interviews into the framework matrix.

Once all 22 HCP interviews undertaken at that point had been charted into the matrix, the process of coding patient and FC interviews began. Initially, one coding matrix was going to be used for all participants as it was thought that many of the codes would be applicable across the whole cohort. While this was borne out to an extent, the codes created from HCPs interviews did not always accurately reflect the patient or FC experience, nor did they encompass every aspect of the data within these transcripts. Appendix 21 sets out the changes proposed to the original coding matrix as a result of applying this to the first six patient and FC transcripts.

It was therefore decided to code the next six FC and patient transcripts from scratch to see how alternative codes might be generated. This exercise led to the development of two matrices – one for HCPs and one for patients and FCs – see Appendix 22 for an illustrative extract from the patient and FC coding matrix.

In the coding and charting of the data, there were both joint and separate codes for the data gathered from FCs and patients regardless of whether the interviews were conducted jointly or separately. For example, Category B codes related to the patient journey and experience, so that whether a patient talked about their own diagnosis, or an FC talked about the patient's diagnosis, this was coded to the same code. There were separate patient and FC codes in Category C – 'Emotional impact and effects of illness' so that while code C2 related to patient feelings, needs and concerns, code C5 related to FC feelings, needs and concerns. Similarly, code C3 related to the patient's support network while code C8 related to the FC's support network. Code C4 related to the patient's coping strategies while code C9 related to the FC's coping strategies. In addition, one code, C6 related to the FC role and responsibilities specifically, while code C7 related to the dynamic between the patient and FC, whether indicated indirectly through the interview, or directly expressed.

It was not possible to undertake a detailed longitudinal analysis of the data across participants due to the limited number of multiple interviews achieved. Changes in needs over time were assessed for individual participants, where multiple interviews had taken place.

4.10 Mapping and theorising from the data

Initially, different conceptual models were tested with regards to the analysis and presentation of the patient, FC and HCP findings. These were Fitch's Framework of Supportive Care Needs for cancer patients (1994) as applied to patient interview data, the conceptual model of family caregiving (Fletcher et al, 2012) as applied to FC interview data and Donabedian's conceptual model of healthcare quality (1966) as applied to HCP data. These are described in turn below.

Fitch's Framework was identified as being potentially relevant to the study in the early stages of the background reading into supportive cancer care conducted at the outset of the researcher's PhD. Though originally published in 1994, it continues to have relevance in terms of the domains covered (Krishnasamy et al., 2023) and how these might be applied in the context of this study (see Table 2 – page 23). In addition to the seven domains of need, the Framework considers three time points - the diagnosis, treatment, and later phases, as being important in assessing needs. This element of the Framework informed the timing of patient and FC interviews, referred to earlier in this chapter.

Fitch (1994) also identified five basic clinical standards for supportive care of cancer patients and their FCs as follows: People should receive ongoing assessments of their supportive care needs; they should be offered referrals to appropriate supportive care resources and have the opportunity for self-referral to such resources; people should have access to information about the physical, practical, and emotional aspects of their cancer and its treatment; and people should receive supportive care that is relevant to their needs and sensitive to their age, gender, language, culture, sexual orientations, religion, and economic status.

In a later publication (2008), Fitch also provided a means of conceptualising patient needs, at four levels of service or intervention (see Table 4 below).

Table 4: Fitch's Framework for conceptualising patient and family need (2008)

Level of Need	**Service or intervention type required and proportion of patients requiring this**
1	All patients require ongoing assessment of supportive care needs with provision of relevant information, emotional support, good communication and symptom management
2	Approximately 30% will require additional information and education as well as encouragement to seek help and engage in peer support groups
3	Approximately 30-40% will also require specialized or expert professional intervention for symptom management and/or psychosocial distress
4	Approximately 10-15% will also need intensive and on-going complex interventions

The Framework therefore appeared logical, systematic and a comprehensive way of thinking about patients' holistic needs.

Fletcher et al's Conceptual Model of Family Caregiving (2012)

This model was identified as being potentially relevant to the study during field-work when the stress of being a FC was repeatedly highlighted by participants.

Fletcher at al. based their model on earlier work on the stress process developed by Weitzner, Haley and Chen (2000) but enhanced this earlier model, by incorporating two additional elements, namely contextual factors and the cancer trajectory.

Within the model, ‘Primary Stressors’ relate to either patient illness related factors such as the site and stage of the cancer, the prognosis for the patient and disease symptoms and treatment side-effects, or care-giving demands such as the management of symptoms and side effects, handling patient emotions, coordinating treatment and appointments and accessing services and navigating care. Secondary Stressors relate to ‘spillover effects’ i.e. those part of the caregiver’s life that become affected by their caregiving role. These could include work and family commitments, the enjoyment of a social life, financial challenges and role changes, as well as stressors related to the physical effects of caregiving and living with the patient i.e. fatigue and sleep disturbances.

It is suggested that caregivers make an appraisal of their stressors i.e. their significance and meaning, in order for them to formulate a response to those stressors. For example, a family caregiver may make either a positive appraisal of a primary stressor such as considering it a privilege to care for someone, or a distress appraisal by feeling the demands of caring as time-consuming and burdensome. The appraisal of the stressor, determines the cognitive-behavioural response or coping strategy which can in turn affect an individual’s health and wellbeing.

Fletcher et al.’s model (2012) then considers the importance of contextual factors to the family caregiver’s situation i.e. their personal and social context such as their own health status, financial or work situation. Contextual factors may also include the relationship the caregiver has with the person for whom they are caring – for example whether this is a warm and loving relationship or already a relationship under strain. The health system wherein the caregiving is situated, is also considered as a contextual factor. The cancer trajectory forms the third element of the model. Two overarching trajectories are possible - one leading to survivorship and one leading to bereavement.

Donabedian's model of Quality of Healthcare Quality (1966)

Donabedian's model of healthcare quality was previously known to the researcher and was therefore identified as a potential model for assessing the quality of the care being provided at an early stage of the study. The model consists of three domains – the 'Structure' of healthcare, healthcare 'Process' and healthcare 'Outcome' and explains the chain of causation between these three elements. The structure of healthcare relates to the context of care which Donabedian suggests is easy to simply observe. This domain would include the physical buildings and equipment used to deliver healthcare, the staff involved, and training provided to staff. The process of healthcare is the sum of all actions that make up healthcare and Donabedian suggests these can be gleaned from reviewing medical records or from interviews with parties involved such as patients, HCPs and FCs. This domain might include the processes of diagnosis, treatment, preventive care, patient education and interpersonal interactions between staff and healthcare users. The outcome of healthcare is the effects of healthcare and these may include changes to health status, changes to health behaviour, changes to health knowledge, increased patient or FC satisfaction or improved QoL.

Rejection of alternative methodological frameworks

While both Fletcher et al.'s and Donabedian's models were relevant and offered a means of exploring the data from interviews with FCs and HCPs in an alternative way, the use of three separate models ultimately lacked coherency. Firstly, the separation of patient and FC data into two chapters to allow for the application of different models, created significant repetition between the chapters as both groups of participants talked about the same events and situations, regardless of whether they were interviewed separately or jointly. And while Fletcher et al's model was illuminating in its focus on stressors, context and the cancer trajectory, the separation of data between the two groups of participants felt artificial in that the experience of receiving supportive care was ultimately a shared experience and much was obtained through joint interviews.

While the use of Donabedian's model allowed for a consideration of the context of care specifically – an important element for a case study of this nature, its application also created repetition and a lack of coherency between the chapters.

Fitch's Framework of needs was therefore applied to both patient and FC data in a single chapter, using her seven domains of care and three time points as an organising architecture. This subsequently led to the HCP data being presented using the same architecture, allowing for consistency and comparison between patient and FC experiences of receiving care and support and HCP experiences of providing support and care. This approach also allowed for the integration of analysis themes and contextual themes in Chapter 7’s case assertions, a characteristic of a case study approach (Creswell and Poth, 2018). The case studies or lessons learnt represent the last stage of analysis in a case study, where the researcher makes sense of the data and provides an interpretation of it (Stake, 2005).

The approach to data analysis in this case study is a ‘holistic’ analysis of the entire ‘case’ i.e. the delivery of supportive care to patients and FCs, as opposed to an ‘embedded’ analysis of a specific aspect of the ‘case’ (Yin, 2009).

Several middle-range and micro-theories are drawn on in Chapter 8 in order to discuss the implications of the case studies. Middle-range theories relate to specific aspects of human interactions with each other or with structures or organisations while micro-theories focus on individual-level phenomena (Higgins and Moore, 2000). Theories considered in Chapter 8 include middle-range theories related to patient experience and descriptive micro-theories such as emotional labour (Hochschild, 1983) and help-seeking behaviour (O’Mahoney and Hegarty, 2009).

4.11 Rigour within the conduct of the study

Credibility, transparency and trustworthiness

Traditional concepts of reliability and validity in the scientific context refer to the ‘replicability’ of a study’s findings i.e. whether if it was conducted again using the same methods, the same results would be generated, and there has been much debate as to whether these concepts can and should be applied to qualitative research (Sandelowski, 1986 and Mays and Pope, 2000). The general consensus though is that in order for findings to be considered transferable or generalisable, the findings should be considered reliable, 'correct', or 'authentic' (Ritchie et al., 2014).

This, the authors suggest, lies in the ability of the researcher to demonstrate 'excellent, well-grounded links between the concepts and conclusions they develop, and examples drawn from the data from which these have been derived,' (2014, p357). The use of verbatim quotes from interviews to illustrate themes or specific points throughout the findings chapters in this thesis is a means by which the validity of the findings can be judged. In addition, the inclusion of raw data in the form of verbatim quotes from three perspectives (patients, FCs and HCPs) demonstrates consistency of themes and concepts, and strengthens confidence in the findings from any one cohort of participants.

The researcher is therefore confident that the raw data presented in these quotes provide a rich, detailed, authentic and corroborated account of the phenomenon under study. In addition, debriefing with supervisors during the analysis, and providing the findings back to participants (members or respondents), as described above, are further means of 'validating' the evidence (Ritchie et al., 2014).

Generalisability and transferability

The concept of generalisability i.e. that the findings can have relevance beyond the study sample, is contested in qualitative research, (Ritchie et al, 2014). To some extent perhaps due to its lowly position in the established hierarchy of evidence (Sackett, 1989), which ranks studies according to the probability of bias.

The concept of generalisation, also variously described as transferability or external validity, can be taken to mean both the application of findings to populations or settings beyond the study sample known as empirical generalisation, or theoretical generalisation – the generation of theoretical concepts which might have wider application (Ritchie et al, 2014). Empirical representation may be broken down further into representational generalisation - findings can be generalised to the whole of the population from which participants were drawn – in this context people affected by inoperable pancreatic cancer, and inferential generalisation - findings can be inferred as being relevant to other settings or contexts.

Ritchie et al. (2014) argue that representational generalisability depends on two factors – firstly, whether the sample of participants is representative of the population being studied and secondly whether the phenomenon under study has been accurately captured and interpreted.

As regards being representative of the population being studied, the study participants were based in a range of geographical locations within England, and had received their care from both specialist hospitals and District General Hospitals. The sample of patient participants also included a range of ages and an almost equal split between genders. FC participants comprised a balance between adult child carers and spousal carers. NHS HCPs were drawn from five geographical areas and represented a broad range of professional backgrounds, while the three PCUK specialist nurses provided a national service.

With regards to whether the phenomenon under study has been accurately captured and interpreted, the feedback from participants who were sent a summary of the findings, and from other stakeholders who were also sent a summary specifically for comment (see section 8.4), would indicate that this is the case.

The researcher would therefore attest that the study has generated meaningful evidence about the experiences of people affected by inoperable pancreatic cancer which has representational generalisability for the wider population of this cohort of people.

The researcher makes no claim to inferential generalisation, though it is possible that some aspects of the patient and FC experience highlighted in the study are common among other cohorts of people affected by a terminal diagnosis i.e. the difficulty in receiving a referral to community palliative care services or referrals for psychological support.

4.12 Reflexivity of the researcher

I anticipated that sharing their experience might be burdensome for people with pancreatic cancer and their family members. In the event, I felt that people saw their involvement as a much needed opportunity to talk freely and openly about their experiences, without feeling that they were ‘burdening’ anyone with their emotions and concerns. Participants also talked about their involvement as being an opportunity to contribute towards improving care for others, and several commented on how important they felt the study was.

I developed a rapport with interviewees, which I believe was key to my ability to retain participants' engagement in the study and interview people more than once. The quality of this relationship was evident I think in the fact that two of the FC participants contacted me to let me know how their family members were after our interviews had concluded. Significant events had arisen for them both i.e. one patient was able to have surgery after neoadjuvant chemotherapy and another patient received very positive blood results after their course of chemotherapy. A daughter of one of the patients also contacted me after her mother's death and volunteered to be interviewed. The patient had told her daughter about the conversation she had had with me, and her daughter wanted to help too.

Though there was the potential for these conversations to have been emotionally challenging, I did not find them so at the time. During the interviews, I was focused on creating the right sort of environment to put people at ease and to develop rapport, and I was concentrating on the information that was being shared and asking appropriate follow up questions or seeking clarification. I believe I remained empathetic and sympathetic but not emotional.

After each interview, I wrote up a summary which was shared with my supervisory team. This helped me to process what I had heard in a structured way. After receiving the summaries of several of the interviews which re-told particularly challenging experiences, my supervisors would check in with me via email to see if I needed a verbal debrief. I did not need to do this at any point. Instead, the emotional nature of the conversations and the encounters affected me most when I discovered that the participant had subsequently died. The conversations I had with those individuals will stay with me and I feel that is an entirely appropriate response for the privilege of hearing their stories.

The research endeavour is inevitably influenced by the researcher in terms of their beliefs, assumptions, existing knowledge and prior experiences and it is appropriate to reflect on the impact of these factors on the research in order to demonstrate transparency.

Despite not having a clinical background, I have previously worked for the NHS in managerial positions, often working closely with clinical teams. I have also worked closely with HCPs during my career as an academic, and through both careers have developed an affinity and empathy with HCPs. I believe this enabled me to be mindful of, and sympathetic to the challenges of working within the NHS but also enabled me to develop an informed naivety about contexts and processes, so that HCP participants would in some cases explain scenarios or events in more detail than they might have done had I been a fellow HCP. In addition, I think HCPs may have been more open about their own emotional response to working with this cohort of people, than had I been a clinical colleague, as there was no fear of censure or judgement from me.

Because I was not a HCP (and this point was made clear to participants), I believe my neutrality also meant that patient and FC participants were very open with what they disclosed about their experience, sharing a considerable amount of detail and becoming emotional at times. I believe this factor also encouraged participants to share examples of what they perceived to be poor practice by HCPs, without risk of censure and without the risk of their comments affecting their care in any way. Specific codes within category B – 'the patient journey and experience', were used to code such examples of care i.e. code B4 = confusion and uncertainty, code B5 = delays and mis-steps, code B11 = Attitude of staff and dynamic with patient/family carer and code B13 = opinions on quality of care/care provision.

Though I have previously undertaken research into aspects of pancreatic cancer, these have involved curative pathways rather than inoperable pathways, and more general aspects of care, such as the feasibility of introducing a national audit. I have not previously worked in a service providing care to terminally ill patients, nor researched aspects of incurable cancer. I was therefore completely new to the experiences of people with a terminal diagnosis and their FCs and largely new to the literature relating to palliative care and EoL services, so had no preconceived ideas about what these experiences might entail.

In relation to the analysis of the data, I feel the contribution and guidance of my supervisors helped to mitigate the potential for any biased interpretation. I sent summaries of each interview to supervisors after each interview and emerging themes and conceptual ideas were discussed at supervision sessions. In addition, supervisors had access to each audio file and transcript from every interview and were able to see the raw data for themselves. In addition, a level of triangulation through multiple analysis (i.e. the use of different analysts to compare and check data and its interpretation) (Ritchie et al, 2014) occurred, as the supervisory team reviewed the coding framework and double coded a sample of transcripts to provide a comparative check.

When writing the summary of findings for participants, I was aware of balancing the need not to shy away from the reality of the stories shared, while being mindful of how the presentation of these findings might be received by HCPs. I did not wish the presentation of my findings to create any defensiveness which might negatively impact the opportunities for making improvements to care in the future.

Given the nature of the patient cohort, I felt the importance of ensuring the research would be meaningful to participants and would be capable of making a positive impact on the care and support provided to people. At times, I felt an almost overwhelming responsibility to do justice to the objectives of the study, and occasionally felt downhearted when it seemed as though my contribution would become overshadowed by recent strategic developments. I have therefore worked hard to maintain a relationship with members of the pancreatic cancer community to ensure there are meaningful opportunities to share and disseminate findings.

4.13 Summary of chapter

The chapter has positioned the research study within an ontological and epistemological framework, providing a justification for the chosen philosophical paradigm of pragmatism – a choice driven by the overall aim of the research which explicitly states a need for action for social benefit. The rationale for undertaking a qualitative approach using an intrinsic case study design with semi-structured interviews, incorporating a longitudinal element, has also been provided.

Further details on the research methods and processes are outlined including participant eligibility and recruitment processes. This section provides detail on the three groups of participants - HCPs, patients, and FCs, and their recruitment source i.e. five NHS sites, PCUK and social media. It is noted that when possible, patients and FCs were recruited as dyads and interviewed together, or separately, up to a maximum of three time points. HCP participants were interviewed once only.

The methods used for data analysis, including the application of the Framework Approach (Gale et al., 2013) are explained. This includes the processes of coding, charting, mapping and theorising from the data. This section describes the use of two coding matrices – one for HCP data and one for patient and FC data. It also provides a justification for the theoretical framework chosen for the study – Fitch's Framework for Supportive Cancer Care, together with an explanation of alternative theoretical frameworks which were considered but discounted during the study.

A description and timeline of the ethical and governance issues that arose during the study are presented, including the amendments required to mitigate for the challenges of recruiting patients and their FCs. In addition, the patient and public involvement and engagement (PPIE), and clinical engagement activity, undertaken at the outset of the study and throughout are described.

The chapter concludes with a discussion on rigour within qualitative studies and sets out how rigour has been demonstrated within this study.

Chapter 5 – Patient and family carer findings

'No-one has enough time with this disease.'

5.1 Introduction

This chapter presents an analysis of the data from patient and FC interviews. As noted in the previous chapter, Fitch's Supportive Care Needs Framework (1994) and its seven domains is used to provide an architecture for the presentation of the findings. Fitch's definitions for each domain (2008) are provided at the start of each section to indicate the issues that will be addressed. As noted in Chapter 4, the interviews were conducted, when possible, at time periods that broadly align to Fitch's Framework i.e. within a month after diagnosis (diagnostic stage), within three months of diagnosis (treatment stage) and within six months of diagnosis (palliative/EoL stage).

The chapter starts with an overview of the findings providing details on the number and characteristics of the participants and a general commentary on the nature of the interviews themselves and what was observed from the longitudinal aspect of the research.

5.2 Overview of findings

A total of 13 patients and 12 FCs were interviewed for the study, between May 2022 and December 2023. Twenty-one additional packs were handed out by NHS sites to people who gave their permission for their contact details to be passed on to the researcher but who, when contacted, either declined to participate, or did not respond to messages left. In a few instances, people declined to take part because they felt too unwell to do so, while others who did not respond were subsequently discovered to have been hospitalised.

A further four people (three FCs and one patient) contacted the researcher as a result of the study being promoted by PCUK's research newsletter and other social media channels, but unfortunately they did not meet the eligibility criteria to take part. The patient had cystic pancreatic tumours and the family members of the FCs had died well in advance of the eligibility period for participation.

A total of 36 interviews were conducted. The full breakdown of this number in terms of the composition of patient and FC interviews, separate and joint interviews and single or multiple interviews is shown in Table 5 below. Briefly, 10 of the patients were interviewed more than once, either separately or jointly with their FC. Of these, two were interviewed three times and eight were interviewed twice. Interviews lasted an average of 47 mins (range 13 mins – 1 hour, 37 mins). Twenty-five of the interviews were conducted by phone and 11 by Zoom video call.

Table 5 below provides details and characteristics of the participants along with their pseudonyms, their estimated age group (participants were not directly asked their age), the nature of the relationship between patient and FC, whether the individual was employed at the time of diagnosis, and the number, and type, of interviews undertaken.

Table 5 – Breakdown of participants by age group, work status, relationship between participants, number, and type of interviews

Patient ID	Age	Work status	Relationship of patient and FC	FC ID	Age	Work status	Interview Type	No of Interviews
P1 – Angela	65-74	R	Declined to nominate					3
P2 – Ben	45-54	W	Husband and wife	FC1 - Belinda	45-54	W	Separate	3 (Patient 1 and FC 2)
P3 – Christine	75-84	R	Mother and daughter	FC2 - Carol	45-54	W	Joint	2
							Separate	1 (FC after patient's death)
P4 – Delia	45-54	W	Wife and husband	FC3 – Daniel	45-54	W	Separate	4 (2 each)
P5 – Ed	65-74	R	N/A *					3
P6 – Frank	55-64	W	Husband and wife	FC4 – Felicity	55-64	R	Joint	2
P7 – Gloria	75-84	R	Mother and daughter **	FC10 – Naomi	45-54	W	Separate	2 (1 each)
P8 – Helen	75-84	R	Declined to nominate					1
P9 – Keith	65-74	R	Husband and wife	FC6 - Katrina	65-74	R	Joint	1
P10 – Labib	65-74	W	Father and son	FC9 - Nazim	35-44	W	Joint	2
P11 – Mikhailo	55-64	W	Husband and wife	FC7 - Lara	35-44	S	Separate	1 (FC)
							Joint	2
P12 – Nadia	55-64	W	Declined to nominate				Separate	2
P13 – Oliver	55-64	W	Husband and wife	FC11 - Phoebe	35-44	SE	Separate	2 (1 each)
							Joint	1
Deceased ***			Mother and daughter	FC5 – Joanna	35-44	Not known	Separate	1
Patient did not take part***			Husband and wife	FC8 - Mary	65-74	R	Separate	2
Deceased ***			Mother and daughter	FC12 – Rachel	44-54	W	Separate	1
Work status – R=Retired, W=Working, S=Full-time student, SE = self-employed * FC (wife) was present for both interviews but did not contribute to the discussion and therefore not counted as a participating FC. ** Patient declined to nominate but daughter contacted study to take part after patient's death *** FCs recruited after amendment to allow recruitment of FCs without patient participating								36

Almost all the participants self-identified as White British (84%) except one patient who self-identified as Asian and one FC who self-identified as British Asian and one patient and FC dyad who both self-identified as White European. All participants except three were completely fluent in English. Two of these participants were able to participate without an interpreter and one participant was helped by his wife (and FC) with translation through the interviews, when necessary.

5.2.1 Patient/family carer dyads

Nine patient/FC dyads were recruited (see Table 5). Four female patients chose not to nominate their FC to take part in the study. In three of these cases, the FC was an adult child, and the patients explained that they did not wish to nominate them to protect them from experiencing any additional distress or discomfort that might arise from being involved in the study. The FC would have been a daughter in two of these cases and in the third case, the FC role was shared between a son and a daughter. In the fourth instance, the FC role was shared between a daughter, a sister, and a sister-in-law – the patient declined to nominate any of these three individuals as she felt they would not have the time to take part, as all three worked full-time.

The patient participants were nonetheless prepared to talk about the role of their FC and what they perceived their needs to be, where these were identified. These data are incorporated within the presentation of the findings in this chapter. In one of the above cases, an adult child subsequently contacted the researcher after her mother’s death and consented to be interviewed. This individual is recorded as Naomi, FC 10, in the table above.

Three FCs were recruited without the patient taking part. Rachel and Joanna were recruited after their mothers had died, while Mary took part without her husband, as he did not wish to be involved. These FC participants spoke about what they perceived to be the needs of the patient, as well as their role as FC. These data are incorporated within the presentation of the findings in this chapter. Pseudonyms have not been given for these patients as they were not participants – they are therefore referred to in verbatim quotes as [patient].

5.2.2 Nature of relationship

Interviews with spousal FCs tended to yield more data on the effect of the diagnosis and prognosis on other family members, specifically, the effect of the patient’s diagnosis and prognosis on their children (the age of which ranged from three years old to middle age), while interviews with an adult child FC tended to yield less data about the effect of their parent’s diagnosis on other family members, except when their parent had a surviving spouse.

Spousal FCs talked about the joint support networks they had with the patient – often long-established friendship circles and local community relationships, while adult child FCs did not tend to mention their own support networks, unless specifically asked.

Where the FC nominated by the patient was the spouse, the role of FC was effectively undertaken entirely by that one individual, though others within the couple’s support network occasionally offered support or carried out specific tasks, such as collecting prescriptions. Where the FC was an adult child, additional sibling support was mentioned in three of the four cases. However, this support appeared to be limited to logistical activities such as taking their parent to medical appointments when the primary FC was unavailable, and therefore the adult child FC’s role did not appear to be equitably shared among siblings.

It was apparent that the adult child FCs in the study had a close and warm relationship with their parent – this could be ascertained in the interaction between the pair in interviews, when conducted jointly, and in comments made by both participants, in joint and separate interviews.

The closeness of the relationship between spousal FCs and the patient was less obvious, though spousal FCs talked about how their lives together had changed dramatically because of the diagnosis, and what they felt they had lost as a result.

The personal impact of their family member’s diagnosis was clearly quite different between spousal FCs and adult child FCs. The former were facing a future without their spouse with all the changes that was likely to bring. The main issue for most spousal FCs was coming to terms with bringing up their children on their own, or where their children were young adults, continuing to support them in education or at important transition points in their lives. With adult children there were still concerns for their wellbeing and how they would cope with the loss of their parent. A few spousal FCs were also affected by the financial implications of a future without their family member.

For the adult child FCs, the context was not about facing a future on their own but making other adjustments and taking on new roles and responsibilities. For Carol and Joanna for example, the deaths of their mothers meant they were providing ongoing support to a surviving parent.

5.2.3 Separate versus joint interviews

Seven patients took part in separate interviews and six took part in joint interviews with their FC. Five FCs were involved in joint interviews – two of these were also interviewed separately, while three only took part in joint interviews – see Table 5 above for additional information.

There were observable differences in the nature of the data gathered from separate interviews with FCs and those from joint interviews with patients and FCs. Unsurprisingly, there was a tendency in joint interviews for FCs to act as a prompt to patients about aspects of their care or experience that they may have forgotten or had been misremembered. (In almost all cases, FCs kept quite detailed records or diaries of appointments and the chronology of events, though none appeared to have used the log sheet provided in the participant information pack). FCs in joint interviews also amplified specific points that patients made, confirming the details or significance of the event or occurrence.

It was rare that a FC offered an opinion that was different to the patient in joint interviews. This happened on just two occasions, both in relation to the FC's alternative view of what might be helpful support for either the patient or themselves. It is possible that both participants used the interview to voice sentiments that were difficult to articulate or reinforce in ordinary conversations with their family member.

FCs tended to only speak about their own situation as a carer when asked directly about their own feelings and experiences, or when encouraged to do so by the patient.

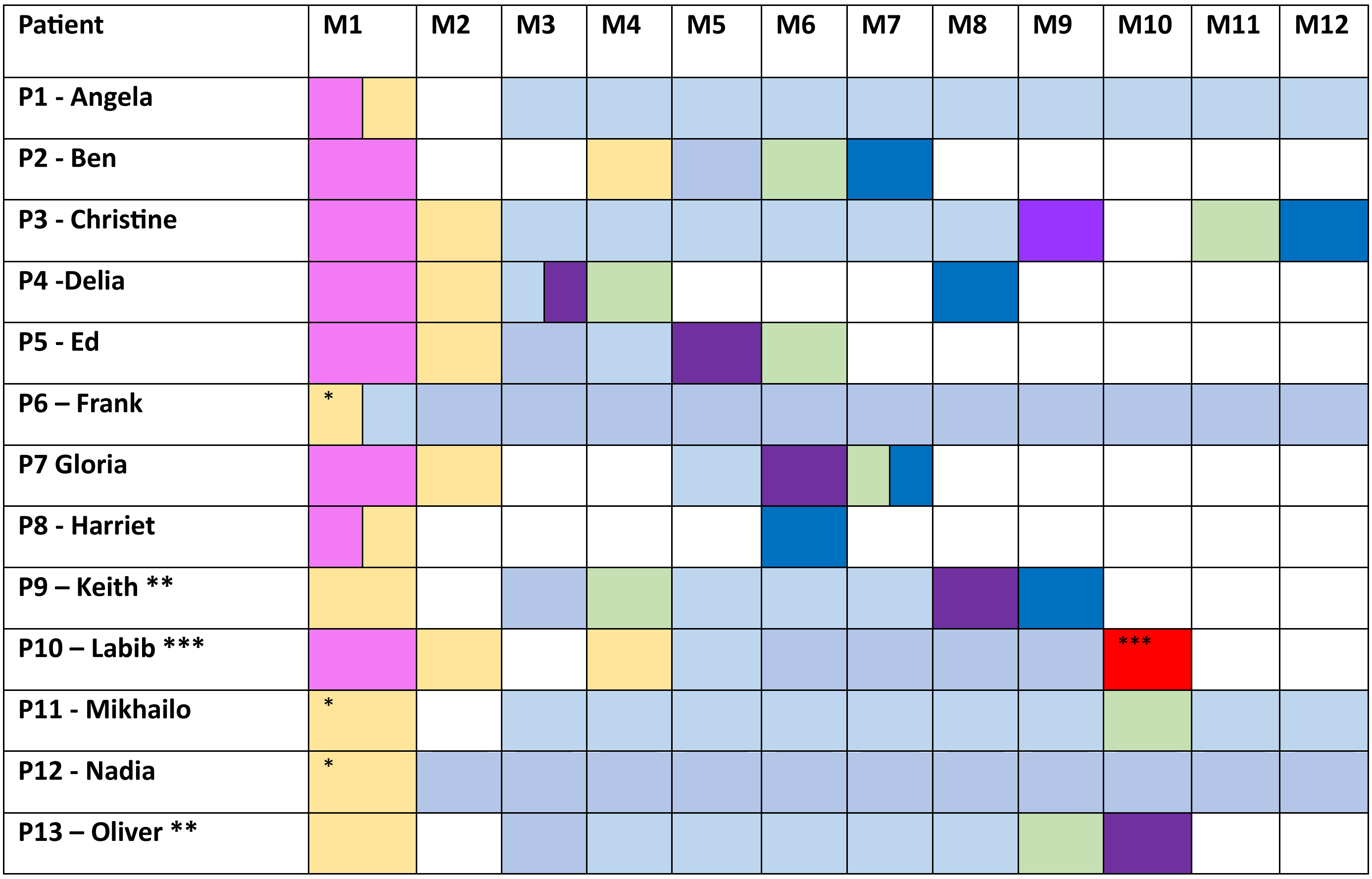
When interviews with FCs were conducted separately, they were more likely to talk about their feelings, whether in terms of their response to certain aspects of the patient's journey such as diagnosis, or the cessation of treatment, or the prognosis and the inevitably of the conclusion to their situation. FCs also became emotional when sharing their feelings in separate interviews whereas this tended not to happen when interviewed together with the patient. For example, one spouse emphasised the emotional impact of their family member's diagnosis on them and appeared to be experiencing what has been conceptualised as anticipatory grief – the feeling of loss experienced by someone before their family member dies (Rando, 1986). This was not the case in joint interviews.

5.2.4 Longitudinal observations

The purpose of multiple interviews was to ascertain how the needs of participants might change over time and whether health and care services were able to respond to these changes effectively. The specific cancer trajectory or journey for each patient in the study was different and unpredictable, depending on how they came to be diagnosed, what treatment they had, what complications ensued, if any, and how quickly their disease progressed. There were nonetheless common critical events and transitions i.e. presentation, diagnosis, start of treatment (or decision that there would no treatment), end of treatment, palliative care and for six of the patients, the end of life within a 12 month period.

The table below summarises these critical events or transitions. The chronology, over the course of an illustrative 12 month period, is determined from the details provided in interviews by both patients and FCs, rather than from the patient's medical records.

Table 6: Summary of critical moments in the cancer trajectory for patients over the course of an illustrative 12-month period



Patient	M1	M2	M3	M4	M5	M6	M7	M8	M9	M10	M11	M12
P1 - Angela												
P2 - Ben												
P3 - Christine												
P4 -Delia												
P5 - Ed												
P6 – Frank	*											
P7 Gloria												
P8 - Harriet												
P9 – Keith **												
P10 – Labib ***										***		
P11 - Mikhailo	*											
P12 - Nadia	*											
P13 – Oliver **												

Key	**Colour of cell**
Presentation	🟪
Diagnosis	🟨
Chemotherapy	🟦
End of Chemotherapy	🟪
Palliative Care referral	🟩
End of Life	🟦
Curative Surgery	🟥

***This diagnosis relates to a diagnosis of metastatic pancreatic cancer, and therefore inoperable cancer, and not the patient's first diagnosis of the disease**

**** Keith and Oliver had been having a range of symptoms for many months and had had multiple contacts with their GP over the proceeding year before their diagnosis – this delay isn't included in the table**

***** Labib was initially diagnosed as being operable but was re-diagnosed as inoperable after a delayed PET scan. He then had neo-adjuvant chemo before having a Whipples operation**

Broadly speaking, two cohorts of patient participants could be identified as a result of multiple interviews – those whose disease stayed largely stable during the series of interviews and who did not identify any particularly different needs between the first and subsequent interviews such as Angela, Frank and Nadia, and those patients who deteriorated rapidly and whose needs changed such as Ben, Delia, Gloria and Harriet. Of the 13 patients whose trajectories are included above, six died within a period of 12 months from diagnosis and four within six months of diagnosis. In some cases, the patients were able to articulate their changing needs themselves, while in others this was left to their FCs to relay, after their family member's death.

As well as the speed of deterioration, other noticeable changes over the time of the interviews, included changes in treatment. As shown in the table above, chemotherapy treatment commenced for 12 patients but some patients had the intensity of chemotherapy dose reduced, or stopped treatment altogether, because of the side effects they were experiencing. One patient, Harriet, chose not to start chemotherapy.

Three patients were referred to palliative care at approximately the same time as they began treatment, while three other patients did not have contact with palliative care services until they stopped chemotherapy. Three patients died within a month of being in contact with palliative care services. Four patients did not have a palliative care referral.

In one or two cases, there had been a period of adjustment following diagnosis, and the mood or outlook of the patient or FC appeared different in subsequent interviews from the initial interview. This was the case for Mary, who felt that her husband had become less withdrawn over time.

> *'But recently we have been getting out more, and he does seem to be a bit brighter... We've had more friends round, I think it was just such a dramatic shock that first month, just like oh my goodness, what's going on kind of thing. So yeah, so we have friends round and we have been going out a bit more…'* Mary – FC8

For the group of patients that stayed relatively stable, optimism or hope, was expressed in one or two interviews undertaken at the three month and six month time period, when chemotherapy seemed to be keeping the disease at bay. Several of the participants felt able to go away on holiday and resume other social activities.

There was little evidence that people changed their minds over what sort of emotional or psychological support they felt they wanted or needed over the time period, though they might seek additional support for their physical or practical needs. For example, Frank maintained his view that he didn't want a referral to counselling and didn't want a referral to palliative care. However, he did need additional support with his physical needs as he experienced the side effects of chemotherapy, and he and his wife Felicity did seek out support for accessing benefits when it became increasingly apparent to Frank that he could not return to work.

In general, what emerged from these interviews was a picture of ongoing unmet needs, medical complications and hospital admissions, and ongoing confusion and uncertainty for both patient and FC.

5.3 Supportive care needs

The following sections organise the interview data against each of Fitch's seven domains of need, using her definitions to describe what is covered within each domain.

5.3.1 Physical needs

'Need for physical comfort and freedom from pain, optimum nutrition, ability to carry out one's usual day-to-day functions' (Fitch, 2008, p9)

The physical needs of inoperable pancreatic cancer patients are extensive and complex, and while there were commonalities between the needs of the study participants, each one's combination of needs, their severity, and their timing, were highly individualistic.

These needs required a speedy response, given the terminal prognosis, the often rapid decline for those with the disease, and acuity of illness. However, study participants did not always experience a speedy response, as the findings below demonstrate.

Diagnosis phase

The main physical needs for patients in the diagnosis phase were related to symptom control, though the range of symptoms experienced by the patients who participated in the study, and their severity, varied considerably. These included jaundice, weight loss, loss of appetite, indigestion, bloating, reflux, back pain, stomach pain, flank pain, changes to urine and stool colour and stool consistency, constipation, a rash, severe itching, fatigue, and breathlessness.

All of the participants except one initially sought help through their GP. Helen's symptoms were more acute, and she called 999 with extreme breathlessness and unable to move. Angela, Christine, Delia, Gloria, and Nadia received an immediate referral from their GP for further investigations or were told by their GP to go straight to A&E. Others experienced multiple visits to their GP as their symptoms were assessed as being caused by other issues, such as musculoskeletal problems, as was the case with Ben, or indigestion like Keith and Oliver. Oliver talked about having numerous visits or telephone consultations with his GP, sensing something wasn't right, but unable to get a referral for further diagnostic tests. It was only when he finally saw a different doctor at his practice, that his multiple visits seemed to trigger alarm bells and he was finally sent for an ultrasound.

For some patients, like Angela and Christine, the treatment of jaundice was their main physical need initially, as this was causing unpleasant symptoms such as nausea, itching and feeling generally unwell. The treatment for jaundice involved a procedure to insert a stent into the biliary tract to relieve the obstruction causing their jaundice.

Watching their relative experience any severe disease related symptoms was difficult for FCs. For example, Joanna described observing her mother's faecal vomiting caused by an obstruction as being particularly distressing. Distress appeared to be increased if there were problems getting a timely response from HCPs.

> '*I mean she was left all that Tuesday evening with no pain relief and wasn't till I got to hospital on the Wednesday, and I was asking and asking and asking and eventually they brought her in some morphine that they could actually inject her with.'* – Joanna, FC 5
>
> *'I mean you were supposed to phone, leave a message. I mean that's hard, just leaving messages, and then if you left it before three o'clock then they phoned the next day or something. But you know, it didn't always happen, it really just did not happen…. I mean obviously resources are stretched, but it was really, really, really, really tough and so he was not in a good place.'* – Mary, FC 8

> *'… I felt awful because when you're watching your mum…And she was very brave about this sick, puking all this stuff up… I thought, 'oh, you can't keep doing this,' it was not nice to see her.'* – Rachel, FC 12

Treatment phase

Digestive issues

Several of the participants had experienced a loss of appetite prior to diagnosis and were continuing to lose weight and in two cases, this was a significant loss. Others encountered gastro-intestinal symptoms such as diarrhoea, constipation, reflux, and bloating, indicating PEI. Effective management of PEI requires the prompt prescription of PERT, along with nutritional supplements and changes to diet, where necessary. However, the patients experienced variable specialist support to manage their PEI, with some patients receiving comprehensive advice and support, and others receiving little information or explanation. For example, Christine was given PERT tablets when discharged after having a stent inserted but received no information about the need to continue taking the medication indefinitely. She therefore didn't realise she would need ongoing repeat prescriptions of PERT when her initial supply ran out.

> *'…they gave me some, what do you call it? Creon®? Creon® tablets, and to take them with food. So, they gave me a box with 100 in. After that, I wasn't told to go to your doctor once they've gone because I've always got to take them. … (consultant oncologist's name) – she said, 'Well you should have*

> *been taking them.' And I said, 'Well they didn't say that to me. They never said a word.'* – Christine, patient 3

Though there is an expected element of individual trial and error to work out an appropriate dose to take, yet people still felt they were not given adequate information or specialist support to help them titrate their dosage appropriately depending on how many meals and snacks they were eating and what they were drinking.

> *'And then they've changed his medication, they've now got him on Creon®, but [Doctor 3] just said, 'oh, you're going on Creon®', but didn't explain how they need to be taken, it was just this is the prescription, and I think sometimes just a little bit more explanation would have helped both of us.'* – Felicity, FC 4

This was also the case for Angela who found the instructions she had received ambiguous and ended up taking a dose that was much too low for her.

> *'Now you see perhaps I wasn't listening or maybe somebody didn't explain it to me, but I didn't realise that's what it was, so that almost everything I ate, should have a Creon® capsule taken with it.'* – Angela, patient 1

For Angela, her initial lack of understanding about how to take PERT contributed to digestive issues and weight loss which caused her real concern.

> *'I think I'm weak because I've lost quite a bit of weight from what I was before. I'm down to about 9 [stone] now which for me is quite skinny. … I did say every time I went, 'I've lost quite a lot of weight again,' but nobody says*

> *anything. … it was a surprise to me how quickly I went sort of downhill, with the loss of appetite. That was the biggest worry that I had no appetite whatsoever.'* – Angela, patient 1

Though some patients were referred to a specialist dietician to provide support and advice, this was not consistent for every patient experiencing difficulties. This omission was disappointing for some, including Keith.

> *P: '…we asked about that at the very early stage and was basically fobbed off saying that's really only for people who… What was it?*
>
> *FC: For gastroenterology cancers like oesophagus, stomach, that kind of thing. …*
>
> *P: … we've just worked out hit and miss over the months that we've been going, what I can eat, what I can't eat, how much I can eat.'* - Keith, patient 9 and Katrina, FC 6

The most commonly prescribed brand of the medication did not suit Mary's husband, and though he was eventually able to change brands, it took some persistence on their part to get the problem sorted, and in the interim, his physical state continued to deteriorate.

> *'… cause these pills that he was having to try to get him to stop losing weight…work in 99% of people and they didn't work with [Patient]. So, he was really struggling keeping food down…so he was losing weight like there's no tomorrow. So, it was absolutely devastating because we just didn't know what to do.'* – Mary, FC 8

Chemotherapy side effects

For those participants having chemotherapy, the management and amelioration of treatment side effects sometimes overshadowed their cancer symptoms. The side effects people experienced as a result of chemotherapy treatment were similar to any patient undergoing chemotherapy such as nausea, diarrhoea, fatigue, peripheral neuropathy, oral thrush, mouth ulcers, and mood changes. However, certain side effects such as changes to taste, nausea and diarrhoea compounded the problems experienced by people who were already nutritionally compromised. Some patients, like Frank, even felt that the side effects were more debilitating than their initial symptoms.

> *'From the very beginning the only pain I had was in my back and out the front and getting comfortable, but everything else I would say has been a side effect … I've still got side effects like loss of taste, funny taste in me [sic] mouth, pins and needles from the chemotherapy, numbness in me [sic] feet, forgetfulness, tiredness.'* – Frank, patient 6

Angela mentioned how frightening she had found the side effects she experienced.

> *'I also found the chemo quite traumatic. .. I found it difficult - the physical side effects of it – I found some of them quite frightening I suppose not having any medical knowledge at all.'* – Angela, patient 1

Oliver was left with quite severe neuropathy in his feet and legs after chemotherapy and had become less steady on his feet to the extent that he had fallen downstairs at home. He was frustrated that no-one seemed to be concerned about the effect of this on his QoL and felt that his concerns were being dismissed. He was told that a referral to physiotherapy was a possibility, but this was not offered as an immediate course of action.

> *'…and he said, 'Well if it gets any worse we could refer you to physio.' And it's like well how much worse?'* - Oliver, patient 13

Several patients, including Ed, paused chemotherapy, or stopped having the treatment altogether as a result of the side effects and the way they felt it compromised their QoL.

> *'… to me it's like a prison sentence for doing no crime. It has been horrendous…. Put it this way in a nutshell, to get quality of life I can't have chemo then that's it, chemo bye-bye, I'm gonna go home and live and just die with my cancer.'* – Ed, patient 5

In addition to the side effects of the treatment, patients were also having to either inject themselves, or be injected by their FC, with anticoagulants to prevent blood clots while on chemotherapy. This proved difficult to do for some FCs like Mary. Anti-emetic drugs, given to patients for nausea as a result of chemotherapy, also caused patients some problems with constipation, giving rise to additional complications, such as painful haemorrhoids.

Complications and hospital admissions

For a small number of patients, pre-existing conditions, or co-morbidities, such as diabetes, increased the complexity of their physical needs, as these either needed ongoing management alongside their cancer treatment and care, or they affected what other treatment they could tolerate.

Physical needs intensified if patients experienced complications because of the progression of their disease or reactions to treatment, such as chemotherapy. These complications included infections (including neutropenic sepsis) which sometimes required a hospital admission for the administration of intravenous antibiotics – this was a recurrent issue for several patients.

Delia was admitted to hospital with complications after her first round of chemotherapy and stayed as an inpatient for 18 days, during which time she lost 20% of her body weight. Though only middle-aged, the experience left her feeling physically weakened and frail beyond her years. When she asked if she could have physiotherapy to help her recover, she was challenged as to why she felt she needed this support:

> *'I had the physio in hospital say to me, 'why do you want physio, you're better than everyone else in the ward.' I said, 'Yes, everyone else in the ward is 30 years older than me, and they were frailer when they came in!'* – Delia, patient 4

Gloria and Christine both needed their stents replacing due to obstructions. Gloria was also admitted twice to hospital in severe pain due to a partial bowel obstruction and on both occasions, her daughter, Naomi, reported that her mother was often left waiting for extended periods of time for pain relief to be administered. The experience proved particularly traumatic for Christine as she developed sepsis due to a biliary obstruction. Though a third stent was fitted, and antibiotics given, Christine's daughter, Carol, felt her mother never recovered from this complication and deteriorated fairly rapidly thereafter. Carol attributed this rapid decline in part to a lack of clinical involvement and oversight of her mother's care at the time.

> *'But you know at this point, apart from the paramedic [999 call response], she hadn't seen a doctor, she hadn't, no doctor had come to the house, no nurse had come to the house, it was really a lot of being left to sort of get on with it a bit.'* – Carol, FC 2

Most of the patients who required hospitalisation at some point during their cancer trajectory, reported that at least one of their physical needs was not being met, whether for the administration of timely pain relief, personal care needs, or simply for rest. Gloria's daughter, Naomi, wondered why a terminally ill patient still needed to be woken up every two hours at night for observations to be carried out, and noted that on both occasions her mother was hospitalised, it would take her two to three days at home afterwards to recover from the fatigue, brought on by the intrusive ward routine.

Only Labib appeared to have had a completely positive experience while an inpatient. This may have been because he was admitted to an oncology ward, which may have been better equipped to deal with his specific needs, unlike most of the other patients in the study, who were not admitted to an oncology ward but general surgical or medical wards.

Patient advocate

FCs often reported acting as the patient's advocate in their encounters with clinical staff, reminding them about the patient's physical needs or preferences.

> *'One week they used a child-size cannula, which was easier to get in, but they don't always have them...I mean they do warm mum's hand up, but sometimes they don't seem to know from week to week…I'm usually there being a bit of a bully going, 'No, she has to have her hand in the water for 10 minutes before, to warm up'*.' – Carol, FC 2

This role as the patient advocate, increased in intensity if the patient was admitted to hospital. For example, FC Naomi, had to ask the ward to make a note on her mother's records that she was deaf and wore hearing aids and requested that they stroke her arm to wake her up to tell her if they were going to do anything to her. This followed an incident where her mother was given an injection into her abdomen without her consent. This was a particularly painful episode for her mother as her abdomen was already very swollen and tender.

Joanna felt she had to constantly remind ward staff about her mother's pain relief.

> *'they needed two staff each time to get mum her meds because it was strong meds, but I would let them know about two hours before, oh, she'll need her meds in two hours, I'd let them know half an hour before, I'd let them know on the time and they still couldn't get it together to get it in time.'* – Joanna, FC 5

In addition, Joanna's continued requests for a commode for her mother to use were not acted upon for several days. This caused unnecessary discomfort and a loss of dignity as Joanna and her mother had to access a ward toilet trailing drips and carrying paraphernalia such as pads and underwear.

Family carer physical needs

A few FCs talked about the impact of their family member's situation on their own health and well-being. Rachel, for example, talked about feeling anxious, fatigued, and not sleeping while she was caring for her mother.

> *'I felt that my blood pressure was probably a bit high, but then I wasn't really sleeping very well. I'm not a fan of taking things like sleeping medication, I just thought I can work through this, but I just need room to breathe.'* – Rachel, FC 12

The instances when FCs disclosed their own physical needs were rare however, and tended to crop up in separate, rather than joint interviews, no doubt in part because FCs did not want to make their family members feel caring for them was a burden.

Palliative care and end of life phase

None of the patients interviewed could recall having any formalised ACP discussions with HCPs, so their wishes for care in the event of certain circumstances, or in the last weeks of life, were not necessarily known or recorded. Few patients had even thought about this, should certain events occur. In some cases, this was perhaps to avoid 'tempting fate' or to appear overly negative about their prospects for the sake of their family members. It is also possible that HCPs did not wish to raise the topic with patients for fear of causing distress.

When asked whether she had been involved in an ACP discussion, Nadia responded that she had not but would have welcomed the opportunity so she could ensure others weren't left to make difficult decisions on her behalf.

> *'I'd much rather be able to have a discussion with my family while I'm completely of sound mind and compos mentis [mental capacity] and say well this is what I would actually like, please don't worry, I've made the decision, I want to go into a hospice rather than be nursed at home, or I don't want to be resuscitated or whatever….'* – Nadia, patient 12

5.3.2 Emotional needs

'Need for a sense of comfort, belonging, understanding and reassurance in times of stress and upset' (Fitch 2008, p9)

Diagnosis phase

The experience of receiving a diagnosis of inoperable pancreatic cancer was described by many patients and FCs alike as a huge shock and extremely distressing, particularly as the symptoms experienced in the lead up to the diagnosis often appeared benign or explainable.

> *'…he'd been slightly ill since Christmas. Just a bit off colour ... he was still working but he did go to the doctor, and they thought it was probably a muscle issue.'* – Belinda, FC 1

> *'Also, he had, at the same time, some sort of like stomach issues... So that was playing up a little bit, but nothing too significant. So, he went to his GP as well and had some blood tests, all the blood tests came back normal, so there was no indication that anything serious was going on.'* – Mary, FC 8

For three of the patients and their FCs there was some prior suspicion or knowledge of the disease, either as the result of a recurrence of previous disease, or an instinct that something 'wasn't right.' The diagnosis was still distressing but not necessarily the complete 'bolt out of the blue' experienced by others.

Most of the patients however had no prior knowledge of this particular cancer and therefore no sense that the prognosis would be so bleak.

> *'…and me son said to [Doctor 1] how long's me dad got? We're thinking he's gonna say, 'oh, couple of years, 18 months', something like that. Four to six months! You know, that was, that really did take a chunk out of me.'* – Ed, patient 5

Phoebe explained that she and her husband Oliver were initially told his diagnosis was *suspected* pancreatic cancer, until further tests were undertaken. They were therefore living in hope that the worst would not be confirmed. Phoebe described the consultation when they received confirmation of his diagnosis as being 'completely bleak,'

> *'That's when I saw Macmillan nurses, like a little card that said Macmillan nurses, and I just thought, 'Oh my God, is that where we're at?'* – Phoebe, FC 11

Oliver also felt angry that he had been back and forth to his GP multiple times and his concerns had been dismissed for so long.

> *'…and you see that there's an advert on television, if you don't feel right, you know you're not right, go and see a doctor... You know, the cancer advert, I was watching that every day just thinking, 'Jesus Christ, I've just been through all this, and no-one really listened.'* – Oliver, patient 13

Unresolved anger and regret were evident with other participants too, who felt that had they either sought help sooner, or had their concerns listened too sooner, things might have turned out differently.

Patients and FCs also reported that the setting of the diagnosis conversation, and the way the news was given, could exacerbate their distress. Two patients received their diagnosis by telephone, which was recalled as being particularly difficult by Helen.

> *'…and then the oncology nurse just phoned me up and told me I'd got cancer, pancreatic cancer, which was very abrupt and a great shock.'* – Helen, patient 8

Several other patients and FCs talked about the lack of an appropriate environment or privacy when the diagnosis was given. In Ben's case this was in an A&E cubicle, with very little privacy available, while for Christine, this was in a side room of a ward, which felt as though it had been left in a neglected state.

> *'…after waiting an hour for the Registrar to come round, that's the time they decide to drag you into what I can only describe as an empty barren room*

> *with an unmade bed and an empty desk and nothing else, to give you the news... And it's just not on.'* – Carol, FC 2

Covid restrictions also had a role to play in increasing distress at the point of diagnosis. Angela, who was hospitalised at the time she was given her diagnosis, could not have visitors due to the restrictions. She talked about her difficulties in talking to her adult children on the phone, as being in hospital and apart from them made her feel very emotional.

> *'I was having problems actually speaking to them [son and daughter]. It made me very tearful being in there. So, I tended to text them nearly all the time. I said, 'you're just going to have to put up with a text because I don't want to hear your voices.'* - Angela, Patient 1

The experience of feeling supported by HCPs at the point of diagnosis varied across the participants. A number expressed their disappointment that they did not have the opportunity after receiving the diagnosis to spend time with a HCP to help them process what had happened, particularly if their route to diagnosis had been problematic. Phoebe felt she and her husband Oliver were treated quite abruptly and left with many unanswered questions.

> *'We just got given this folder, she [CNS] sort of walked out with us, she said, 'If you've got any questions this is the number to ring me, I'm really sorry,' and that was it, and then we left. … Yeah, and we were just left with a thousand questions and no answers really.'* – Phoebe, FC 11

Treatment phase

Accepting the reality of the prognosis and the prospect of treatment were described as an emotional rollercoaster by patients and FCs alike. It was clear from interviews with patients, that their main concern was for their family more so than for themselves, and this was what was causing them the greatest sense of distress. Ben became emotional talking about the impact his illness was having on his family, with his eldest son helping with his care, and his own perceived helplessness to provide his wife with the emotional support he felt she needed.

> *'You know I feel quite bad because there's not a lot that I can do to help her... I'm still conscious that some of this happened so quickly that it's difficult to kind of, …I don't know …for any of us to take stock or think about.'* – Ben, patient 2

Patient participants talked about a range of ways in which they coped with their emotions. Helen talked about drawing on her own reserves of resilience to cope, while Angela dealt with her situation in a very matter of fact way once the shock of the diagnosis had passed. There was minimal discussion of her situation with her family, both because that was her natural coping mechanism, but also to protect her adult children. Instead, she talked about the need to keep upbeat and positive in order to support them.

> *'I suppose I feel that I have to be cheerful for them. Being older I suppose I think oh well, you know, I can manage this, I can cope with it, and as long as I'm cheerful they're cheerful.'* – Angela, Patient 1

Nadia talked about taking one day at a time and appreciating the good days.

> *'…we're just sort of bibbling along and that's brilliant, and I'm just sort of taking it one day at a time, cause you just think to yourself one day me luck's gonna run out and things are gonna change, so let's just take it as it comes.'* – Nadia, patient 12

Mary described her husband as being in denial about the situation at least initially and not wanting to talk about it, which she found particularly difficult to cope with.

> *''…it's just rubbish, because you're not gonna come out the other end, really, that's the crux of it really…he's found it really, really, tough; … [Patient] didn't want anybody to begin with, didn't want people to know as well to begin with…'* – Mary, FC 8

The relentless burden associated with organising and co-ordinating appointments, treatments and care was striking in the interviews, and FCs talked about feeling overwhelmed with all the responsibility at times. For Rachel, the administration of her mother's medication at the outset, felt daunting.

> *'So effectively what happened was she said to me, 'Look, you'll know when I've got to take it, I can't work this out, can you just let me… You be the guide; you tell me when I've got to take it.' So, I'm thinking 'how are we going to do this then?' Because some of this starts the minute she wakes up in the morning, and then it's all the way through the day…'* – Rachel, FC 12

But despite the demands of caring, there was little sense from the interviews with FCs that they resented the care and support they provided for the patient. Instead, FCs felt that what they were doing for the patient was entirely reasonable, given the circumstances.

Rachel explained that while she had found it exhausting to care for her mother at home in her last days, she was glad she had done so, as it had been her mother's wish to die at home. She also felt a responsibility to take care of her mother, whatever the circumstances, because of a promise she had made her father many years earlier.

> *'I think when my dad died, and it's a silly thing, isn't it, but I always… He always said to me, 'Will you look after mum? If something happens to mum will you look after her?' So, I always felt I should do that. So, it's one of those things that you sort of carry with you.'* – Rachel, FC 12

Naomi described the experience of looking after her mother as being a privilege and rewarding even though it had also been extremely challenging, both physically and emotionally.

FCs talked about spending time with other family members and friends, to distract themselves from their role as a FC. Lara also talked about her full-time university course as a helpful distraction while Daniel focused on work to provide an antidote to the stresses of being a FC.

> *'…one of the things that I can sort of separate myself from the stresses and strains of home is going into the office, and I've probably done that more. …certainly, when Delia was in hospital I was going in every day, because I didn't want to sit at home alone.'* – Daniel, FC 3

Phoebe used hobbies and crafting to help her disengage from the realities of her situation and used social media postings on her and her husband's experience as a means of coping with the situation.

> *'I was just posting things that had happened to us or that we'd learnt about, just in the hope that it might help someone else, … now I know that it's actually helping people, and it helps, it does help me, it really does help me to write it all down…'* – Phoebe, FC 11

Hopelessness and hope

Seemingly small events or occurrences could make a significant difference to how people felt about their situation. A few participants talked about conversations with their consultants which they felt were rather brutal and left them feeling very low.

> *'I know they're very hardened to talking to people that are coming to the end of their life, but I did sort of feel, you know, perhaps I'm wrong, but I did get a feel from him, not that I was complaining, but you know, 'you're 71, you've had life, you know, this is what you've got left sort of thing! It did sort of down you a little…'* – Ed, patient 5

> *'I mean every time he speaks to this consultant, every little gram of hope he's got is sucked out of him. He feels worse by seeing the consultant than better, because this consultant's just talking about, 'oh, we'll keep you comfortable, oh, you know, it's like there's no hope there.'* – Phoebe, FC 11

Phoebe’s husband Oliver also experienced a particularly difficult set of circumstances when he was consented to take part in a clinical trial only to be subsequently told he couldn’t participate, due to a change in his clinical status.

> *‘It’s like they’re lifting my, giving me…hope, and then dashing it again. That’s twice that’s happened…’* – Oliver, patient 13

Labib also had a particularly stressful experience as he was initially told he could have curative surgery and had gone through all the necessary consent paperwork and pre-op assessment. However, when a scan showed the cancer had spread, the surgical option was no longer viable and instead he was offered chemotherapy with the hope that it would shrink his tumour. Labib and his family remained hopeful however that he would eventually be eligible for surgery, and indeed this was the case. Whatever the surgical outcome would prove to be longer term, Labib’s son and FC, Nazim, felt that at least as a family, they had done everything they could for their father.

> *‘But I think just at least getting to this phase is I think a big cognitive, like subconscious win, at least he’s had the option to say that we’ve at least done everything we could together as a family, ...’* – Nazim, FC 9

For patients receiving palliative chemotherapy, the build up to scans and consultations to see whether the treatment was keeping the cancer at bay were times of heightened emotion, as Mary explained.

> *'Now that's the meeting when he will see the scan and the blood test and things, and it will tell him whether the chemo is holding back the cancer or not, so that's a big crucial meeting.'* – Mary, FC 8

Frank talked about receiving the good news that his cancer markers had dramatically reduced while he and his wife were on holiday, while Nadia explained how she was delighted when her most recent MRI scan had indicated the tumour had not progressed and that she could go away on holiday with her family. A few participants, including Nadia and Keith, talked about feeling hopeful about their situation.

> *'…this is gonna sound a bit mad, but given the circumstances I'm still feeling quite positive, which sounds a bit stupid really…But I'm very much a cup half full kind of person, and I'm very much a case of I won't be beaten until I'm beaten...'* – Nadia, patient 12

> *'And if anything, over four sessions of chemo so far it has eased things, whether that's psychological or not I don't know, but it certainly feels as if the pain is subsiding, and that in my mind equates to the growth of the cancer being arrested or stopped, I would hope.'* – Keith, patient 9

For Angela, feeling almost back to normal after finishing her chemotherapy treatment and having her hair start to grow back, gave her a big boost emotionally.

> *'…and also, my hair has started to grow back, of course because I haven't had any chemo for a while. That's made me feel much, much, better.'* – Angela, Patient 1

Other participants felt less hopeful. Daniel, for example, talked about preparing himself for bereavement.

> *'…and understanding I don't have much time left with my wife, and there's part of the beginnings of bereavement process and trying to say prepare yourself...'* – Daniel, FC 3

Managing the emotional fall-out

Several FCs talked about the effort of trying to manage their family member's emotional needs, as well as their own. Mary talked about supporting her husband to organise activities that would give him a boost, while Phoebe felt she was constantly trying to be positive and raise her partner Oliver's spirits, particularly after appointments with his consultant.

> *'I mean we joke and say he's like a death eater, it's just you walk in and it's like…all the hope's gone, and then it takes me forever to try and boost him back up, because obviously he's just like 'Well that's it then, they've written me off.'* – Phoebe, FC 11

Other FCs described managing their family members' anxiety, sometimes by finding out information about their treatment to reassure them, or in Rachel's case, maintaining the false impression that her mother's illness was not as serious as it was, in order to keep her mother from worrying about it.

> *'And if I'm honest I took part in that delusion, because I did not want… I didn't want her worrying about it… It's very exhausting, because what you're*

> *doing is you're giving them a sense of everything is normal as best it can be.'* – Rachel, FC 12

Conversely, other participants talked about being open and honest with each other and talking things through, as well as being open with their wider social circle.

> *'…right from the outset, from the initial diagnosis, we spoke quite freely and openly about how are we going to deal with this and have said that we want to speak to as many people as possible, tell as many people as possible, be really open.'* – Katrina, FC 6

For a couple of the adult child FCs, coping with their parent's emotions became particularly challenging at times. Carol's mother became very withdrawn and uncommunicative, spending lengthy periods of time in bed in the last weeks of life.

> *'… she wouldn't even speak, she kept turning over, if she did speak she just said leave me alone…'* – Carol, FC 2

Not realising that her mother was nearing the end of her life, Carol tried to cajole her mother into getting up and dressed and trying to get her to eat and drink, but to little avail. This attempt to rally her mother took its toll on Carol emotionally.

Delay and uncertainty

The gap between a diagnosis and seeing a specialist or starting treatment was a stressful time and patients and FCs talked about feeling 'in limbo' during these uncertain periods. For Phoebe and Oliver, the gap between seeing a specialist initially and then seeing an oncologist to discuss chemotherapy was stressful, as they were left without knowing if they should be doing something themselves.

> *'… nothing seemed to be happening, I was quite concerned, I wasn't really sure whether we should be doing stuff, what we should be doing,...'* – Phoebe, FC 11

Belinda also expressed her anxiety about waiting for her husband Ben to see an oncologist as he seemed to be deteriorating quickly.

> *'…it was quite stressful at the time because he was getting worse quite rapidly... And then it actually took probably three weeks, so during that time I was phoning quite a lot of people just to try and get him seen a bit earlier.'* – Belinda, FC 1

Felicity felt great uncertainty about what lay ahead for her and her husband Frank, and she felt ill equipped to support him.

> *'… all the way through there's never been …an explanation, not for Frank of how it's going to affect him, and also for me as his carer - what that's gonna mean for me to ensure that I'm giving him the best care.'* – Felicity, FC 4

Interactions with healthcare environment and healthcare professionals

The healthcare environment itself caused some participants emotional anxiety. Carol explained how she felt physically sick after taking her mother for her first chemotherapy session and seeing the busy unit.

> *'First couple of times you walk in there it's a pretty scary…I felt quite sick actually when I first came out...'* – Carol, FC 2

As well as the physical environment being a potential cause of anxiety for participants, interactions with the healthcare system, and in some cases, individual HCPs were also occasionally upsetting. A few participants were negatively affected when things didn't go according to plan with care or treatment.

For example, Carol and Mary both raised issues with the running of chemotherapy sessions which they felt caused unnecessary distress and inconvenience to their mother and husband, respectively.

> *'…when Mum went up for her first treatment, … it wasn't clear … whether Mum should have a 100% infusion or 80%, … We sat there for about three hours …they couldn't find her [the oncologist] and they couldn't then work out whether she should or shouldn't have it, so we didn't have it. So, we went all the way up to the (hospital's name), Mum had sat there for three hours and never had any treatment.'* – Carol, FC 2

> *'… [Patient] had already waited an hour, and then the nurse said sadly it [chemotherapy drugs] wasn't ready and it was going to be another hour, … So [Patient] said, 'I just can't face it', cause he was just a bit low at that point, so he just left hospital and didn't have it, which was a bit sad...it's rubbish, you know, to have blips like that is not good'* - Mary, FC 8

In some instances, the coordination of treatments or other interventions, or obtaining medication were viewed as unnecessarily frustrating.

> *'…then when we needed more of them [CREON®] mum phoned the doctor, doctor said 'you need to go to hospital', hospital said 'doctor', doctor' back to hospital again', and then the hospital prescribed them again, so everything was like a bit of a fight…Which you don't need when you're dealing with what you're dealing with.'* – Joanna, FC 5

Mary talked about finding the half hour wait in a pharmacy for her husband's prescription to be a trigger for a major stress response.

> *'I was obviously having major meltdowns because I can't wait in a queue when [Patient]'s been ill, so I was completely disintegrating, so the doctors kindly bypassed the system for me, because I was sobbing! So, they just sorted it and just said don't wait in the pharmacy, because there were these queues for half an hour.'* – Mary, FC 8

Ed talked about his disappointment that his CNS was often absent when he went for his appointments, while Delia was also disappointed in what both she and her husband described as her oncologist's cold and detached manner during consultations. She was delighted at the prospect of seeing someone different, only to be disappointed when this didn't happen.

> *'So, we turned up the following week expecting to see [Doctor 2], only to discover [Doctor 2] was on holiday, … and it was [Doctor 1] again. And I was very, very, upset, having been told that it was going to be somebody else.'* – Delia, patient 4

Lara described the lack of continuity of care with her husband Mikhailo's GP practice as being stressful as they were seeing different GPs whenever they contacted the practice and had to keep re-explaining their situation. Lara also felt that a lack of continuity of care and telephone consultations contributed to Mikhailo's pain being poorly managed, and it was only when they were able to see someone face-to-face that the extent of his pain could be properly assessed.

The lack of a positive and empathetic response from HCPs was something that both Joanna and Nazim experienced when they contacted HCPs on their parent's behalf. Nazim felt he was dismissed and given 'the brush off' when he tried to contact his father's consultant for information.

> *'… to be honest reflecting back was fairly like, a fairly rude response to be honest, … And all it was, 'oh, this is a conversation that should be face-to-face, and I can't communicate over e-mail.' And it was almost like stonewalled, each and every single thing.'* – Nazim, FC 9

Joanna meanwhile was made to feel that as an inoperable patient, her mother wasn't a priority, and she became emotional recalling the experience.

> *'During one of the appointments they actually said we prioritise… Sorry, I'm gonna get upset now. We prioritise people who are curable … one nurse was lovely and was really patient and really kind, and the other nurse was just really rushed and couldn't wait to get you off the phone…. It was just really hard to feel like you're being an inconvenience when you know your mum's dying.'* – Joanna, FC 5

Daniel also recalled a bruising encounter with a ward-based HCP that had made him very upset and on the verge of tears. Covid measures were still in place at the time and while these resulted in what were seen as legitimate restrictions on visitors, the application of these restrictions could be heavy-handed. On arrival at the ward where his wife Delia had been admitted, Daniel was told that he couldn't see her as she had already had her allotted visitor for that day - the person in question having been there to discuss Delia's wishes for her funeral.

> *'a nurse … came bustling after me telling me I wasn't allowed to go and see my wife and that I had to leave…. And I found that very hard, very hard to take. There weren't any niceties, they made sure that I left, or she made sure that I left, saw me out the door... I got back in the car and drove home, almost in tears all the way home because it was really hard...'* – Daniel, FC 3

Such interactions with HCPs left both patients and FCs feeling frustrated, demoralised, and belittled at times.

After her mother died, Joanna decided to make a formal complaint about the poor care her mother had received while an inpatient but had found this process stressful.

> *'…they said they need proof that I am mum's… What did they say? I need to see evidence that I'm mum's, my mum's legal representative. …they said that they need a will or something,...'* – Joanna, FC 5

This final frustration for Joanna after her mother had died, seemed particularly harsh to her.

Palliative care and end of life phase

FCs were generally unprepared emotionally for the speed at which their family members deteriorated, in some cases moving from the diagnosis stage to EoL in a very short space of time, as was the case with Ben, and Joanna's mother, who both died within four months of diagnosis. A few FCs felt their family member was initially doing quite well with treatment but then declined quickly as the result of something unexpected. Carol felt her mother, Christine, deteriorated rapidly after experiencing sepsis and having a third replacement stent.

> *'… I think it just gave the blimming disease a chance to get hold I guess, because she was already obviously very weak and then had had the chemo.'* – Carol, FC 2

Carol felt that her mother fell into a gap when it came to getting appropriate input from palliative care services, partly because she didn't recognise her mother was dying but also because no-one else had suggested a referral. She felt this was down to the lack of continuity of care her mother experienced, seeing a different doctor each time.

> *'We sort of knew there was a palliative care team, but we didn't know we were at that point, you know…'* – Carol, FC 2

Both Joanna's and Naomi's mother's rapid decline came as the result of obstructions caused either by the tumour in the pancreas growing or by the cancer invading into other structures. Again, they felt unprepared to face their respective mothers' death.

5.3.3 Social needs

'Needs related to family relationships, community acceptance and involvement in relationships' (Fitch, 2008, p9)

A main concern for both patients and FCs was the impact on other family members and friends, and in particular, concern for any children they had. Lara talked about giving their children (between 3 and 16 years old) minimal information about their father's illness so as not to distress them. But even when a patient's child was an adult, this did not lessen their concern for them. Angela, Helen and Felicity all spoke about being preoccupied with the emotional needs of their adult children.

> *'I'm trying to be strong about it all, and I'm trying to support both of our sons who're finding it difficult, they aren't talking about it really, either of them, I think they're both in a bit of denial.'* – Felicity, FC 4

Mary described going away on a planned holiday with her daughter and son-in-law while her husband was waiting for a diagnosis and trying to keep everything that was happening a secret from them during that time.

> *'… if I'd said that I wasn't gonna go then [Daughter] would have guessed that something was wrong, and we didn't want to spoil their holiday because it would have been dreadful.'* – Mary, FC 8

Daniel recalled that his most pressing thought when his wife received her diagnosis was how they were going to tell their two sons, one in their late teens and one in their early twenties. Rather than address the reality of Delia's prognosis with them in terms of timescales, they had instead spoken about it 'not being good.'

The reaction of close family members to their illness could be a cause of concern or tension for patients and FCs. Delia talked about her brother’s reaction to her illness and how he was struggling to cope emotionally, while Oliver felt let down by his brother’s response and lack of engagement.

> *‘I just want to shake him, but I can’t, I just think if the shoe was on the other foot, which it was, because he had to have scan and various things, the very next day I phoned him, like how did you get on? … and I’ve got no expectation on him whatsoever now, and that’s the only way I can cope with him.’* – Oliver, patient 13

Phoebe meanwhile talked about feeling awkward socialising with casual friends that she had made through her young daughter, as she felt she didn’t want to become emotional and make the encounter difficult for others. She also felt that she needed to moderate her behaviour with her closer friends to ensure she didn’t demand too much of them emotionally.

> ‘*When things were really bad I was messaging them all the time, and I know that that becomes quite exhausting for them as well, so I try not to wear them out!’* – Phoebe, FC 11

Whatever the response of close family and friends to their illness, patients also talked about the importance of their family and friendship circles to help them feel like they were still able to do ‘normal’ activities, like having people round for coffee, or going out for meals. Delia purposefully took the opportunity when she felt quite well before her chemotherapy started, to meet up with lots of friends and ‘to do nice things.’ After starting treatment, she still enjoyed having friends round to the house and appreciated the normality of these situations.

> *‘…and what’s been lovely is they’ve all come once and then they go, ‘oh, we had a nice time, we’ll come again!’ … because I’ve not made them all feel desperately miserable, …’* – Delia, patient 4

The patient’s physical state meant their energy could be quickly depleted if they did too much, so co-ordinating visits from friends and family became important.

> *‘…we would try to have one friend or family visitor in the day, but if I didn’t get them in before two o’clock in the afternoon mum had had enough by four, and she just wanted to close her eyes…’* – Rachel, FC 12

Ben and his wife kept a diary of visitors so they could manage when people came, and how long they stayed for.

Patients found it very frustrating not having the same reserves of energy that they once had for sociable activities such as taking part in exercise classes or going out for meals and visiting people.

> *‘…we’ve done a couple of things, went out to a local pub on Sunday, went to see some friends in [City 1] yesterday, and that drained me, I felt really drained, very tired yesterday, even just sitting in a car for an hour… So, we are still getting out a little, but nowhere near as much as I would like to.’* – Keith, patient 9

The need to still have a social life, whatever this meant to people, and whether this involved the more routine events, or celebratory occasions, was clearly important for patients. While this had to be managed carefully to avoid exhaustion, they were described as being rewarding and enriching experiences.

5.3.4 Psychological needs

'Needs related to the ability to cope with the illness experience and its consequences, including the need for optimal personal control and the need to experience positive self-esteem' (Fitch, 2008, p9)

Access to, and uptake of, psychological support was variable among patient participants. Though happy to talk about their needs, or lack of them, it didn't appear as though patients' psychological needs were explored in any depth in consultations or conversations with HCPs. In only a few cases were psychological needs assessed in a systematic way, through either the completion of an HNA or a specific tool to screen for psychological needs.

Diagnosis phase

Though other participants would have welcomed this, only Nadia reported receiving any specific psychological support to help her come to terms with her diagnosis, with counselling arranged for her by her CNS. However, she had not connected with the psychologist that she saw, and instead, had arranged alternative counselling through her workplace. Nadia felt this was an important means of being able to talk about her feelings without distressing family and friends.

> *'…there are lots of things…when you're facing what you're facing, you can't actually speak to your family or your friends, because if you do that, you put the burden on them….you can tell the counsellor and it's left at the counsellor's door and they help you sort of cope with it.'* – Nadia, patient 12

Treatment phase

Patients at one site were routinely invited to complete a psychological screening tool each time they attended for outpatient appointments. This led to support being offered to Ed who welcomed the opportunity to talk to his 'bad day nurse' on the occasions when he felt particularly low in mood. On one occasion however, when he had felt particularly depressed, Ed also contacted his GP for support with his mental health. They were unable to help and instead he was signposted to the charity Macmillan Cancer Support.

Both Ed and Oliver took up the offer of free Bupa counselling sessions sponsored by Macmillan Cancer Support, but both discontinued them after a couple of sessions. Ed felt the sessions were too general to provide any psychological benefit, while Oliver felt the scheduled time slots for sessions did not meet his need for support when he felt he needed it most.

> *'There was a time this week where I was like I don't know, I just felt like I needed to talk to someone, but I can't… and by next week, by next Wednesday I might be alright again anyway.'* – Oliver, patient 13

Joanna felt her mother was not given the right support when experiencing suicidal thoughts. Her mother was prescribed medication for anxiety, but nothing further in the way of counselling was offered, which Joanna felt was a gap in her support.

Keith had been signposted to various sources of psychological support but chose not to pursue this, feeling that he and his wife had already come to terms with the situation.

> *'So as far as our mental states are concerned, we've come to terms with what lies ahead, accept that there's very little that we can do, although we can try various things to make life a little more comfortable for both of us.'* – Keith, patient 9

Frank and Mikhailo had also been offered support but declined it, though their wives both felt they would have benefitted from some sort of psychological support. Felicity felt that Frank was reluctant to talk about his feelings because it would make him face the reality of the situation. Mikhailo talked about not needing any other support because he had his wife and family around him, but his reluctance was probably also partly due to not wanting to cause anyone any inconvenience. Both he and Lara mentioned several times that they did not want to bother people and wanted to remain as independent as possible.

Palliative care and end of life phase

While palliative care services do provide psychological support to patients and their carers, participants in this study who reported being referred to this service, did not mention psychological support. Instead, they talked about the practical and physical support offered, such as pain relief and equipment. It is not known whether this was because it was simply not an element of the support provided or because it was provided in a way that was not recognisable as being psychological support by the patient.

Christine’s oncologist requested her GP to assess her for psychological support, during the final stages of her life. But though she was assessed by the community mental health team as likely to be suffering from depression, there was no time for any service or support to be put in place before she died - a situation her daughter, Carol, felt could have been handled much better.

Other psychological needs

Generally, people did not talk a great deal about body image changes and self-image problems, except for hair loss and weight loss. Angela made a reference to how much better and how much more like herself she felt when her hair started to grow back after chemotherapy. This had been a key reason why she had been reluctant to resume some activities, such as visiting her allotment, during her treatment. Angela also talked about appearing to be ‘very skinny for her’ after losing weight.

Naomi talked about her relief that her mother had not lost her hair during treatment, as this had been her mother’s ‘crowning glory,’ and she knew its loss would have been devastating for her mother. Two male patients talked about their hair loss but joked that as they were balding anyway, further hair loss didn’t make much difference to them.

Sexual problems were not raised during interviews and the very nature of the disease meant that fear of recurrence was not a relevant topic to discuss. While a couple of people talked about experiencing ‘chemo fog’ and being forgetful, or unable to concentrate, there was no evidence of diminished cognitive ability among participants, as may happen when the disease itself directly affects cognitive function.

5.3.5 Information needs

‘Need for information to reduce confusion, anxiety and fear; to inform the person’s or family’s decision-making; and to assist in skill acquisition’ (Fitch, 2008, p9)

All the participants expressed unmet information needs on some aspects of care, at some point in the cancer trajectory.

Diagnosis phase

FCs often began information seeking activities by researching the probable cause of their family members’ initial symptoms. This was usually via the internet, either in conjunction with the patient, or independently. FCs were often the ones encouraging their family member to seek medical advice, either because their research suggested something more serious could be the cause of their symptoms, or to provide reassurance. FCs continued in their role as information gatherer, continuing to research symptoms as they changed, or worsened, and researching the implications of the kinds of tests their family member might be having and the results of these, once available.

Patients' appetites for information varied. Keith undertook lots of internet-based research with his wife, Katrina, to find out everything they could about the disease and treatment options.

> *'And I think it was around about January we started doing a lot of reading up and a lot of digging around and research on what is it that I've got, what can I do, what can we do, what help is there out there available to us, what support...'* – Keith, patient 9

While Helen meanwhile was reluctant to look up any information because she felt there was little point.

> *'…but really I don't want to, because there's no point, is there? My children did and will do, but for me there's no point, because it is what it is, I know what the prognosis is, I don't want to compound it by dwelling on it.'* – Helen, patient 8

Several patients spoke about feeling very alone and lost after their initial diagnosis, and before their first appointment with a specialist, mainly because they did not know who to contact if they had any questions or needed advice. Daniel felt he and Delia weren't given any information from the gastroenterologist who gave her the diagnosis, about what to expect, or what would happen next. They were simply told that they would get an oncology clinic letter and they were only provided with contact details for the gastroenterologist's secretary.

Even when patients were given the contact details for a CNS before they saw a specialist to discuss treatment, patients reported that they were often hard to get hold of, so patients still felt uncertain about what was happening and what they should do.

> *'And then he was given these nurses, these specialist nurses, as contacts…. They were nice people, but quite hard to get hold of. So lovely, but we hadn't got a clue what was going on at all, …'* Mary, FC 8

In some instances, this vacuum of information led people to access the PCUK website or the charity's helpline for information. Nazim researched the availability of clinical trials for his father, using the PCUK website, while Lara contacted the charity's Helpline to ask for advice on pain management for her husband.

Though patients and FCs talked about finding PCUK's resources and support helpful, few patients were given PCUK-branded information at any point. Most of the leaflets in the packs provided by the CNS, at some point after diagnosis, appeared to be Macmillan Cancer Support-branded, or locally produced, and not necessarily pancreatic cancer specific.

While most patients talked about receiving this information pack, it was not always considered helpful. Keith thought that in general there was so much printed and online material, that there was almost too much to take in and he would have preferred something more concise and visual like an infographic or diagram or a 'blueprint'.

> *'You know, you get diagnosed with terminal cancer, X is gonna happen, you're gonna go through chemotherapy, this is gonna happen, this is what chemotherapy means.'* – Keith, patient 9

Some patients like Christine, and her daughter Carol, were able to spend time with a CNS to go through all the information and to ask whatever questions they wanted, while others like Oliver, did not seem to have the same opportunity.

> '*And that's where I think I feel a bit let down, is that no-one's, like you say you get the diagnosis and then a month later, six weeks later you've got a million different questions because you have to do your homework on the disease…'* – Oliver, patient 13

Most patients and FCs seemed to be aware of their local Macmillan Cancer Support hub, with many stating that they would go to the hub if they felt they needed any non-clinical advice or support. These information 'hubs' or 'pods' are ubiquitous features of many hospital sites, providing a space for people to talk to advisors, or to browse information leaflets and other resources. Those who had access locally to a Maggie's Centre[6] indicated they would also access this if they needed information or advice or support.

Treatment phase

Several FCs raised the issue of managing their family members' medication or supporting them with it. They felt they were being expected to take on this role with little to no information to tell them how to do it properly.

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[6] Maggie's is a charity that provides free expert care and support for people affected by cancer in centres across the UK and online.

> *'And actually, the first day when he came home after his first chemo, again cause I couldn't be there, he had this bag of medication, but he had no idea when he was supposed to take it, how he was supposed to take it. I ended up googling the names of all the different medication to work out what it all was and how he was supposed to have it. I mean it was just, it was diabolical, it really was.'* – Phoebe, FC 11

Patients also noted information needs regarding their chemotherapy treatment, either in relation to what to expect generally, or what potential side effects they might experience. Ed was given a leaflet about having chemotherapy, but as a less confident reader, he would have preferred a conversation with an HCP about what to expect and potential side effects.

Phoebe undertook some research on Oliver's behalf about what to expect when he went for his chemotherapy treatment, and both Oliver and Carol talked about the importance of an orientation visit to the unit to help prepare. Oliver didn't get this opportunity but would have appreciated it while Carol asked specifically for her mother to be shown the chemotherapy suite before her first treatment.

> *'…We had to ask for it because I know what Mum's like, when Mum can see where she's got to go and what she's got to do, I think some of the fear and worry goes. So, Mum knew what that room looked like and how people were sat because that can be very scary.'* – Carol, FC 2

Patients and FCs also felt that the information given to them by their oncologist was sometimes vague or open to interpretation. The consultant's letter to Christine referred to an ‘induction’ course only which Christine took to mean a short course. Carol wondered if this was done deliberately so as not to raise any anxieties about how long treatment might last, which might put people off starting chemotherapy.

Both Delia and Oliver felt they weren’t given enough information about the benefits of chemotherapy and the trade off in terms of toxicities and side effects and how these might relate to them individually. Oliver felt that had he been given more information about neuropathy as a potential side effect of chemotherapy, and the fact that it could be permanent, he might have thought more about the pros and cons of continuing his treatment for as long as he had.

> *‘I was never informed that the neuropathy you start to suffer at the end of, coming to the end of the chemo, could be permanent … On a cold day I have a job to walk now. One of my legs is quite numb from the knee down. … it’s like so much about it I’m ignorant, and if I was a bit wiser it’s like well would I have gone with the last two or three treatments?’* – Oliver, patient 13

Angela wasn’t clear what would happen following her chemotherapy treatment as she couldn’t recall that this had been explained to her.

> *‘Nobody’s told me anything and I don’t think to ask I suppose. I just assume that if it’s shrunk enough then I don’t have to have any chemo but then I presume I might have regular scans to see that it stays like that – I don’t know.’* – Angela, patient 1

Following chemotherapy, Delia wanted to know what her scans showed about her tumour's growth, but she felt getting this information out of her oncologist was unnecessarily difficult.

> *'… I said to [Doctor 1], I said you've done a scan, it was the same one, what did it show about the cancer growth? 'Oh, it wasn't looking at that,' he said. 'I said oh, but it must have shown something. Have you compared pictures?' So, I said, 'did it show exponential growth, a little growth, growth that you'd expect, less growth than you'd expect?'* Delia, patient 4

The extent to which patients wanted to know their likely prognosis once it was clearer how they were responding to treatment was highly individual. Some patients, like Delia, were keen to know more than she was told. Frank and Keith both wanted a clearer idea of their prognosis to be able to plan ahead, as far as possible and arrange things to look forward to with other members of the family.

Navigating the health and social care system

Navigating the health and care system and knowing who to contact, when, and what for, caused some anxieties and confusion for patients and FCs. Angela talked about not knowing 'the hierarchy' of services, and what might be appropriate depending on the situation, while Frank and his wife Felicity thought their first point of contact would always be Frank's CNS, though they also confessed that they didn't really know what her remit was and if this was the right thing to do.

> *'… there's no first point of call, if that makes any sense. … So I rung her [CNS] yesterday, but you think well that's really not her remit, …you'd have*

> *thought there'd be something somewhere where there's a centre point that can direct or nudge like the doctors or somebody else …I've got high blood sugars but I can't get anywhere to get any answer.'* – Frank, patient 6

Phoebe mentioned the confusion she had experienced trying to work out who to contact when Oliver experienced side effects from chemotherapy. Though she had been given a card with a number to call in an emergency, she wasn't sure what constituted an emergency.

> *'I didn't know what to do, I didn't know if that was an emergency or not, and so I didn't ring the number ...And then as it turned out it doesn't have to be very bad at all, that's just somebody there to give you advice and guidance, and it's a 24-hour line…'* – Phoebe, FC 11

Phoebe also made the point that it wasn't always obvious when they needed to reach out to a professional because she and Oliver would try to figure things out for themselves, especially in a context when they felt HCPs would not be available.

> *'And I'm so sick of hearing that, 'you know where we are', because actually at two o'clock in the morning, 'where are you when we really need you?'! …it kind of makes a mockery of all the adverts that you see on the telly about 'you'll never be alone', cause you bloody are!'* – Phoebe, FC 11

Mikhailo and his wife Lara were new to the UK, and the NHS, and didn't know what the role of their GP was, nor how to go about getting a referral to a specialist HPB dietician which they felt would have been beneficial. Navigating the community palliative care system, with a limited understanding of the different support the service offered, was also confusing and stressful for Lara. Using an automated telephone enquiry line was challenging when she did not understand what was meant by the options available.

> *'I called … the palliative care hub … you have like, when you called you have four options, …when I call I don't know what options, …First time I tapped the second button, and then to contact somebody, she said, 'Oh no, you're not in the right address, I will give you a phone number.'* – Lara, FC 7

This lack of knowledge and understanding about who to contact, in what circumstances, was a common theme among patients and FCs and was often a source of stress, even for those who were familiar with the UK health system.

Palliative care and end of life phase

Though a difficult concept to think about, Delia talked about wanting more information on what to expect physically as she neared EoL as she had found what information she had received rather unsatisfactory.

> *'…and one of my questions has been, 'how will I know things are getting worse?…I know that everyone varies, but there must be some kinds of trends … all I seem to be able to get out of people is that you will get more tired, and that you will just find yourself sleeping rather a lot more, and wanting to do less.'* – Delia, patient 4

The need to be prepared for dying was also expressed by other participants, though more often the FC indicated they wanted this information, rather than the patient.

Carol described the sense of responsibility she felt in being constantly alert to her mother's condition and that this was particularly difficult to navigate without any real understanding of what to expect as her mother drew towards EoL. Rachel also talked about her lack of understanding of the progression of the disease and the likely physical consequences of this for her mother.

> *'I think if I'd had that kind of opportunity for someone to talk me through what was likely to happen, or a little bit of a storyline, … you know, this is the kind of pathway that's gonna kind of fall out in front of you, don't worry too much about this, don't worry too much about that, it would have just been really helpful.'* – Rachel, FC 12

5.3.6 Spiritual needs

'Needs related to the meaning and purpose in life and to practice religious beliefs' (Fitch, 2008, p9)

The search for meaning and the expression of existential concerns were not apparent in the interviews. Nor did people articulate any sense of having a spiritual crisis or resolution – all spiritual needs suggested within Fitch's framework (2008). A few participants did talk about re-evaluating personal values and priorities; and making memories with family members, was an important activity for people to do. This involved spending time with family and friends, having trips out, going on holiday, or doing special things, like renewing wedding vows, or celebrating family birthdays. Christine's daughter Carol, talked about the heroic effort her mother made to celebrate her father's birthday when she was nearing the end of life.

> *'…now mum got up …, and got dressed, did her hair, put her makeup on, looked really, really lovely, it's the last photographs we've got of her, and we drove to [Location 1] and she walked from the car park all the way along the riverfront to…this restaurant where we had an afternoon tea, … and then we went on a little boat ride…'* – Carol, FC 2

The subject of spiritual needs in relation to practising religious beliefs came up only a handful of times in interviews. It was referred to in passing by Delia when she mentioned having a visit from the chaplain while she was an inpatient and talking to someone about her funeral wishes.

Ed talked about his belief in spiritualism and explained that 'the sun' was his religion.

> *'(I) open the kitchen window, …say my good mornings to the sun and say to him thank you for another day, any help with the cancer would be most appreciated, and take care of my wife … and all that, and then at the end of the day I say goodnight to him and thanks very much for what he's done for me this day. That's my religion!'* – Ed, patient 5

Labib may have been referring to the 'will' of a spiritual being as regards his destiny when he said,

> *'To be honest I don't want to very much think about it that much to be honest with you, if that's what's written for me, that's what's written for me.'* – Labib, patient 10

It was not apparent from the empirical data that there were any unmet needs identified by patients or FCs in relation to spiritual needs.

5.3.7 Practical needs

'Need for direct assistance in order to accomplish a task or activity and thereby reduce the demands on the person' (Fitch, 2008, p9)

A patient's practical needs largely depended on their age, their domestic situation, and how they were affected by their cancer.

Diagnosis phase

Sorting out personal finances was generally the most pressing practical need for most patients soon after diagnosis. Participants had usually been signposted to Macmillan Cancer Support for help with claiming benefits and allowances and generally people had found this straightforward, and the financial help was very welcome. Only Mary noted that she and her husband had not been given any advice in this regard or told about what benefits they might be entitled to.

For those patients who had been in work until their diagnosis, sorting out finances also involved negotiating their entitlements from employers. For Ben, it was important that his wife, Belinda, was involved in conversations with his employers about his critical illness insurance policy and pensions, so she knew that she and their children were financially secure.

> *'…we have a kind of tame financial advisor in the company who has been dealing with me for years … so he kind of knows what needs to be done and has been very helpful around that and he's helping Belinda around that and*

> *so, I was keen to make sure that Belinda was involved in that process from the start.'* – Ben, patient 2

Treatment phase

Accompanying to appointments

FCs routinely drove or accompanied their family members to and from appointments and treatment sessions, and waited while they had their treatment, often for lengthy periods of time. They talked about the importance of being with them to provide moral support, but also mentioned the importance of them being another pair of ears at appointments to take information onboard and understand for themselves what was happening. This was not always possible however when Covid restrictions were in place, as was the case for Felicity.

> *'I mean pretty much everything at [Hospital 1] I had to leave him to go into on his own, which is really, really difficult because you don't take in fully what's being said to you.'* - Felicity, FC 4

It was also not possible for Phoebe to accompany Oliver into A&E when he experienced complications, because they had their young daughter with them.

> *'I haven't been able to go in with him because we don't have anyone to have my daughter, and each time I've gone in with her they've basically not… They've barred the door and said you can't bring her in, and so I've had to go and wait in the car.'* – Phoebe, FC 11

Though most patients were able to rely on their FC for transport, this did cause an issue for Keith as his wife didn't drive. Transportation therefore had to be arranged with the help of friends and family who lived locally.

> *'Yeah, [Katrina] doesn't drive, so that is the challenge that we currently find ourselves under, but so many people have stepped up and helped in one way or another.'* – Keith, patient 9

Mikhailo's wife, Lara, was also not able to drive. Lara had looked into arranging patient transport, but this had proved more complicated than anticipated, and Mikhailo ended up driving himself to and from his chemotherapy appointments instead. Lara and her husband were generally reluctant to ask neighbours for help. They had once had to ask neighbours to look after their children when attending a hospital appointment but had done so very reluctantly as they were determined to be as independent as possible and not cause people any bother.

Organisation and co-ordination of care

For many FCs, much time was spent making multiple phone calls to administrative and clinical staff to try and get advice or a clinical intervention. Several FCs talked about having to constantly keep chasing and pushing for a response or a specific action to happen, such as getting prescriptions filled accurately and quickly - an activity which caused considerable anxiety for some FCs. This appeared to be a persistent problem and especially affected the prescription of CREON® but also prescriptions for painkillers and other medications to relieve symptoms and treat side effects. In one instance a nurse at Frank's GP practice had forgotten to write up a prescription for medication for him, which frustrated Felicity.

> *'… it just doesn't get done in the timely manner that's expected. I just don't see why people can't just go through and do what is their job and just get it sorted, instead of me constantly having to chase.'* – Felicity, FC 4

In another instance, Mary experienced great difficulty sourcing PERT medication for her husband, as the one most commonly prescribed was not suitable for him.

> *'Nobody had it in [Town] and [City 2], I was racing around pharmacies for this gold dust tablet, and it was beyond a joke, and then it was like a bank holiday… I think I'll just block it out my mind, ... It was terrible… it was absolutely terrible.'* – Mary, FC 8

Organizing blood tests before their family member's chemotherapy sessions was another task FCs took on. Though this would usually happen quite smoothly, there were occasions when things went wrong, requiring multiple phone calls to chase people to respond, as was Katrina's experience.

> *'…So, I explained it needed to be done before the end of the week. I didn't hear anything, so I rang back, and then I took a phone call, was it yesterday? No, this morning… saying that they had no space whatsoever. .. I rang the palliative care hub and asked if she could put some pressure on the GP to get something sorted out. And that's hugely, hugely, stressful as well, you know, I was on the verge of tears...'* – Katrina, FC 6

Lara found contacting the GP to sort out her husband's pain relief extremely stressful, particularly because of language barriers and the frustration of trying to make herself understood in a crisis.

> *'…he's in pain, they started with liquid morphine, it didn't help, and then mostly it's GP, but it takes a lot of effort,… like to call, to explain, like it's really a problem for us, we're struggling with it…'* – Lara, FC 7

<u>*Day to day household chores*</u>

Only a few patients talked about their needs in relation to taking care of day-to day household chores, such as shopping, cleaning, cooking, and gardening. Older female patients like Gloria and Christine, talked about wanting to remain as independent as possible, for as long as possible, and still managed their own cleaning and gardening, at least initially. Angela was managing this largely by herself with some help from her son and was gradually doing more as she felt stronger after her chemotherapy sessions. Nadia had also relied on help from family members for shopping and cleaning but had also started to reduce her reliance on others, as she began to feel stronger after her chemotherapy ended.

For Delia however, the effect of her cancer-related fatigue, and a more rapid progression of her disease, meant that the family had engaged a cleaner and some help with the gardening earlier on in her cancer trajectory.

Male patients did not generally identify these day-to-day activities as unmet needs, perhaps because these tasks were often already undertaken by their spouse.

Sorting out equipment as their physical needs changed was another practical concern for patients and FCs. Ben and Delia arranged the use of wheelchairs so they could go out with their families.

> *'I mean we did put off getting a wheelchair really, I suppose he felt like he didn't want a wheelchair, and when we got one it was just really great, because suddenly he could go anywhere really easily!'* – Belinda, FC 1

Delia's community palliative care team also arranged for her to have a bath seat and a portable shower stall which though she wasn't using initially, she knew she might need in time.

Larger pieces of equipment like hospital beds were also required by some patients, like Gloria, so she did not have to try and get upstairs to bed in her final weeks.

Work-related issues and financial concerns

Though five of the FCs were known to be working at the time their family member was given their diagnosis, only Rachel raised employment issues as a major concern. Rachel found her employer's lack of understanding and appreciation of her situation to be extremely stressful during the few weeks she was intensively caring for her mother, and she worried about the situation constantly. Rachel's employers indicated that she could have five day's paid special leave to look after her mother but after that point she would have to take annual leave – a situation that Rachel found difficult, given the unknown trajectory of her mother's disease at that stage. Eventually, Rachel reached the point where she broke down in tears when a palliative care nurse asked her how she was coping.

> *'And I remember just thinking, 'No, I'm really not OK about everything, … I'm struggling here, I'm really struggling, I'm worried about my job, but I haven't got time to think about my job, I know my line manager's not that happy, but I can't, they're not here, they can't see what I'm going through, …' And I got upset in front of them and I cried a lot and said I really am struggling'* – Rachel, FC 12

Finances were a concern for a couple of FCs, but the stress of worrying about money was relieved once they had been able to access the benefits they and their family member were entitled to.

> *'I mean I am getting Carers Allowance now, … I didn't think that having a little bit of extra money would make that much difference, but it really has, … A lot of my worries were managing financially, but Frank since he got the Personal Independence Payment … and she helped me to do the carers, and that's taken a little bit of the financial worry away.'* – Felicity, FC 4

> *'…that has taken a huge pressure off us, because we have now got enough money to be able to go to the café and have a coffee and just kind of sit…We can do that now, we can pay all our bills. Yeah, it's huge, it's been a massive help…'* – Phoebe, FC 11

Other caring responsibilities

Other practical issues such as juggling other caring responsibilities and domestic duties caused concern for both patients and FCs. Phoebe was caring for her daughter as well as supporting her mother, while Lara was studying fulltime as well as caring for five children. Lara expressed her anxiety that with everything else she was juggling she wasn't able to give her husband the attention or environment he needed to rest.

> *'…our family, with a lot of kids, not the best place for him like to…to rest, …and I can't give him my attention a lot because of children. …he don't have a place to rest, to be quiet, a lot of noise all the time, …'* – Lara, FC 7

Rachel felt that she was neglecting her own home life as she spent increasing time at her mother's house.

> *'…the ducks and chickens were my kind of thing, and [Partner] did admirably, but he's not very good at sorting them out and stuff like that, it's not his fault, they're just not his hobby. …So, he was trying to cope with everything up here, me dashing in and out and saying, 'I'm here for half an hour, I've got to go again.' I mean food shopping and stuff was just, didn't happen really.'* - Rachel, FC 12

Naomi described feeling as though she was failing in all aspects of her life during the time of her mother's illness and felt that she wasn't doing justice to any of her roles as an employee, her mother's carer, or as a mother.

Wills and funeral plans

Thinking and talking about wills and funeral plans brought emotional challenges but several participants talked about the importance of doing this. Delia spoke about the time critical aspect of making her funeral plans.

> *'…and then I had arranged for somebody to come and discuss funerals with me, because when you've got a three to four month prognosis, you can't, …delay these conversations.'* – Delia, Patient 4

Moving from the hypothetical need to update her will, to the actual need to do so, was difficult for Gloria to think about but she knew she had to do so.

> *'…and we've had a draft done of my will, revised my will, …That's hard, looking at your will. When I was well it was easy, but now I know there's a terminal point … it's hard to broach.'* – Gloria, patient 7

Nadia had been wanting to have a conversation with her daughter and sister about her funeral wishes but each time she broached the subject, they shied away from talking about it. Eventually, a family gathering provided a natural opportunity to talk about her wishes in a positive way that enabled her daughter to accept the discussion.

> *'…we were all sitting having a drink and chatting in the living room, and it came out naturally in the conversation and we ended up having a really positive conversation and we were laughing about things and making jokes about the music I was going to have. … it was the way that we talked about it, my daughter could handle it.'* - Nadia, patient 12

Palliative care and end of life stage

Where the FC was an adult child and their other parent was still alive, looking out for the welfare of that parent became a significant stressor for some towards the end of the patient's life. Things came to a head for Carol when the hospital palliative care team suggested her mother could be discharged back home, after an admission for sepsis.

> *'… my focus did then have to change a bit to protect dad, … there was no way I could have them coming in, sticking a bed in the dining room, putting grab rails on the wall, being in four times a day, all the upset, and then when mum did pass away just going and withdrawing all that and leaving dad in the middle of all that mayhem….'* – Carol, FC 2

Rachel and Naomi, who both supported their mothers to die at home, provided a full range of personal care needs as well as managing other aspects of their mothers' care. Rachel noted how she had to steel herself to carry out some of these tasks because she was not a natural carer and found the situation very stressful.

> *'I mean I changed a colostomy bag, things I never thought I would have to do, you just do it…When they showed me the bag and how you empty it, I remember thinking, 'don't faint, you're just gonna have to do it!' Awful really, but you think I've just got to do it, I can't not do it.'* – Rachel, FC 12

For Joanna, her mother's death brought many practical issues to deal with such as helping her father sort out her mother's possessions and getting probate sorted.

> *'…because you've just got so many practical things you have to do, and obviously having dad to look after as well, and then mum's personal effects, her clothing and stuff like that all needed to be dealt with, and now we're in probate and things like that, there's been lots of practical things to do.'* – Joanna, FC 5

5.4 Impact of Covid on care

The interviews were conducted at a time when Covid restrictions were still in place to an extent. The impact of these restrictions has been referenced in previous sections above when FCs were unable to be present at appointments or treatment sessions or were restricted in visiting their family members in hospital.

In addition to this, the healthcare system's response to Covid restrictions also meant that telephone and video consultations were far more commonplace than they had ever been before the pandemic. It was clear from the interviews that patient participants had experienced telephone consultations as an alternative to face-to-face appointments with both hospital clinicians and GPs. Several of the participants talked about the difficulties and limitations of these.

> *'…she was getting a bit of acid reflux, and she had a bit of pain, so she contacted the doctor, got a telephone appointment, couldn't get a face-to-face appointment. The doctor first of all thought she had a urinary tract infection, so gave her antibiotics. That didn't clear anything up, so she went back to the doctor again, it was another telephone appointment not a face-to-face, and she was given antacid tablets.'* – Joanna, FC 5

The lack of face-to-face appointments seemed to result in two issues. Firstly, and most worryingly from a clinical safety perspective, participants felt that assessments were not always as thorough as they should have been, and the most clinically appropriate course of action was not undertaken. This was the case both in relation to the patient's initial presentation to a GP and their onward referral for a timelier diagnosis to be made; or in relation to diagnosing complications, or in relation to a patient's deterioration.

> *'…so mum, obviously she had these blockages, we didn't know she had these blockages, but she would phone them to say that she wasn't able to go to the toilet, and they gave her Movicol. … and it was always a telephone call and it was always different things to help her go to the toilet, even though they knew she had stage four pancreatic cancer… and in actual fact on the day that we got her to hospital she'd rung the doctors, again it was a telephone call, again they gave her stuff to help her relieve, you know.'* – Joanna, FC 5

The second negative aspect of telephone appointments was the type of interpersonal dynamic they introduced into the consultation and the consequences of this. Carol felt that telephone consultations did not give clinicians the same opportunity as a face-to-face consultation might have done to engage with her mother, and for them to assess how she was coping mentally. This was an aspect she found unhelpful in retrospect, as it compounded her mother's sense of denial about her disease and prognosis.

> *'If you're hiding your head in the sand anyway and a doctor says, 'well are you happy to have a phone appointment or do you want to come in person?' 'Phone appointment's fine, thank you.' Which means I can give you the minimum amount of information and then I can shut you off and get on with my day, like this isn't happening.'* – Carol, FC 2

Joanna felt that telephone consultations did not give her and her mother the time and space to ask the questions they wanted to, and to make them feel they were cared about.

> *'We kept asking to meet the oncologist … and to be able to meet someone face-to-face to go through everything… if we had an appointment where we could have sat down face-to-face and had them talk us through the whole procedure, and reacted differently to when we asked questions rather than talking over us and not letting us finish, not letting us fully ask the questions, and not making us feel rushed, not making us feel like an inconvenience, that would have been amazing.'* – Joanna, FC 5

Health service practices will have changed permanently in some regards because of arrangements made during Covid and telephone consultations are likely to be a routine feature of some service delivery. However, it's clear from the empirical data that while telephone consultations and appointments may be more convenient for all parties in some instances such as very routine check-ins, saving patients and FCs time and costs in travel, for most encounters that would occur for this cohort of patients, they are likely to be sub-optimal.

5.5 Summary of chapter

This chapter has presented the findings from interviews with 13 patients and 12 FCs, using Fitch's conceptual model of Supportive Care Needs (1994) as an architecture for presenting the data. Findings show what needs patients and FCs perceive themselves to have against Fitch's seven domains of needs: physical, emotional, social, psychological, informational, spiritual, and practical.

The data suggests that the domains of greatest need among patients are the physical and emotional domains, unsurprising, given the physical complexities of the disease and heavy symptom burden, and the shock and distress of the diagnosis and prognosis. The information needs domain was also important however, with people's needs for advice and support often not being met.

Findings from FC interviews emphasised the extreme stress people experienced because of their family member's diagnosis and illness. The findings also highlight the relentless nature of the FC role, supporting their family member and helping to co-ordinate their care, while in many cases, continuing to combine this with existing responsibilities and commitments.

There were observable differences in the nature of the data gathered from separate interviews with FCs and those from joint interviews with patients and FCs. Separate interviews with FCs tended to be more emotional and were sometimes upsetting. The focus of the interview was more often on the FC themselves rather than the patient and the FC's reflections were perhaps on a deeper level than in joint interviews. This was particularly apparent when the FC was talking about the likelihood of the patient dying and in those cases where the patient had already died, the manner of their death.

The personal implications of their family member's diagnosis were understandably different between spousal FCs and adult child FCs. Spousal FCs were faced with the implications of facing the future on their own, while adult child FCs were faced with making other adjustments and taking on new roles and responsibilities, in some cases caring for a surviving parent.

Issues were also raised relating to people’s overall care experience. In particular, care coordination and empathetic and compassionate communication were highlighted as sometimes lacking. These deficits impacted negatively in a range of ways on both patients and FCs.

Chapter 6 – Healthcare professional findings

'…with the heavier burden of disease, that's a very, very narrow window to treat them.'

6.1 Introduction

This chapter sets out the findings from interviews with 24 HCPs. The interviews were conducted in order to explore the perceived barriers and challenges to providing optimal care and support for people with inoperable pancreatic cancer and their FCs, providing important contextual data for the case study. HCPs were interviewed between May 2022 and June 2023. On average interviews lasted 39 mins (range 27 mins -57 mins). Ten of the interviews were conducted by Zoom video call and 14 by phone.

Participants were recruited from five NHS sites, third sector organisations, and three GP practices. Participants were from a broad range of clinical backgrounds as follows: CNS (4), palliative care nurses (4), specialist nurses employed by PCUK (3), oncologists (3), GPs (3), specialist HPB dieticians (2), palliative care consultant (1), diagnostic radiographer (1), acute oncology nurse (1), psycho-oncology care manager (1) and an Information Services Manager employed by Macmillan Cancer Support – See Table 7 below for details.

The chapter has been structured according to the domains represented in Fitch's Framework (1994), so that it can be read as a 'response' to the findings set out in the previous chapter.

Table 7. Breakdown of HCPs participants by pseudonym and profession

Participant ID	**Name**	**Job title**
HCP1	Anna	PCUK specialist nurse
HCP2	Bryony	PCUK specialist nurse
HCP3	Caroline	Oncologist
HCP4	Denise	PCUK specialist nurse
HCP5	Erin	CNS
HCP6	Fiona	CNS
HCP7	Georgina	Specialist HPB dietician
HCP8	Harriet	Diagnostic radiographer
HCP9	Isabel	Acute oncology nurse
HCP10	Jemima	Palliative care nurse
HCP11	Kathryn	Specialist HPB dietician
HCP12	Laura	Psycho-oncology care manager
HCP13	Melanie	Hospital-based palliative care nurse
HCP14	Natalie	Macmillan Cancer Information services and support manager
HCP15	Orla	Community palliative care nurse
HCP16	Patricia	Community palliative care nurse
HCP17	Paula	Oncologist
HCP18	Rebecca	CNS
HCP19	Simon	Palliative care consultant
HCP20	Tania	CNS

Participant ID	Name	Job title
HCP21	Tom	Oncologist
HCP22	Valerie	GP
HCP23	Wendy	GP
HCP24	Yolanda	GP

6.2 Addressing physical needs

Diagnosis phase

Several HCPs commented on the various routes that patients might take on their way to a diagnosis and how this could lead to a range of difficulties for patients and HCPs. These difficulties included patients being without specialist support for a period, and non-specialist HCPs having to break ‘bad news’ to people, for which they might feel ill equipped.

Patients referred on a Two Week Wait (2WW) pathway specifically for pancreatic cancer would be allocated to an appropriate clinic and told the result of their CT scan at that clinic appointment. Different terms might be used to tell patients these results. For example, they may be told that they had a suspected cancer, or a ‘mass’ or tumour had been detected on the CT. However, a definitive diagnosis of pancreatic cancer would not be given until the patient had a biopsy and these results were available. HCPs noted that when a patient was given their CT scan results, before a biopsy result was available, it was probable that they would be provided with the contact details for the relevant CNS team, but this did not always happen. This led in some cases to patients being without specialist support for some weeks until their case was discussed at an MDT meeting, and they were formally allocated to a CNS.

A pathway for suspected cancers of unknown origin, known as the SCAN (Suspected Cancer) pathway, was in place at a few of the sites included in the study. Harriet, a diagnostic radiographer, advised that pancreatic cancer was the second most common cancer diagnosed, after lung cancer, through the SCAN pathway at her site. When a CT scan and blood tests showed the strong likelihood of pancreatic cancer, patients at this site might be referred straight to the organ site specific CNS team, before a biopsy confirmed the diagnosis. Otherwise, where the CT and blood test results were less conclusive, the patient would be told of a likely cancer diagnosis but advised that a biopsy would be undertaken for confirmation. In these circumstances, the patient would be given the contact details of the SCAN team, to raise any queries, in advance of their first appointment with a specialist doctor.

HCPs also noted the high proportion of patients who were diagnosed through routes such as A&E, or Medical Assessment Units (see Chapter 1). HCPs suggested that patients diagnosed through these routes were often receiving ‘bad news’ either from clinicians who were not cancer specialists, or in follow-up phone calls. Isabel, an acute oncology nurse[7], described a not uncommon scenario at her site, whereby a patient who attended A&E or the ambulatory assessment unit over the

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[7] An acute oncology service supports cancer patients admitted to hospital with complications of their cancer, side effects of their cancer treatment or with an unexpected new diagnosis of cancer.

weekend, would be flagged to her team on the Monday morning. The team would then need to follow up by phone. She explained this was often a difficult conversation to manage.

> *'…over the phone is awful really – we all sort of fight not to do those ones. …usually if they go home without seeing us, the medical staff are supposed to tell them but sometimes they don't, so you, you have to tread so carefully and find out what they've been told. And …people don't always take it on what they've been told anyway, on the first time they've been told it. So, you're probably having to say things again anyway and that's quite difficult, so yeah, it's not ideal for the individual either.'* – Isabel - HCP 9, acute oncology nurse

Isabel noted that in this scenario, the patient would be given the contact details for a member of the acute oncology team until their case was discussed at an MDT meeting when an organ specific CNS would be allocated to them.

Several HCPs mentioned the inflexibility of MDTs which were routinely scheduled on a weekly basis, potentially delaying discussion of new patients' cases and further diagnostic tests.

> *'… it would be so amazing if those clinicians could contact (CNS name) team and say to them, 'Look, I have this patient…I've given them a diagnosis, can you give them a ring before they see an oncologist?' … Because what happens is I don't hear about these patients until they get to the MDT so that could be a delay of another week, or even two weeks and then by the*

> *time I see the patient after the MDT, it's another week… I just feel that the nurses could pick these patients up ... And I just feel that in our service anyway, that's a real gap.'* - Caroline - HCP 3, Consultant Oncologist

The specific role of a CNS working with this cohort of patients varied between organisations. Each organisation had its own working arrangements depending on whether it was a specialist unit, or a DGH, the composition of the CNS team, inpatient activity, and the clinic schedule. Upper GI CNS, Fiona, noted that the ad hoc nature of where patients came into the system meant that CNSs were often attending a range of clinics.

> *'So, we go wherever we're needed to go to support patients having a new diagnosis. But that can be with gastroenterologists, that can be with some of the Upper GI surgeons, it just depends, you know, which clinic the patients are put into.'* – Fiona - HCP6, CNS

Variation between sites was also apparent with regards to when a CNS would be in contact with a newly diagnosed patient. Denise, a specialist nurse working for PCUK felt strongly that patients should routinely be followed up by a CNS the day following their diagnosis to see how they were feeling, make sure they understood what was going to happen next, and be available to answer any questions the patient might have at that point. Her experience from talking to patients who contacted the helpline was that this wasn't happening. Indeed, a CNS from one of the participating NHS sites, noted that her unit's practice was to phone every new patient a week after their first appointment with the oncologist, for a follow-up call.

The point at which a patient is provided with the details of an organ specific CNS for support and the point at which that CNS contacts the patient directly can therefore vary according to pathway, extent of disease, and individual organisational and professional practice. This variation in practice could potentially leave some patients feeling isolated without that immediate support.

Treatment phase

Treatment options are limited for people with inoperable pancreatic cancer and HCPs noted that this was a difficult conversation to have with patients, many of whom might have unrealistic expectations about what's possible, based on their knowledge of how cancer survival rates have improved for many other types of cancer.

> *'…it's about symptom management and disease control. That's always really disappointing – it's like, everyone talks about all the work that's been done in cancer, all the progress that things have made, the survival rates for cancer… for these pancreatic patients, for lots of them, it's like 'Oh, but cancer survival rates are brilliant nowadays,' and it's true but they've got the wrong cancer!'* – Harriet - HCP8, Diagnostic Radiographer

Health Needs Assessments

HCPs talked about the heavy symptom burden for patients with inoperable pancreatic cancer and how the HNA process is a means by which patients can highlight their concerns and symptoms. The process usually consists of three parts: a questionnaire or checklist for patients to complete, a guided discussion between the patient and an HCP, usually a CNS, and a resulting Personalised Care and Support Plan to help address the patient's concerns. The process which encompasses all cancer patients, is entirely optional.

Though an HNA can be a particularly useful means of prioritising patients’ needs, helping HCPs to focus their support on what is most important to patients, several HCPs felt that undertaking HNAs for inoperable pancreatic cancer patients was challenging. In part this was due to their own time constraints but also to the often rapidly changing circumstances of the individual, which meant that even if an HNA had been completed, it could quickly become out of date. CNS, Rebecca, reported that few of her inoperable patients ended up completing the process because their rapid deterioration meant there was little opportunity to do so.

> *‘Often for our group of patients…particularly the ones that are in the supportive care, palliative care category, they can often deteriorate quite quickly and may well not come back to the hospital again, not after we’ve met them only the one time, and so we have a much lower take-up with that group.’* – Rebecca - HCP18, CNS

There were differences in opinion among CNSs as to when the optimal time was for the initial HNA to be undertaken. Fiona explained that although she tried to do one for every patient after their diagnosis had been confirmed, she wasn’t sure this was the best time.

> *'I think, for me, the initial HNA isn’t always that helpful because everything is very fraught and there isn’t necessarily a robust plan.'* – Fiona - HCP6, CNS

Tania was also trying to work out the best time to undertake an HNA with patients.

> *'I'm trying to work out when's best to do it, because the new patient clinics can be a lot of information overload, so I don't necessarily think it's the right point to do it then. But especially with the patients that aren't fit for chemotherapy, their follow-up can be weeks later, so it's trying to work out when's best to do it with them.'* – Tania - HCP 20, CNS

Erin tried to undertake the HNA process within 2-3 weeks of meeting new patients but recognised that this was not always happening due to CNS workloads. She also felt her team could use the HNAs more effectively and be more proactive in meeting patient needs.

> *'…we will try to complete it within two to three weeks…. The reality is, that doesn't always happen because of staffing levels and work pressures, it can just sort of go on the back burner sometimes. I feel that they can be a bit of a tick box exercise in terms of, we are just asking the patients about, you know, what their concerns are. Other cancer teams run health and wellbeing events and have partner support groups.'*– Erin - HCP 5, CNS

The view among CNSs seemed to be that it was helpful to attempt to undertake the process as soon as possible, as patients were likely to have concerns that needed addressing. They also felt that the process could help to make the patients feel better supported.

Dietetics/nutritional support

HCPs talked at some length about the challenges of managing patients' nutrition with PERT. In three of the sites included in the study, a specialist HPB dietician was embedded into the CNS team, providing specialist advice to patients, and colleagues. In these sites, the CNS and dietician could discuss any patients requiring specialist dietary support with ease and make joint visits to see inpatients, with the intention of avoiding any unnecessary delays in getting people the support they needed.

Georgina, one of these specialist dieticians, explained how she also routinely attended the patient's first appointment with their oncologist, and any follow up appointments if they needed regular input.

> *'…I get asked to speak to patients about how they are actually taking it [PERT] and if they're taking it correctly because often patients do get prescribed it but not actually given information as to how it works, how to take it, how to adjust the dose.'* - Georgina - HCP 7, Specialist Dietician

Georgina mentioned her initial discomfort in being party to the often difficult conversations between oncologist and patient but had subsequently realised how beneficial her involvement was at that point, for continuity of care.

> *'…obviously, it's a very, very emotional time for them …and me being involved in that felt wrong in a way, but over time, I've come to realise that it's important to build that rapport with a patient … so you can then support them in an effective way … And you know, not having to go over what*

> *symptoms they’ve got, you know, when they have already gone over that with the oncologist.’* – Georgina - HCP 7, Specialist Dietician

Other HCPs talked about the importance of ‘rescuing’ people nutritionally, as stabilising a patient’s weight was the priority for most patients, to allow palliative or neo-adjuvant chemotherapy to commence as quickly as possible.

> *‘…being able to try and stop that sort of domino effect happening really, the intervention at the right point is so key to rescue those people, that they don’t inevitably just lose all the options for treatment because of nutritional failure essentially.’* – Rebecca - HCP18, CNS

Rebecca, noted that they had seen a difference in the number of their patients they could stabilise and get fit for treatment, at her site (a specialist centre) since embedding a full-time specialist HPB dietician within the CNS team. Rebecca’s team was also trying to forge closer links with the DGHs in their area, where there might not be specialist dietetic support, to encourage colleagues to get their pancreatic patients started on PERT as soon as possible.

Tom, one of the oncologists interviewed, talked about the importance of being clear with patients, and managing their expectations up front regarding the likelihood of them being able to receive treatment, if their overall fitness did not improve, including their nutritional stability.

> *‘…we do try to say, ‘look, there is a window of opportunity, you’re not fit enough for chemo now,’ I make it as clear as I can do, and the patients get copies of the letters, at the bottom it says, ‘I’ve met you today, I’ve talked to*

> *you about the possibility of chemotherapy, I don't feel you're fit enough at the moment, we're gonna try and make you better to be suitable for chemotherapy, ….'* – Tom - HCP 21, Consultant Oncologist

Despite the obvious benefits of having access to a specialist HPB dietician, not all patients were routinely seen by one. Though this was often the case in a DGH where specialist dietetic provision was not routinely available, Paula, an oncologist at a specialist centre, noted that she would only make a referral to a specialist dietician if a patient had a particular problem with their nutrition, as she knew capacity was lacking at her site, in spite of it being a specialist centre.

> '*We have specialist dietitians, but they're thin and far between. So unfortunately, not all patients are seen routinely, so it's if there's particular problems with nutrition or absorption then we would have to do a referral, and they're not seen that quickly either.'* – Paula - HCP 17, Consultant Oncologist

In addition to PERT, patients might also be offered nutritional supplements to help them optimise their nutritional intake, though it was acknowledged that people may lose their ability to tolerate them over time, due to the progression of their disease.

> *'…they get to a point where actually, they're not tolerating them anymore and that's often a part of the inoperable cancer progressing. And then it's having those sorts of conversation actually about sort of eating for comfort ….'* – Kathryn - HCP 11, specialist dietician

Kathryn felt that accepting the limitations of what could be achieved for some patients, in terms of their nutritional status, came with the territory.

> *'…ultimately it's nutrition as well as their disease that will cause them to come to the end of their life. So, it's those discussions which are quite difficult to have …'* - Kathryn - HCP 11, HPB Specialist Dietician

Chemotherapy treatment

Like fellow oncologist Tom, Caroline also talked about the need to rapidly see and assess a patient's fitness for chemotherapy, given the speed at which patients often deteriorated.

> *'…the patients deteriorate quite quickly so if you've got a two to three week wait for chemo and you're not seeing patients for two to three weeks after their diagnosis, for the patients …with the heavier burden of disease, that's a very, very narrow window to treat them…'* - Caroline - HCP 3, Consultant Oncologist

In some cases, where a patient's cancer had rapidly advanced, a decision would be made to refer the patient for palliative care, without them seeing an oncologist. At Tom's site, this was occasionally the situation, when one of the very experienced CNSs felt a patient was too frail and would not be suitable for chemotherapy.

> *'…they're in the breaking bad news clinic, they know what I do. If they see an 89-year-old who comes in a wheelchair, they will talk to them with the gastroenterologist. The gastroenterologist tells them the diagnosis, the CNS will stay on afterwards and say …he's not going to consider you for some*

> *chemotherapy. …and I will refer you to the community [palliative care] team.'*- Tom - HCP 21, Consultant Oncologist

Though this might be an entirely appropriate course of action for the patient, Tom also acknowledged that patients would sometimes still want to see an oncologist.

> *'If the family or the patient go no, we need to see a cancer specialist, I will still see them, but they are aware that at 89, performance status three, they're not going to get treatment.'* – Tom - HCP 21, Consultant Oncologist

Radiographer, Harriet also felt that patients could be disappointed if they didn't have the opportunity to see an oncologist and have the chance to discuss the situation properly.

> *'And I've had feedback from the MDT, that this is for palliation only but actually the patient wants to speak to an oncologist. The patient wants to hear it from the doctor, the specialist in that field. And that can sometimes be quite disappointing.'* – Harriet - HCP8, Diagnostic Radiographer

Workload and capacity constraints

Several HCPs spoke of their desire to be more proactive in contacting and checking in with their patients and spending more time with them in general. However, workload and capacity constraints meant this was often not possible.

> *'… we try and catch up with our patients and give a call to say, 'How are things going?' Realistically, that's difficult because of the workload post-*

> *Covid – you know, we're all on catch up. That's not very easy to do.'* - Fiona - HCP 6, CNS

Natalie, a Macmillan Cancer Information Services and Support Manager, explained that she no longer had the capacity to continue to be a physical presence in clinics, potentially reducing the visibility of her service to patients. Natalie had also noticed that she was having to push a bit harder to get a response from CNS teams because of their workloads.

> *'In some teams, where I know the workload is particularly intense, and I'm seeking a response from somebody I might have to push a bit harder. That's sometimes frustrating, but it's not because of the unwillingness of the clinician, it's more the fact that I know they can't breathe.'* – Natalie –HCP14, Macmillan Cancer Information Services and Support Manager

To manage demand, HCPs talked about adopting a 'call us when you need us' approach, which some HCPs saw as unsatisfactory, even if necessary to manage demand.

> *'And I do try and review them but often I have to put the ball in their court and say for them to call me if they've got any questions, or if they've got any concerns because I just don't have time to review every patient... I could offer a lot more support, but I don't have the time to do that.'* - Georgina – HCP 7, specialist dietician

Georgina also noted that patients who were admitted to hospital at some point in their journey might only be getting generic advice rather than the specialist support they really needed at her unit because of staff shortages.

> *‘Unfortunately again, there are staff shortages at the moment, if it is just a small amount of weight that they’ve lost at the moment, they might be told to take some extra snacks on the ward or they might not get a proper dietician review but if it was more fully staffed and we had more time, then we would be able to have a bit more of an in depth conversation with the patient.’* - Georgina, HCP 7 specialist dietician

Other ‘hot spots’ in terms of staff shortages were highlighted by several HCPs. For example, shortages of radiologists and radiographers could have an impact on the turnaround time of diagnostic tests, with patients reported to be routinely waiting three weeks for a biopsy or stent to be fitted.

> *‘…it would be really good if we could get the biopsy done quicker but we’re very much limited by the resources within radiology and radiologists…. radiology is massively under-staffed. The consultant radiologist vacancies are currently running at over 30%. … a radiographer, working on the scanners and stuff like that - the current vacancy in the Trust is 46%.’* - Harriet – HCP 8, Diagnostic Radiographer

Simon, a Palliative Care Consultant, commented on the lack of palliative care specialist doctors nationally – an issue which had been exacerbated by recent changes in training requirements for the speciality. This change had already had a significant impact on recruitment to specialist posts.

> *‘So, there are two consultant vacancies for every newly qualified palliative medicine consultant up and down the country, and because the training has changed recently which means that if you want to pursue palliative medicine as a career you effectively have to do more acute medicine… So, we had six registrar posts advertised last year, and we only managed to, regionally in [Region 1] we only managed to recruit to one of those posts.’* - Simon - HCP 19, Palliative Care Consultant

Staffing difficulties were also apparent within community services as well as hospital services. This included local district nursing services and care agencies.

> *‘Care agencies aren’t able to get staff, so they’re not able to provide packages of care as quickly as we used to get them…So things like fast track, where we used to expedite care earlier or quicker for that end of life, sometimes can take a bit longer to happen… and that can be very difficult, you know…especially in a sort of more crisis situation.’* - Jemima, HCP 10, Palliative Care Nurse

Inpatient experience

When a patient experienced complications with chemotherapy treatment, or other complications related to their condition, and required hospital admission, there was sometimes no option other than being admitted through A&E. CNS Tania, felt this was a poor experience for this cohort of patients.

> *'But if they do need to be in hospital the only way we have is to send them into ED, there's no pathway that we can try and avoid ED when patients are unwell, because it's the only thing we've got....they do end up having to sit in A&E for hours, ... before we can get them a bed, and when someone is in a situation like our pancreatic cancers are it's not great for them.'* – Tania - HCP 20, CNS

CNS Fiona, commented on the challenges of managing pancreatic cancer patients as inpatients and described herself as acting as the patient's advocate in these scenarios in order to co-ordinate their care.

> *'…we have a massive amount of input with these patients because of their complex care needs really. …They need us, as a kind of team, to bring their care together, liaising with everyone that we work very closely with, for example, the gastroenterologists who potentially can do stents and the interventional radiologists that potentially can do biliary stenting if we're not able to do it endoscopically.'* - Fiona - HCP 6, CNS

Fiona noted that her ability to fulfil a co-ordinating role, as a CNS, could be compromised however if a pancreatic cancer patient was not admitted under the care of a specialist. In this scenario, the CNS team might not be made aware of their admission.

> *'…they kind of come into hospital and … they languish a bit. They languish if I don't know about them… things don't necessarily happen that speedily…'* Fiona - HCP 6, CNS

Care co-ordination

Several HCPs expressed the view that care co-ordination in the community was not ideal. CNS Tania felt there wasn't a robust system in place to ensure that patients were being followed up, and having their symptoms managed appropriately by their GP. Tania felt the onus for managing patients always seemed to fall back onto the hospital.

> *'Patients will come to me with their symptoms, which we'll try and sort, but if I say to them, 'have you spoken to your GP?', it's very, very rare that they've been able to get any sort of help from the GP.'* – Tania - HCP20, CNS

Yolanda had a different perspective as a GP and felt there were two distinct scenarios in play. She felt that when a patient was well known to the hospital team and was either still having active treatment such as chemotherapy, or had stopped having active treatment, there were still pathways for that individual to continue accessing specialist support through their hospital-based team. She felt there was a problem though for a patient who might only see the hospital team once before being judged too frail for chemotherapy and being referred to community services.

> *'… it's when your entry point is, 'We think we shouldn't intervene,' that they get left with very little information and actually not much recourse for getting information from secondary care, in my experience, and I think that that is a gap that could be constructively filled, … It might just be filled with some slightly better information or more personalised information or a longer handover.'* – Yolanda - HCP 24, GP

Yolanda felt that while primary care was well placed to support people in that situation, there was no easy route into the acute sector for advice on patient management, whether in relation to PERT titration, new onset diabetes, or any other aspect of their ongoing care. She felt that GPs needed more support with access to resources, or dialogue with specialists, to manage the care of these patients effectively.

> *'… there are lots of interim condition-specific questions that actually there's no-one to turn to and no-one to get advice from, and personally, I think that there's quite a big communication void.'* – Yolanda - HCP 24, GP

Despite Yolanda's confidence that primary care could manage patients appropriately with access to the right support, several HCPs talked about the difficulties they knew patients had faced getting access to see their GP and reported that they had had to act as a go-between with the patient and their GP.

> *'… I would say that a lot of patients are finding it very, very difficult to contact their GPs at the moment and a lot of them say it's impossible, or they can't get an appointment for a long time … we can just write to the GP or email the GP and ask them to prescribe things for them.'* - Georgina - HCP 7, CNS

> *' ... We'll get a call saying can you phone the GP because I can't get through, because I'm number 29 on the list or something.'* – Orla - HCP 15, Community Palliative Care Nurse

> *'…So, we probably spend quite a bit of time actually, … doing that liaison with GPs for the patients, because they say…, 'I've been told to send an e-consult form and I don't know what to say. And then you think well actually if you're in pain we don't want you to do an e-consult form, you need to speak to the duty doctor, and we'll do that now ...'* – Rebecca - HCP18, CNS

Palliative care nurse, Patricia, reported that in her experience, it wasn't uncommon for patients to be seen by an advanced nurse practitioner, rather than a GP, or that they might have a video call with their GP rather than a physical appointment. She felt the lack of a physical appointment with a GP was causing anxiety for patients who felt they were less likely to be treated appropriately as a result.

> *'...so, from their perception of care that's often a great disappointment and concern to them.'* - Patricia - HCP16, Community Specialist Palliative Care Nurse

Palliative care and end of life phase

Outside of the hospital, palliative care services were provided by District Nursing teams and GPs, in the first instance, and by specialist community palliative care services if a patient's needs were complex and unresolved. GP Valerie felt patients should be recorded as being on the Gold Standards Framework (GSF) (see Chapter 2) within their GP practice as this could trigger additional support for that individual.

> *'… so, they often get a separate phone line to ring in to the GP practice, they have a special alert box, so anyone opening their record in the GP practice,*

> *such as a receptionist, it will be an alert that this is a palliative care patient.'* – Valerie - HCP 22, GP

Valerie advised that patients would be told about this additional support when they first saw their GP, following their diagnosis. This post-diagnosis primary care consultation would also be an opportunity to complete various templates the practice would have which might include information on the patient's preferred place of death, and other preferences regarding their care. This consultation would also be an opportunity for the GP to explore any needs that the patient's FC might have. Valerie suggested that this consultation could be triggered by either the GP or the patient, depending on the circumstances.

> *'Because when we receive the letter to say your patient has been diagnosed… So, I received one last week, it was a patient with a lung primary that had spread to the brain, liver, and spine, …. So, I'm not going to wait for that patient to contact me, so that patient was proactively contacted and placed on the palliative care list and a home visit was arranged.'* – Valerie - HCP 22, GP

What was apparent from the three GPs that were interviewed for the study, was the variation in terms of how people with inoperable pancreatic cancer might be supported by their practices. This is likely to be the picture across the country depending in part on whether a practice prioritises meeting QOF targets for cancer patients generally (see Chapter 2), and whether a practice has invested in additional staff to support cancer patients, such as cancer care co-ordinators, which were mentioned by one of the GP interviewees.

Several HCPs talked about the stage at which they would talk to patients about palliative care services and what they would be able to offer them as their disease progressed. Isabel suggested that she might introduce the idea of palliative care to people at diagnosis, depending on the circumstances, though she recognised this was challenging for patients.

> *'Quite often, I talk about palliative care the first time I meet them and that's really difficult. You know, you've got a bit of an upset tummy and perhaps a bit of back pain and you walk in and then somebody's talking to you about palliative care and hospices, and that's actually really, really hard.'* – Isabel - HCP9, acute oncology nurse

CNS, Erin, also felt it was helpful for all patients to have an early introduction to the service but recognised it was a question of professional judgment.

> *'… I also explain that sometimes it's better to have an early introduction to a palliative care team, so that they can build a rapport and when it's necessary, discussions can be had about end of life care. But I er, you do have to just judge it patient by patient.'* – Erin - HCP5, CNS

Oncologist Caroline also felt it wasn't always helpful to suggest palliative care to people who were still coming to terms with their diagnosis, and who were coping ok with their physical symptoms.

> *‘To be honest, we selectively offer palliative care. … I think some of the patients are very, not terribly unwell and don’t have a huge number of issues and actually they’re still coming to terms with the diagnosis and then throwing palliative care into the mix is a bit much at the beginning.’* – Caroline - HCP3, Consultant Oncologist

Conversations about a referral to palliative care had to be managed carefully as people might equate palliative care to EoL, and this could cause unnecessary distress, as CNS Fiona noted.

> *‘It’s all about the pitch. … if I just phoned somebody up and say, ‘Oh, you know, the doctor wants you to be referred to the Hospice team,’ they’re like, ‘Oh my God! What are you telling me?’ So, it is how it is explained to the patient.’* – Fiona - HCP 6, CNS

Other HCPs noted that while making patients aware of palliative care might be useful, because it was the start of the conversation about them having a life limiting disease, there was little point referring people to community teams when they were largely asymptomatic, as such services were generally stretched, and could only see people who had an immediate need for them.

> *'I’ve referred patients who we know have got a very poor prognosis, ...but because right at that minute they are fairly OK, the district nurses have to discharge them until they are absolutely needed.... the district nurses just don’t have the ability to be able to go in, unless it’s really required, which is a*

> *shame really because making those contacts earlier on can just help with that side of things with our patients.'* – Tania - HCP 20, CNS

Oncologist, Tom, acknowledged how busy his local community palliative care service was, but felt it was counter-productive for them not to accept a referral for a patient with advanced pancreatic cancer.

> *'… I would argue a patient with metastatic pancreatic cancer who is currently not ill enough for their care will soon become ill enough, be it in a month or three months or four months, surely it would be more useful to say, 'We will leave you with an open thing, we won't come to see you until you ring us'. But to actually discharge them, so that they then ring and say, 'I'm not feeling so well,' and we go, 'OK, we will rerefer you for what we referred you for two months ago, to get you back on their books.'* – Tom - HCP 21, Consultant Oncologist

As difficult as it might be for HCPs to talk to patients about palliative care, Melanie, a hospital-based palliative care nurse, also talked about the difficulty HCPs might have in recognising when there was little more that could be done medically for the patient. She felt it was part of her role to help less experienced colleagues recognise when it was time to step back from undertaking interventions of little benefit to the patient.

> *'What I see in my junior colleagues, or teams on the ward, that wait for either something to work, or that realisation and acceptance that we might not be able to manage that symptom completely – that's very challenging… I*

> *think sometimes our role is recognising that time is short...some of it is I guess acknowledging it and sometimes challenging views of others to say, 'We can see these changes which mean that actually the prognosis could be this limited.''* – Melanie - HCP13, hospital palliative care nurse

Addressing personal care needs at the end of life

When a patient needed support with personal care, palliative care services helped direct people through the process of arranging a social services care package, or if they were self-funding, a private care agency. In some areas, palliative care teams had recourse to a Hospice at Home service for patients. This service could provide personal care in a crisis until another care agency could step in, potentially preventing an avoidable hospital admission down the line. In other areas where this was not available, HCPs expressed their frustration at the difficulties in arranging this kind of support for people.

> *'You know, we can see that they need the help, and then we make the referral, but then that takes a while for that to get put in place, and in the meantime you can see family getting more tired and patient becoming less able….And what you don't want is a crisis to happen...'* – Orla - HCP15, Community Palliative Care Specialist Nurse

Inoperable pancreatic cancer patients would usually qualify for the Continuing Health Care (CHC) Fast Track scheme for personal care services in the home (DHSC, 2022). CHC funding allows for a maximum of four double-up calls a day and up to three nights a week. Palliative care nurse, Patricia noted however that even this input was not necessarily sufficient to support the FC.

> *'Well, if somebody's disturbed every night, three nights is still a big challenge for a family to either get a rota together if they're still trying to work or manage, it's still a lot to do really, to look after somebody…'* – Patricia - HCP16, Community Palliative Care Specialist Nurse

Advance care planning

Though the preference for some patients and FCs would be to care for the individual at home in their last weeks and days, several HCPs felt that people needed to know what the reality of this might be. The process of ACP while inevitably bringing up difficult conversations with people, was seen as providing an opportunity for these issues to be discussed.

> *'…you know, everyone's got the intention, yeah, we're definitely gonna keep them at home, this is where they want to be. But I always, always say to them, is that I can hear what you're saying, and that's what our plan will be, however sometimes things don't happen the way we'd like them to happen. …sometimes carers, their expectations, it's very different to what they thought it was going to be, and it's not that they're failing, it's just that it's too overwhelming.'* - Orla - HCP 15, Palliative Care Nurse

While hospice provision was an alternative to caring for someone at home, variation existed among participating sites, in terms of what was available to people locally. GP, Wendy, noted her disappointment that their local provision had recently closed.

> *'… if the patient isn't possible to manage their symptoms at home and they have to go to a hospice, it's the distance for the family to hospices. Because we used to have a community hospital … and so that hospital's gone, and that has had a massive impact in palliative care patients … They get wonderful care in the hospices, but they're not very local in miles.'* – Wendy - HCP 23, GP

6.3 Addressing emotional needs

Diagnosis phase

Regardless of the route by which a patient received a diagnosis, all HCPs recognised the shock for the patient and their family members that this brought.

> *'...they've gone from a couple of months ago either perhaps working or having a fairly normal family life, to sort of hopes and dreams dashed really quickly with an illness that has a very sudden impact…,'* – Rebecca - HCP18, CNS

HCPs also commented on the anxiety they felt people experienced waiting for the next steps to happen to them, after their initial diagnosis.

> *'…people are left floundering. ...if you're waiting and waiting with a cancer diagnosis, waiting to hear what the next steps are, two weeks is a long time.'* – Denise - HCP4, PCUK specialist nurse

Consultant Oncologists, Caroline and Tom, noted that their discussions with patients at their first appointment, had to be managed carefully, as though the expectation was that patients would have already received a diagnosis, the patient might not have understood the gravity of their situation, or they might have been holding out hope to hear something different.

> *'And interestingly, when we confirm the diagnosis it still comes to some of the patients as a little bit of a shock because they were hoping that I would say something different even though they've come to see an oncologist..'* – Caroline - HCP3, Consultant Oncologist

> *'I've had other cases where you are not convinced the patient was fully aware of the severity of what they have, so you are trying to gently unpack that, to go 'we are not in a good place.'*- Tom - HCP 21, Consultant Oncologist

HCPs were therefore acutely aware of the need to proceed cautiously when talking to patients at the point of diagnosis, to ensure they did not cause additional emotional distress.

Treatment phase

Having difficult conversations with patients and their FCs about their diagnosis, their treatment options and managing people's expectations for the future, was a feature of everyday life for the HCPs interviewed for the study. HCPs also talked about the fine line between managing expectations about what was viable in terms of treatment, while also recognising that people needed to cling on to some sense of hope to be able to face the future.

> *'… I guess people are trying to be very hopeful and saying well, we'll fight this to the end, and you know if we can't have this treatment, we'll look at other treatments, … people do cling on to hope and I think they have to.'* (Denise – HCP 4, PCUK specialist nurse)

HCPs noted the importance of the interpersonal communication they had with patients as a means of providing them with emotional support and comfort. Consultations and conversations could therefore become a form of therapeutic intervention in themselves, if managed well. As oncologist, Tom, noted, the interpersonal relationship was of prime importance when medicine could only do so much for these patients.

> *'As my wife says, you do as much for your patients by what you talk to them about and you care for them, as actually most of your treatment.… What most of these patients need is a hug, not high-tech care.'* – Tom - HCP 21, Consultant Oncologist

Natalie also talked about the doctor-patient interaction as important in helping to manage patient anxieties.

> *'And obviously clinicians tell their stories in different ways...often a clinician would say, 'I can't cure this, but we can take steps to try and manage it, to control this, to keep it in order, by looking at some chemotherapy. Then we'll review and see what's going on, and then you know, if it's responding that's*

> *great, if it's not responding we'll try something else.' so that patients are sort of managed in terms of their anxiety.'* – Natalie - HCP14, Macmillan Cancer Information Services and Support Manager

CNS, Fiona, felt that doctors could be better at managing difficult conversations with patients to try and speed up decision making, while still managing to be sensitive to their situation. She felt there was a reluctance sometimes among clinicians to be honest with people about their situation and this may allow things to drift in terms of a management plan.

> *'… I think there is definitely room for improvement because most of the patients, … they need some frank conversation and some decisions. They need some clinical decisions and people don't seem to be that kind of happy to have those discussions..'* – Fiona - HCP6, CNS

There were specific points in the care pathway where HCPs noted that conversations could become increasingly fraught emotionally for patients and their FCs – for example in the transition from active treatment to symptom control.

> *'…that conversation about I'm sorry, we've got no other treatment options, and it's just symptom control, that's always very, very difficult.'* – Paula – HCP 17, Consultant Oncologist

A few HCPs had considered setting up patient and carer support groups to provide emotional support to people to help them cope through these difficult times, but acknowledged the inherent difficulties in organising them, given people's prognosis, their fluctuating health, and staff capacity constraints.

> ‘*But that is difficult especially because we know that their prognosis isn’t going to be long...And it’s a discussion that we’ve had as a team but it would just be so difficult to kind of set up, you know, unless it was something that we ran but then again with capacity and workload ...'* – Erin - HCP5, CNS

Where HCPs had direct experience of trying to run these groups, they reported that they had often been poorly attended, either because people didn’t want to travel too far, or because they didn’t feel well enough to attend, so they had fizzled out over time.

Palliative care and end of life phase

Palliative care professionals noted that sometimes, it was the FCs who needed their support, rather than the patient, and that they needed to be alert to this, and respond as appropriate.

> *‘We do find we get referrals,… and it might be their family member, their carer that really wants the referral because they're struggling and they want the opportunity to talk to someone, to be able to, you know, look at what might be ahead.'* – Jemima - HCP10, Palliative Care Specialist Nurse

HCPs were therefore constantly having to make professional judgements, often in the moment, about how to broach topics and what to tell people, and when. After a patient’s death, conversations with FCs turned towards what emotional support they might need and what they could access.

It was usually the community palliative care team that would provide FCs with information about what bereavement support was available to them. Jemima described how her team would proactively contact the bereaved party to explain what was available but the point at which this happened would depend on the circumstances surrounding the death of their family member – if the event had been particularly traumatic, they would make contact as soon as possible. Otherwise, it might be within a week of someone dying.

Though bereavement support was not necessarily something that was formally offered by the participating HCPs themselves, many nonetheless did have contact with the bereaved and a number reported that they sometimes felt unprepared for the role, as they were not trained psychologists or counsellors. Specialist nurse, Denise felt that though she could listen to people if they called her charity’s helpline for support, she often felt that she hadn’t got the answer for them, or the right support. She also noted that though bereavement services such as counselling, were available, there could be a delay in accessing them which was problematic for people experiencing distress.

> *'I guess the really difficult thing is that those services again (bereavement services), it’s often a six week wait, um, and people, you know, they want help now, they don’t want it in six weeks. Because now, is often the crisis point.'* – Denise – HCP 4, PCUK specialist nurse

6.4 Addressing social needs

HCPs talked about the importance of seeing people as individuals in terms of their response to their illness, their coping mechanisms, and their priorities, but also the importance of seeing the patient and their family members as a unit, undergoing the traumatic journey together. A number of HCPs could recall specific domestic and family situations which meant there were particularly challenging consequences arising from the patient's disease, such as arranging ongoing care for dependents.

> *'… my latest, recent patient, really sad, she's got [children with mental health challenges], … she needs to make provision for their care, so there's all those concerns as well.'* - Caroline - HCP 3, Consultant Oncologist

Palliative care nurse Melanie explained that she undertook her own holistic assessment of a patient's physical and psychospiritual distress, and what concerns they might have about home or family life. Using the Integrated Palliative Outcome Score (IPOS) (KCL, 2024) patients were asked to grade their top three concerns or symptoms. The tool also considers the patient's insight, their understanding, how they're coping, and how their family are coping. The results of this would help Melanie and her team prioritise their support for that patient.

6.5 Addressing psychological needs

Several HCPs noted that while patients were usually willing to talk about their physical symptoms, they might be more reticent to talk about their psychological needs and this needed to be approached sensitively.

> *'… I do ask, 'Well how do you feel about what you've been told?'... And I just ask a general question like, 'Well how are you coping with everything?,' sometimes that will open up a discussion about it and sometimes, it won't...'*
> – Caroline - HCP3, Consultant Oncologist

Caroline felt that being open about mental health symptoms was crucial in ensuring the patient was able to access the right support.

> *'But I do highlight that depression is very common and I do say to family members to keep an eye on an individual and there is lots of help available … the way I discuss it with patients is that the chemo is one part of their treatment, nutrition is another part of their treatment, anti-depressants is another part of their treatment.'* – Caroline - HCP3, Consultant Oncologist

CNSs would usually have Level 2 Psychological skills training (See Chapter 2) in order to assess and support patients with psychosocial needs, but as Oncologist Paula noted, psychological support beyond this level was not given the same attention as support for physical symptoms.

> *'...one thing that we don't do well is assessment of psychological support needs. It's very much a clinical model, we treat cancer, we treat the symptoms, but we don't spend a lot of time on psychological aspects.'* - Paula - HCP 17, Consultant Oncologist

And though each participating site had in-house psychological support services to which patient referrals could be made, issues with vacancies and short staffing, meant long waiting times for people to access such services seemed commonplace. Paula and fellow oncologist Tom both noted that this was not acceptable for people with a diagnosis of inoperable pancreatic cancer where speed of access was critical.

> *'...we do have access to clinical psychology here, but they're not easy to access...often months in advance, (for) newly diagnosed patient who's*

> *struggling with a diagnosis, it's just not practical, it's really not helpful actually*.' – Paula - HCP17, Consultant Oncologist
>
> *'Everyone is very stretched, so the challenge we always had was you would refer for in-house psychological services and they would say there is a three-month waiting list…'* – Tom - HCP 21, Consultant Oncologist

Given the limitations of in-house services, several HCPs said that they would signpost their patients to charities for free counselling support instead.

Primary care's role in providing psychological support to patients appears to be limited to a review of needs within Cancer Care reviews (See Chapter 2) – where these take place. Valerie's assumption, as a GP, was that a psychological assessment of the patient would have taken place in the acute setting at diagnosis, or soon after, and that patients would be referred onto specialist services, as necessary. Her role as a GP was to assess whether the patient's needs were being met and whether they needed anything additional such as antidepressants or counselling.

For this population therefore, with a limited life expectancy, it is highly probable that their psychological needs are rarely reviewed by their GP, as they are unlikely to survive long enough to take part in a 12 month review session, and may miss out on a three month review session, due to difficulties accessing their GP, as noted previously.

Only one site in the study had a process whereby all cancer patients were routinely screened for low mood and depression, at the point at which they checked in for an outpatient appointment. Patients at this site were sent texts inviting them to fill out a questionnaire on their psychological symptoms. Patients scoring above a certain amount were flagged for follow-up. The patient's consultant might then raise their responses in a consultation, though practice among specialities and individual consultants was reported as being variable.

Patients with a high score were also contacted by a member of the psych-oncology support team, and this could result in a referral for dedicated psychosocial support, if appropriate. The service was delivered by care managers (nurses and Occupational Therapists), with access to consultant psychiatrists for people with the most complex needs. If deemed helpful, 1:1 sessions, based on the depression care for patients with cancer (DCPC) model (Walker and Sharpe, 2009) were provided. The sessions covered three components: Use of anti-depressants, goal setting and problem solving. If patients didn't improve after the intervention, they were referred on to community mental health teams through their GP.

A gap identified by the service however was the lack of support for FCs, as the support provided existed solely for patients.

6.6. Addressing information needs

Diagnosis phase

HCPs routinely observed the variation between people, in terms of what they knew about their disease, and how much information they may have been given, or found out for themselves. Specialist HPB dietician Georgina felt that patients were not receiving enough information at the point when they were told there was a likely problem with their pancreas but their diagnosis hadn't been confirmed. The dilemma for Georgina though, was who was best placed to answer the patient's questions and address their concerns during this period.

> *'…and there's a lot of anxiety and worry there and not a lot of maybe information given…we weren't really sure how best to do that because for nurses and certainly for me as a dietician, giving a diagnosis to patients or giving information which will lead to more questions and more anxiety doesn't feel right and they do need an oncologist to do that or a doctor to do that.'* – Georgina - HCP7, specialist dietician

This is undoubtedly an increasing dilemma for clinicians in an age when so much medical information is easily accessible via the internet, and when so many people's first response to something they don't know or understand is to 'google it'.

Treatment phase

After a confirmed diagnosis, CNSs were routinely giving patients packs of information provided by Macmillan Cancer Support, such as diet sheets, information on chemotherapy and its common side effects, and information on practical issues such as claiming benefits. A standard leaflet on PERT was also given to patients where appropriate. In some cases, information packs contained information on mental wellbeing and psychosocial support, but this was not always the case, as CNS Erin, observed from her own team's practice.

> *'…actually, we were just having a discussion recently about our new information packs because we don't have anything in our packs about*

> *support for, um, mental wellbeing. So, [there's] … a leaflet about how to contact us, loads of information about diet and benefits but we don't even have anything for mental wellbeing.'* – Erin - HCP5, CNS

HCPs were routinely signposting patients to their site's Macmillan Cancer Support hub for further information and support, and to Maggie's Centres where they existed, and they were universally positive about the contribution these organisations could make to someone's support. HCPs from one site would personally take patients and their family members across to their local Maggie's Centre and introduce them to the staff there and the centre's facilities.

> *'…it is quite a good safe space to step away and go to somewhere very calm and peaceful'* – Rebecca– HCP18, CNS

GP practices were also giving out generic information to patients, and directing them to Macmillan Cancer Support, as the first port of call for further information – one GP suggested there was a requirement for general practices to inform cancer patients of the Macmillan Cancer Support website, though the origin of this requirement was unknown.

Some HCPs were providing patients with PCUK and Pancreatic Cancer Action leaflets but this was the exception rather than the rule. And while in general, HCPs had at least heard of PCUK, some were unaware of the charity's helpline, and many did not know that the charity provided support for HCPs too, through their training sessions and other resources. Specialist dietician, Kathryn, acknowledged that PCUK had some useful resources to direct patients to but hadn't used them herself and confessed that she felt she ought to make more of an effort to do so.

> *'And Pancreatic UK have got some great resources that we can ask people to have a look at but that's not something that I do that regularly… There's no reason why I couldn't utilise those resources more and actually I went on a study day, the other day, and they had some great resources … so actually I just need to think about other places to direct people to have a look at their sorts of resources really.'* - Kathryn - HCP 11, specialist HPB dietician

There is wide variation in practice it seems regarding the provision of information to patients and their FCs about specialist resources such as those produced by the relevant charities. This was an unexpected finding and indeed, others, like GP Valerie expressed the assumption that tailored information would be provided to patients by their CNS as a matter of course.

Navigation

In addition to information regarding the specifics of their disease, or treatment, HCPs also observed that it could be difficult for people to understand the complicated web of services that might be involved in their care.

> *'It's still confusing for people sometimes and overwhelming. I think people will still say, 'Oh, I'm not really sure, you know, I've got this person here who says I can ring them, and I've got you now and the GP and oncology triage and I don't know who am I ringing at what time.'* – Jemima - HCP10, Community Palliative Care Nurse

Denise noted that many of the calls she received to her organisation's helpline were from people who needed help navigating the system, because they weren't sure who to contact. CNS, Tania also identified uncertainty among FCs as to who to contact in an emergency or crisis. She felt that this was particularly the case as the patient neared the end of life.

> *'Especially when patients are nearing end of life, I think there's a lot of concerns with family, because especially in our patients it's all so sudden and these things then happen quite quickly, they're never prepared for it. So, I think it's the not knowing what to do and who to talk to.'* – Tania - HCP 20, CNS

Communication

Several HCPs raised concerns about the poor communication of patient information between organisations and this was particularly the case between hospitals and GP practices.

> *'…for a lot of people, they find that when they contact their GP, their GP is not aware of what they've been told from the hospital …. so, there's certainly a huge communication gap there between hospitals and GPs.'* – Denise - HCP4, PCUK specialist nurse

Clinical letters are routinely sent electronically from hospitals to GP practices, and in theory, as Valerie explained, specific actions for GPs should not be missed as practices have document management systems that should flag up if a specific action is required.

> *'And each GP practice or PCN [Primary Care Network] will have their own, it's called doc man filtering mechanism, so we no longer need to see every single letter. If there's a specific GP action it will go to the GP, otherwise it will be filed in the patient's record, and when the patient makes an appointment to see the GP that's when the GP can review it.'* – Valerie – HCP 22, GP

Oncologist, Tom, however, felt the electronic system could mean communications were overlooked within GP practices, and said he impressed upon patients the importance of taking the initiative themselves, and proactively contacting their GP to let them know what was happening.

> *'I write the letters, so the GP knows what's going on, I'm not sure they are read, because I think they are scanned electronically because they don't arrive in the post… So usually, what I now do is, because the patient gets a copy of the letter, I say when the letter arrives with you, you can ring the GP to say, 'can you help me sort out this problem?'* – Tom - HCP 21, Consultant Oncologist

As a counterpoint to this, GPs Wendy and Yolanda spoke about their practices' investment in mechanisms to ensure that important messages or documentation were not being missed.

> *'… we have a medical records team, and because of the amount of documentation that comes through the surgery they take out a lot of the stuff that doctors don't need to see…,'* – Wendy - HCP 23, GP

> *‘So, somebody looks at everything coming in… And if somebody needs something doing today we’ve got a continually updated list that we all look at throughout the day and people will take ownership until it’s done…. So, the reason we filter everything in is to make sure that we get things that need to be acted on that day acted on.’* – Yolanda - HCP 24, GP

Patricia’s community palliative care team used the same IT system as local GP practices and district nursing teams, which ensured that everyone involved in the care of a patient in the community had an up-to-date record of contacts and interventions.

> *‘… because we share an EMIS note system with the GP and the district nurses, we put all our visits on there, all our telephone contacts on there, to try and keep open communication. …I always tend to e-mail my GPs so that they have a full update every time I’ve gone to see somebody, as well as the medication suggestions I’m asking them to prescribe.’* – Patricia - HCP16, Community Palliative Care Nurse

Patricia’s team also used a generic team email address, so that someone would always be able to respond to requests, regardless of whether an individual member of the team was away. Group emails were also used to ensure that everyone involved in an individual’s care was kept informed.

> *'We tend to always do massive group e-mails to everybody that could or has been involved in that person’s care, so that we can make sure that the right*

> *person picks it up and runs with it.'* - Patricia - HCP16, Community Palliative Care Nurse

Communication between individual HCPs and patients or their FCs, was generally encouraged by phone rather than email, to ensure a speedy response. Patients were routinely told by HCPs that if they needed advice or support they should ring a dedicated number for their CNS. If there was no-one available at the time they rang, they were advised to leave a message, with the reassurance that someone would call back within a set time. Tania explained that her team aimed to respond to patients on the same day whenever possible but would also tell patients that if they rang after 3pm, then they might not get a response until the next working day.

Denise however noted that their charity helpline would often receive calls from patients who needed advice or information but couldn't get hold of their CNS, or another member of their clinical care team when they needed them.

In an example of a poor practice, Denise recalled that patients had told her that they had been informed of a cancelled appointment by text. While Denise recognised that texts were often common practice to confirm appointments or send reminders, she felt this was not an appropriate means to communicate the cancellation of an appointment, as this could cause the patient unnecessary alarm.

> *'I appreciate the NHS is stressed at the moment but people getting texts to say that their appointments have been cancelled but no reason why. …that's terrible for people not to be able to speak to someone and have a*

> *conversation as to why their appointment's cancelled, especially if they're waiting for results.'* – Denise - HCP4, PCUK specialist nurse

Palliative care and end of life phase

As noted, there is often a misconception among people as to what palliative care services provide and several HCPs, including Denise, felt better information could help to explain that palliative care could address symptom management and should not automatically be equated to EoL care.

> *'…It can make a huge difference for people, but people aren't aware that that is available for them. I think people still assume that palliative care is only available for them at end of life, in those last weeks of life. So, it's really, it's a huge area, or a huge barrier to try and break down with people actually.'* – Denise - HCP4, PCUK specialist nurse

6.7 Addressing spiritual needs

HCP interviewees did not comment on any needs patients, or their FCs may have in relation to their spiritual needs and how they might support people to address these needs.

6.8 Addressing practical needs

Little was mentioned by HCPs about the practical needs patients might have, except in relation to arranging for pieces of equipment for use in the home and helping to sort out financial needs. The latter were generally addressed by HCPs completing the necessary forms required for the payment of benefits[8] along with referrals to Macmillan Cancer Support hubs for further advice with other potential financial support and blue badges for parking.

Yolanda noted that some GP practices might employ care navigators and/or social prescribers[9] who might help signpost patients and FCs to other resources and forms of support locally, though these individuals would support all patients registered with a GP practice and not just those with a terminal cancer diagnosis.

> *'… some of the more practical things like the benefits and allowances, …they can signpost a little bit to carer support organisations where they exist….And actually they can also sometimes do things like if people were needing to go into hospital and needing respite afterwards they have been able to help with that.'* – Yolanda - HCP 24, GP

The next two sections explore important aspects of HCPs' experiences in providing care to this cohort of people, which are not represented by Fitch's Framework.

6.9 Addressing healthcare professional training needs

During the interviews, several HCPs talked about the training they had either had, or needed, to undertake their role effectively. Advanced communication training

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[8] The SR1 form is used for claiming benefits under the special rules for people with a terminal illness.

[9] 'Social prescribing is an approach that connects people to activities, groups, and services in their community to meet practical, social and emotional needs that affect their health and well-being.' Social prescribing: Reference guide and technical annex for primary care networks (NHS England, 2023)

and Level 2 psychological competencies are standard requirements for CNS roles, and Erin, relatively new to the role of CNS, explained how the advanced communication training she had received had been particularly beneficial to her practice.

> *'…the reality of dealing with the prognosis, when you've got somebody potentially with long weeks, to short months to live, … I felt a bit kind of lost about what to say... But, I have had advanced communication training which probably changed my whole approach to my job.'* - Erin – HCP 5, CNS

Having this enhanced communication training is clearly important for both the HCP to feel comfortable in their role but also to ensure the experience for the patient and FC is as good as it can be in the circumstances, and that they feel they are being treated with compassion and empathy.

Though this training is a standard requirement for CNSs, it is not a standard requirement for other HCPs who may still encounter people receiving a terminal diagnosis. While other HCPs are likely to have all undertaken some communication training during their professional education, this may not adequately prepare them for the kinds of conversations they might be expected to have with patients and FCs. Isabel, an oncology nurse, had observed this, specifically in relation to junior doctors.

> *'I've done oncology for over 20 years, but a few aren't used to that – these are general medicine doctors, quite junior, then they prefer not to, to give the bad news.'* – Isabel – HCP 9, acute oncology nurse

Though understandable, this reluctance to give bad news may mean that it is not done at all but passed over to someone else more experienced to do so, as Isabel suggested, or else it might be done poorly, negatively affecting the experience of patients and FCs. When HCPs pass responsibility over to others, they are not developing their own skills, and these may therefore go under-developed through their careers.

Other specific training undertaken by HCPs involved in the care of this cohort of patients, included nurse prescriber training. A couple of the palliative care specialist nurses interviewed for the study had undergone this training and reported that it had enhanced their ability to support patients quickly and reduced their reliance on other members of the care team. They noted however, that the training to become a nurse prescriber took many months to complete and required supervision from a current prescriber, so opportunities were limited not just by funding but also by the availability of supervisors.

A few participants had undertaken training sessions run by charitable organisations such as Macmillan Cancer Support and PCUK and these had been well regarded. HCPs whose posts had initially been funded by Macmillan Cancer Support, and there were a number of participants in the study where this had been the case, were able to maintain an ongoing connection to the charity and could access training the organisation might provide on topics such as communication skills, palliative and EoL care, and personalised care and support planning. However, these would be tailored towards all cancer patients and not just pancreatic cancer patients.

Other HCPs talked about their role in identifying the training needs of staff and either addressing these themselves or arranging opportunities for training to be provided. Melanie explained how part of her role, as a hospital-based palliative care specialist nurse, was to identify training needs among ward-based staff, without these specialist skills, and to liaise with colleagues in the Trust to address these needs.

> *'If we're noting that actually perhaps there's an educational need on that ward then we'll be contacting the Ward manager and the Practice Development Nurse to talk about offering some teaching or a debrief or you know whatever's needed for that ward area.'* – Melanie - HCP13, hospital-based specialist palliative care nurse.

Other HCPs were also involved in facilitating learning events as part of their practice. Patricia, a community based palliative care specialist nurse, explained that her service reviewed all patient deaths at team meetings to explore whether the care they provided could have been improved, and what they could learn and do differently as a result. In a similar way, Wendy, a GP, described her practice's fortnightly in-house educational sessions. Once a year, the practice would also review its cancer diagnoses from the previous 12 months, to see whether any common patterns emerged, and if so, what could be learnt from them.

> *'…what I'm doing is kind of looking for patterns of which ones were delayed, could we have picked them up earlier. And the last time we did it, it was*

> *back pain was a particular symptom that came through that was being treated too quickly as musculoskeletal…'* – Wendy - HCP 23, GP

The opportunity to review practice and to learn from what has gone well and what could be improved is clearly an important element of quality improvement within healthcare. However, providing, and benefitting from these opportunities takes commitment from the organisation and time on the part of the individual HCP - something that most HCPs mentioned was stretched or lacking.

6.10 Addressing healthcare professional wellbeing needs

A few HCPs talked about being emotionally affected when a patient had deteriorated or died and feeling affected by both the loss of the patient and the impact on the family.

HCPs also talked about identifying with particular patients or family members who had shared similar personal circumstances and how this had also affected them emotionally, as they projected the patient's experience onto their own situation.

> *'…the times that it is particularly difficult is perhaps the younger diagnosed people that are in a very similar situation to ourselves. You know, perhaps young, young family, struggling, they are really the ones that are perhaps a little bit close to home, that probably has a huge impact on us.'* – Denise – HCP 4, PCUK specialist nurse

During the interviews, HCPs were asked about how they felt emotionally and psychologically supported at work, enabling them to cope with the realities of their everyday interactions with these patients and their FCs.

Informal peer support was mentioned most often as the mechanism in place, and there were a range of ways by which this might occur, though all involved the opportunity to debrief with colleagues following demanding situations or encounters.

> *'And we do often speak about the patients after clinic, so you know we do share an office and it's really helpful to just kind of talk it through with each other particularly if it has been difficult.'* - Georgina – HCP 7, specialist dietician

> *'I think Informally we've got a great team, …and lots of opportunities to talk…we meet every morning on Teams…we check in to see what the day is looking like, what needs doing but also how we are. So, if you've got a particularly tricky one, or at the end of it, there we do a WhatsApp check-in. We know there's somebody there just to have a bit of a debrief.'* - Jemima – HCP 10, community palliative care nurse

The existence of formal clinical supervision sessions - either 1:1 or team sessions - was mentioned by several HCPs - with both types providing opportunities to reflect and review how situations had played out, and what could have been done differently, and more effectively, if a similar situation arose in the future.

The existence of informal reflective groups was also mentioned by a couple of interviewees – these appeared to have been introduced during Covid but had remained in place in some cases.

> *'And it's kind of just a reflective group really where we sort of listen and share experiences …. for the oncology nurses and haematology nurses, I still offer a Teams once a month reflective group.'* – Laura – HCP 12, psycho-oncology care manager

Tom, one of the oncologists, felt that his preference for support was very much for informal peer to peer support rather than anything more formal, even though this was in place within his site.

> *'It's interesting, cause about a couple of weeks ago there was something from the trust for wellbeing, … going, 'join this online community where you can chat,'. And I was talking to my colleague, … and we sort of commented going 'I'm not sure I would cope if I had to go for support to an online community of people I've never met,' ...I wander up the corridor and grab a cup of tea with a colleague for 20 minutes, and not moan but just chat….'* – Tom - HCP 21, Consultant Oncologist

However, not all interviewees felt that their organisational environment was conducive to showing vulnerability, nor indeed that showing vulnerability was culturally acceptable, particularly within the nursing profession.

> *'You just get on with it, you're just supposed to get on with it. And almost, it's seen as a, I think it's changing and it's good, but it's seen as a weakness, to, you know, we came into this job knowing that people are going to get ill and it's going to be difficult, you just have to get on with it.'* - Isabel – HCP 9, acute oncology nurse

Providing a range of opportunities for people that meet their preferences for support is clearly important within organisations, but a couple of HCPs also alluded to the importance of basic, good, people management principles for supporting staff. Harriet spoke of the importance of knowing what was going on in the lives of her team in order to pre-empt any difficulties that might be raised by triggering or otherwise stressful situations. Responses might therefore involve the allocation of patients, to ensure particularly complex patients were not allocated to vulnerable staff; and the encouragement of staff to take whatever 'Time Off in Lieu' they might have due. Other good management principles mentioned included the emphasis of team meetings as important and necessary opportunities for staff to debrief; supporting staff to be properly equipped for the task i.e. by providing advanced communication training; and modelling the behaviour they wanted others to demonstrate.

> *'I find, especially when new team members start, making sure that they understand that they don't have to be heroes. That knowing their limits is actually really important coz there's no point in spending all your beans on like, the first six months of the year and then you've completely emotionally spent yourself and you don't have the physical or the mental where with all to continue working coz you've just given too much of yourself away.'* - Harriet – HCP 8, Diagnostic Radiographer

GP, Valerie, made the point that looking after the workforce across the NHS should be a priority, to address workforce pressures. Valerie felt that this ought to involve transformational change, by exploring how things could be done differently such as by redesigning pathways, and not just trying to do more of the same.

> *'We need to really look after our workforce, looking after the workforce is absolutely essential. We need to review the workload pressures and start thinking about transformational changes, not just doing the same thing but more of it, but actually transforming pathways.'* – Valerie - HCP 22, GP

This kind of transformation change would take significant commitment from organisations to drive forwards. The introduction of Integrated Care Boards, Primary Care Networks and Provider Collaboratives may allow for some of this kind of redesign work to take place, and this may have been what Valerie was anticipating.

6.11 Summary of chapter

This chapter has presented the findings from interviews with 24 HCPs, exploring the perceived barriers and challenges to providing optimal care and support for people with inoperable pancreatic cancer and their FCs. The picture that emerges is one of complex patient pathways with multiple contacts with a range of individual HCPs, departments, and services.

Interviewees talked about the health system being under increasing pressure, with reduced capacity, constrained resources, and increasing workloads. This was affecting practice, causing certain activities to be compromised. Several HCPs spoke of their desire to be more proactive in regularly contacting and 'checking in' with their patients and spending more time with them. However, they were often having to adopt a 'call us when you need us' approach instead, which many HCPs saw as unsatisfactory both for the patient and themselves. HCPs also expressed dissatisfaction at the limitations of other services for patients. Specific issues with vacancies and short staffing in services meant delays and long waiting times for people to access support.

Findings highlight the everyday experience of having emotionally testing conversations with patients and their FCs, whether about their diagnosis, their treatment options or managing people’s expectations for the future. HCPs talked about the fine line between trying to manage expectations about what is viable in terms of treatment while also recognising that people need a sense of hope.

Several HCPs talked about how they felt practically, emotionally, and psychologically supported at work, enabling them to develop their clinical and interpersonal skills, and to build and maintain their resilience in order to cope with the realities of their everyday interactions with patients and FCs.

The findings demonstrate that HCPs are not always able to deliver the care and support that they would wish to provide.

Chapter 7 – Case assertions or lessons learnt

7.1 Introduction

Taken together, the preceding two chapters provide a detailed analysis of patient and FC experiences of receiving supportive care, and the experiences of HCPs in providing such care. This chapter brings these different perspectives together, combining analysis themes from Chapter 5 and contextual themes from Chapter 6 - a feature of case studies (Creswell and Poth, 2018) in order to develop a series of case assertions, or lessons learnt about the case (Stake, 2005). These assertions are also supported by the literature.

The combining of data was facilitated firstly, by both data sets being derived from semi-structured interviews and secondly, by the approach used to present the findings in each chapter. Hence an issue or gap in service identified by patient or FC participants in Chapter 5 was presented as a service challenge in Chapter 6. It was therefore unnecessary for the researcher to return to the Framework matrices to re-synthesise or integrate these data to develop the case assertions.

These case assertions seek to address the research questions regarding the gaps in supportive care identified by participants. And to determine when they occur, for whom, and in what circumstances? And further, what challenges exist in providing optimal supportive care for this cohort of patients and their FCs.

7.2 Case assertions – lessons learnt from studying 'the case'

7.2.1 Patients and FCs require an urgent response from the health service

The findings suggest that speed of response and effective care coordination are key to optimising supportive care. In the first instance, speed of response is vital in order to optimise patients' QoL and to give them the best chance of having life prolonging treatment i.e. chemotherapy, or symptom management. This may involve 'nutritional rescue', supporting patients with PEI to manage diarrhoea or malabsorption, or for patients with jaundice, stenting to relieve obstructions. This requires referral pathways and diagnostic pathways to be working effectively, ensuring that patients undergo the right diagnostic tests as quickly as possible and that decisions are made on their treatment plan as soon as results are available. Moving patients quickly through the system relies on robust processes and the right workforce in place. However, HCPs noted that speed of response can be compromised due to the complexity of routes to diagnosis and the involvement of non-specialists in some instances such as diagnoses occurring via A&E Departments.

An urgent response is also vital when complications with treatment arise, or the disease progresses, in order to minimise a rapid deterioration in status. Complications and disease progression may be evident through ongoing reviews and follow-up appointments with specialists. However, they are potentially missed during encounters with non-specialist HCPs, such as GPs, as findings here demonstrate.

Furthermore, a timely response is required in all aspects of care to ensure that the experience of patients and FCs is as smooth and stress free as possible and people do not feel that they are wasting their limited time chasing responses from the health services. This encompasses issues such as clinicians responding promptly to patient or FC phone calls or emails, the prompt or pre-emptive provision of information to address queries and concerns, the provision of medication such as pain relief for inpatients, or prescriptions for PERT from GPs, and referrals to supportive care services or other forms of advice or support, including palliative care. HCPs noted that issues with workforce shortages and workload often meant a timely response was compromised in these circumstances – see section 7.2.8 below.

The academic literature is largely silent on speed of response for this cohort of patients and their FCs except in relation to referrals to palliative care – see section 7.2.2 below.

7.2.2 Significant gaps exist in care coordination

The importance of care coordination, and the need to improve aspects of this process, were clearly evident in interviews with patients, FCs, and HCPs alike, and reflect findings from other studies, (Hagensen et al., 2016, Beesley et al., 2018, and Khan et al., 2022). Knowing who had overall responsibility for managing their care and understanding who to contact, when, and in what circumstances, was often confusing for patients and FCs – a gap also highlighted in Chong et al.'s review (2023) of unmet caregiver needs.

The literature notes the positive contribution made to a patient's experience through access to a cancer care coordinator and/or a palliative care team (e.g. Khan et al, 2022). Specifically, the involvement of a CNS has been shown to have a direct and positive impact on clinical care (Pollard et al., 2010), with their involvement resulting in helpful explanations of the patient's diagnosis, general provision of information including medication advice and ensuring appointments and investigations happen as quickly as possible – all vital aspects of care in the early stages following diagnosis. And yet this research shows that care coordination was sometimes problematic at specific time points, and in particular care settings.

A first gap in care coordination occurred at the point of initial diagnosis, when people felt they were left in limbo without the specialist clinical support that would usually be forthcoming following a tissue biopsy and a definitive diagnosis. This lack of specialist support may extend for a number of weeks after initial diagnosis, depending on the speed at which further diagnostic tests may occur and the frequency of MDT meetings.

There are challenges in determining who is best placed to support people at the point of initial diagnosis as a small number of people with suspected pancreatic cancer will go on to have a different diagnosis confirmed, which is *not* pancreatic cancer. However, organisations should prioritise how to provide dedicated support at the earliest possible point in the patient's cancer trajectory, to ensure patients and FCs are not left feeling alone and anxious.

A second gap in care coordination occurred when patients were admitted to hospital in an unplanned emergency without their clinical care team's knowledge. This meant that people were often not seen by their specialist consultant or their CNS while an inpatient, which could cause issues in terms of appropriate investigations or the delivery of suitable care.

A third gap occurred for people who were not receiving active treatment but did not yet require EoL care, leading to feelings of isolation and anxiety, without any regular contact with HCPs. HCPs suggested that ideally, patients should be known to their local community palliative care services from an early stage to ensure their care could be effectively managed, when required. However, as reported in Chapter 6, patients are often not accepted by palliative care services if they have no specific need for such expertise in symptom management at the time of referral. These issues reflect the barriers to referral identified in the literature relating to organisational and resource issues (Pilgrim et al., 2023).

Pilgrim et al.'s research also noted patient and FCs' misunderstandings about the nature of palliative care can act as a barrier to referrals. More needs to be done to promote the role of palliative care services to people, in order to pave the way for planned or systematic referrals, given the strong evidence for clinical, emotional and informational benefits for patients and their FCs (Gonzalez et al., 2023, Lees et al., 2019, Schenker et al., 2018, Maltoni et al., 2016 and Miinalainen et al., 2022), as well as opportunities for enhanced care coordination in the community.

The transfer of information between hospitals and GP practices, and the way in which GP practice systems are set up to 'triage' that information, can also create challenges for effective care co-ordination according to the findings presented here. Technological advances have changed the ways in which healthcare organisations communicate with other organisations, and with patients and their representatives but while such changes have led to significant improvements such as speeding up the transfer of clinical information between parties, there are indications that the automation of information exchange has created new challenges.

A number of patient participants felt their GPs were unaware of their diagnosis, or how they had come to be diagnosed. The Gold Standards Framework (see section 2.15) supports patients with inoperable pancreatic cancer being placed on a register for people with a terminal illness and their care actively monitored and managed by their GP practice. However, the findings suggested little evidence this was happening, in part due perhaps to the oversight of vital information exchanged between parts of the system.

Collaço et al.’s scoping review (2024) of the barriers and facilitators to better integration in cancer care between primary and secondary care, made several recommendations for improving care. These included more clarity between the role of primary care and the oncologist, and more effective communication and engagement between the two parties. The authors concluded that information sharing and communication between primary and secondary care must improve to support people more effectively.

The introduction of other technology in primary care such as E-consult forms could also affect care co-ordination, according to patient and FC participants. E-consult forms are designed to enable patients to electronically request a GP consultation but while these may work well for some people, standardised forms tend towards the ‘one size fits all’ approach. These can make the process of accessing a GP more complicated and stressful for some patients, especially those with complex needs, while the limitations in what details can be provided on these forms can make it difficult for an HCP to determine the most appropriate course of action.

7.2.3 Unmet physical needs exist specifically in relation to PEI and PERT

Most of the patients interviewed for this research talked about their struggles to manage their pancreatic function, with variable experiences of receiving information and support. Though nutritional needs occurred throughout the pancreatic cancer trajectory, there was a specific gap identified at the point of diagnosis. Without specialist support, patients were either not being started on PERT, or were started on it but without proper instructions about how to manage their dosage. Significant variation in PERT prescribing patterns was highlighted in the RICOCHET audit (Lemanska et al, 2023), referenced in Chapter 4.

From the research findings, access to a specialist HPB dietician was key to ensuring that people's nutritional needs were well-managed – a point also made in the literature (Gooden and White, 2013) - but capacity constraints hampered optimal care. This could have been ameliorated to an extent if other HCPs, including GPs, had a better understanding of PEI and PERT.

FCs were also affected by their family member's nutritional needs, increasing their distress when they did not know what to do to help. These findings are also in accord with earlier studies (Wong et al., 2019 and Gooden and White, 2013).

7.2.4 Unmet psychological and emotional needs exist which are particularly acute at diagnosis

As the literature notes, people with pancreatic cancer are recognised as a group at high risk of experiencing psychological stress (Mazzella Ebstein et al., 2020) and yet there was little evidence from the findings of routine assessments of patients' psychological or emotional needs taking place, and/or subsequent referrals to appropriate services when necessary.

According to NICE guidance (2004), psychological assessment and intervention, at least at Levels 1 and 2 (generalist, rather than specialist support), is everyone's responsibility. This means that nurses, GPs, oncologists, and palliative care physicians all have an important role in the psychological care of patients and carers, including assessment of needs.

No single HCP has ultimate responsibility or accountability for ensuring psychological needs are assessed and addressed. In practice, this is usually assumed to be the role of the CNS, using the HNA process as the mechanism by which this happens, though as described in Chapter 6, the process of undertaking an HNA with this cohort of patients is challenging.

A clear gap in the psychological and emotional support offered to patients and FCs was identified at the point of diagnosis – a time of immense emotional turmoil (Engebretson et al., 2015). This could potentially be met with the skilful intervention of an experienced CNS, taking time to talk people through their diagnosis and prognosis and its implications and signposting to additional sources of support but this was not always available to people. CNSs interviewed for the research noted that issues with capacity meant their ability to spend time in this way with patients and FCS was often compromised.

Where NHS psychological support services were available to people, there were often long waiting times to be seen and no evidence of a fast track service for patients with limited life expectancy. When psychological support was provided, it was done so on a scheduled basis which some patients found unhelpful, as this didn't necessarily meet their needs for a more responsive service.

7.2.5 Unmet information needs exist across the cancer trajectory

The findings highlighted that patients' and FCs' information needs were not met at all stages of the pancreatic cancer trajectory. Unmet information needs were identified relating to several different aspects of care. This included understanding what the chain of events would be from the point of diagnosis i.e. what diagnostic tests and consultations would happen and what symptoms and side effects patients and FCs may need to keep an eye on – for example with regards to bowel obstructions, or sepsis. These gaps in knowledge are picked up in the literature with Beesley et al.'s study (2018) finding that patients and FCs lacked confidence in recognising the range of symptoms they should monitor, and be alert to, with regards to disease progression.

Patients and FCs also lacked information to assist them with decision making, for example, understanding the potential side effects of chemotherapy in order to weigh up the risks versus benefits of continuing with treatment. Ziebland et al. (2014) suggested that when statistics are available, and the patient expresses a wish to be involved in decision-making, doctors should provide clear information about the potential side effects of chemotherapy, balanced against the length of time treatment might prolong life. The authors refer to Audrey et al.’s observational study of oncology consultations (2008) which included 13 with pancreatic cancer patients. Audrey et al. found that in most consultations, information was given about possible side-effects of chemotherapy, but information about the survival benefit of palliative chemotherapy ‘was either vague or non-existent’ . They suggest that ‘If patients do not know how much longer they are likely to live with any particular treatment and, crucially, what evidence there is about QoL, they cannot make informed treatment decisions,’ (Audrey et al., 2008, p3310).

What was also striking from the findings was the lack of specialist pancreatic cancer information provision for patients and FCs, with few participants receiving tailored resources, such as information booklets from specialist charities, or being signposted to specialist charity websites. Participants also expressed gaps in information, resources, or support to facilitate conversations with other family members, particularly children who were older teenagers, or young adults – a need also identified by Hagensen et al.’s study (2016).

It is apparent that the kind of information people are provided with was largely written material. It is generally provided once, in the form of a folder with multiple inserts, covering a complete range of topics, which patients and FCs may or may not be guided through by their CNS, and which may or may not be tailored to their specific circumstances. Other modes of information do not appear to be routinely provided, though they have been shown to have a positive impact on patients i.e. (Munigala et al, 2018).

In addition to the need to provide information in different formats, two other significant challenges were apparent in the findings. Firstly, HCPs need to determine when to provide information to patients and FCs. This obviously requires HCPs to have well developed skills in ‘reading the situation’ and recognising a patient’s level of understanding and emotional state. HCP participants in the study also observed that their ability to provide information was also dependent on logistics, such as having the space to store information booklets. Given the varied routes to diagnosis, it is possible that in many instances, the HCP ‘breaking the bad news’ to patients would not have access to any specialist material on pancreatic cancer, leading to the initial information gap highlighted in the findings.

The study also identified that HCPs may make assumptions as to what information may have already been provided to, or heard by, patients. For example, GPs might assume that patients have been provided with tailored information relevant to their type of cancer by their CNS. However, the study data suggest that CNSs usually provide patients with more generic information, often for the simple reason that they are unaware of the literature available through specialist organisations such as PCUK, or because they did not have the physical space to store cancer type-specific information in their offices. They may also not be able to transport information packs between office and clinic. Opportunities to supplement more generic information with specialist information, or signposting to more specialist information, may therefore be missed by other HCPs, because of the assumption that this has already been supplied.

HNAs could be a means by which the information needs of patients and FCs could be identified and addressed. However, as is apparent from the findings, they are not always happening for several reasons as highlighted in Chapter 6.

The second challenge for HCPs in the provision of information is knowing what might be beneficial to, and wanted by, patients and their FCs. A number of patient participants indicated they wanted to discuss their prognosis, and how long they might have to live, with their consultant, to help them plan and make decisions for the future but this conversation appeared difficult to broach. This aligns with the findings from Clelland et al.'s study (2023) that found that only 60% of patients had a prognosis discussion recorded has having happened in their notes. The literature suggests that this omission may be due to the difficulties associated with providing accurate estimates; also clinicians are unsure whether people want to know this information (Johnson et al, 2023); and partly because talking about prognosis can be an emotionally challenging conversation to have with a patient (Daugherty and Hlubocky, 2008).

The findings also show that while services such as support groups and emotional support through specialist charities or other cancer organisations, exist for FCs, they don't always know what's available locally. Whilst difficult for HCPs to keep up to date with everything that might be available locally for people to access, there are other means of signposting people to this kind of information, such as via the

Cancer Care Map[10] ,which provides up-to-date information free of charge to people through its website. This is also the information that care navigators or social prescribers[11], based within some GP practices, should be able to provide.

The consistent theme from the findings is that patients and FCs want more information than they were given, and that HCPs assumed they needed or wanted.

7.2.6 Family carers experience significant unmet needs

There was little evidence from the findings that HCPs considered the emotional support needs of FCs, nor provided any. This was despite the obvious emotional, psychological, and practical demands being made on FCs by their caring role – demands which are also evident from the literature (Chong et al., 2023, Huynh et al., 2023, Dengsø et al., 2021 and Gooden and White, 2013). The lack of adequate information available to help FCs to fulfil their caring role also reflects the findings from earlier studies (Huynh et al., 2023 and Chong et al., 2023).

Several FCs talked about the spillover effect of their family member's cancer on other parts of their life, such as their social, family or work life. To cope with these emotional and psychological demands, FCs largely drew on their own networks of friends and family for support, though this could prove problematic if FCs did not want to burden their adult children or friends with their distress and worry.

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[10] The Cancer Care Map is an online resource to help people find care and support services in their local area, anywhere in the UK. The website is run by cancer charity, The Richard Dimbleby Cancer Fund.

[11] Social prescribing 'is an approach that connects people to activities, groups, and services in their community to meet the practical, social and emotional needs that affect their health and wellbeing,' NHS England » Social prescribing. – accessed 23.06.24

There also appears to be a gap in what bereavement support is available to FCs. HCP participants suggested this depended on the capacity within local services, often delivered by third-party organisations. The relationship that a FC has with their GP may help to initiate or fast-track such support. However, there was little evidence that this was the case.

The findings also show that while the gaps in support for FCs may arise from a failure to provide relevant information, FCs may also be reluctant to express their own needs, given the priority they assign to their family member's situation. HCP participants suggested that unless a FC specifically expressed a need, they could be overlooked in a time-restricted consultation when the HCP's priority would always be the patient. HCPs may therefore overlook needs because they are being suppressed or minimised by FCs.

In the literature, Brown and Bliss (2023) suggest that community nurses are well placed to observe carer distress and to make onward referrals for support, or signposting to relevant resources or agencies, where necessary. While this seems an entirely reasonable suggestion, the practicalities of this require the meaningful involvement of community nurses in the patient's care, a situation which is variable, as the findings from this research indicate.

7.2.7 Poor patient and FC experiences exist across the cancer trajectory

While the intention of this research was to identify gaps in the provision of supportive care, as mapped to the domains incorporated in Fitch's Framework, her clinical standards (1994) and conceptualisation of needs (2008), it is apparent from the findings that identifying these gaps and shortfalls does not address all of the issues that were raised by patient and FC participants.

Other issues raised by patients and FCs highlight experiences of care that could be considered poor. In some instances, these experiences were related to delays in care pathways or delays in other aspects of care such as receiving information or support – or times when promised actions simply did not happen, or telephone calls or emails went unanswered. In other instances, these experiences were related to mistakes and oversights, such as confusion over the dosage for chemotherapy drugs meaning they could not be administered, scans that were undertaken but results overlooked, and pain relief that was not given regularly, or on request in inpatient settings.

Participants also talked about poor experiences of care related to interpersonal communication. When the scope for medicine to prolong life, or even to make a significant difference to someone's QoL, is limited, it is apparent from this research that other aspects of care and support, such as empathetic communication and being treated with compassion, became increasingly important to patients and FCs – a priority also identified by earlier research (Saunders et al., 2009). Several patient and FC accounts highlighted upsetting encounters with HCPs, when it was felt they were unsympathetic and lacked compassion – a situation highlighted well over a decade ago (Saunders et al., 2009). In some cases, patients and FCs felt this was a problem with the individual HCP's personality, while in others the issue related to the context in which difficult news was imparted.

There were specific points in the care pathway where HCPs acknowledged that conversations with patients and FCs could become increasingly difficult and they had observed variations in competence among colleagues in how these conversations were managed. It was noted that while a skilfully managed conversation between a patient and a clinician who explains the scenario properly, could help the patient accept the situation, a poorly managed conversation could leave people feeling resentful and written off.

7.2.8 Capacity issues constrain the provision of optimal care

Many HCPs in the study talked about the ways in which their practice was affected by workforce capacity issues. This was particularly the case with the CNS workforce and specialist dieticians and these constraints affected both the provision of specific tasks such as HNAs, or more fundamentally, and yet harder to quantify, the ongoing day-to-day support of people.

Securing the funding for new nursing posts specifically was reported as challenging by several HCPs. It was suggested that in comparison to other cancer types, CNSs supporting pancreatic cancer patients tend to see fewer patients but spend longer with each. The nature of the work undertaken by CNSs varies considerably depending on their specialism but as more than one HCP noted, these nuances are difficult for provider organisations to articulate to commissioners of services who may be more amenable to funding high volume activity, and defined clinical outcome targets, rather than activity which is about supporting someone to optimise their QoL for as long as possible.

Interviews with patients and FCs also highlighted their reluctance to ‘waste’ people’s time or be ‘a burden on the system.’ Patients and FCs were attuned to the pressures on the system and examples were given in interviews of the ways in which people had moderated their behaviour as a result of this awareness. This was particularly the case when people were either making decisions about whether to contact their CNS for advice or information, or whether to raise concerns about their care.

The NHS is estimated, on a full-time equivalent basis, to be short of 189 clinical oncologists, 390 consultant pathologists and 1,939 radiologists, and will be short of 3,371 CNSs by 2030 (HM Government, 2022). All of these posts have a direct impact on the services provided to people with cancer as these shortfalls are likely to lead to delays for diagnostic tests, results, chemotherapy and specialist nursing support.

7.2.9 Significant ‘emotion work’ is required from HCPs to support people with inoperable pancreatic cancer

HCPs talked about the emotional challenge of supporting people affected by inoperable pancreatic cancer, given their poor prognosis. This was particularly the case for those HCPs whose work consisted mainly of supporting this cohort, such as the CNSs and specialist dieticians. Specialist staff working with other cancer patients are likely to have a more mixed caseload where the prognosis for many patients would not be as stark and survival rates are better – there is therefore more ‘balance’ in the day-to-day work of other specialist cancer staff. For HCPs caring for patients with inoperable pancreatic cancer, there are not the same success stories to share and celebrate.

HCPs caring for this cohort of patients and their FCs are therefore likely to undertake significant emotion work and maintaining this could prove stressful and exhausting over time, leading to compassion fatigue – a phenomenon originally identified in a study of nurses working in an emergency department (Joinson,1992). It was later defined to mean ‘a state of tension and preoccupation with the individual or cumulative traumas of clients,’ (Figley, 2002). Compassion fatigue occurs in those who expend high levels of energy and compassion on patients over a period of time, who may not then reap the positive benefits of seeing people get better (McHolm, 2006) - a particularly relevant feature in this context.

7.3 Summary of chapter

This chapter has set out a series of case assertions, or lessons learnt about the ‘case’ – the provision of supportive care for people affected by inoperable pancreatic cancer. These have been drawn from the data from interviews with patients, FCs and HCPs and are supported by the literature presented in Chapter 3, and additional evidence and conceptual ideas, where appropriate. The case assertions address the study’s first two research questions – ‘What gaps exist in the provision of supportive care?’ and ‘What are the challenges in providing optimal supportive care?’

The following chapter considers the implications of these case assertions for policy, practice, education and research. This discussion is contextualised by drawing on existing conceptualisations of supportive care and patient experience. These conceptualisations are also critiqued for their relevance in this context. A series of recommendations are subsequently proposed in response to the study’s third research question - how can these challenges be addressed to help reduce these gaps and optimise the care pathway?

Chapter 8 – Discussion and recommendations

8.1 Introduction

This chapter discusses the implications of the case assertions, reported in the previous chapter, starting with a description of what 'optimal supportive care' could look like for people affected by inoperable pancreatic cancer. The description is extrapolated from the data gathered from interviews with all participants and contextualised by drawing on existing conceptualisations of supportive care and patient experience. These conceptualisations are also critiqued for their relevance in this context.

A series of recommendations are subsequently presented. These were developed to address the issues evident in the case assertions and were refined with input from stakeholders (see section 8.4 below). Examples of good or existing practice are provided alongside these recommendations, together with relevant policy and strategy documents (see Table 8 below).

The chapter concludes by considering the feasibility of these recommendations drawing on the wider literature relevant to the points raised, and to the implementation of change in general.

8.2 What would optimal supportive care look like for people affected by inoperable pancreatic cancer?

Patient and FC participants in the study wanted supportive care that was well co-ordinated, responsive, timely and compassionate. They wanted to know who to turn to for advice and support at all stages of their cancer trajectory and they wanted to know what was going to happen, and when, in relation to diagnostic tests, appointments, referrals to other services, treatment decisions and treatment initiation. Patients and FCs needed information that was accessible and tailored to their own circumstances and to know what other support and resources were available to them. They wanted their specific supportive care needs, whether physical, psychological, emotional or practical etc. to be acknowledged and addressed appropriately and speedily.

Patients and FCs felt the HCPs that they came into contact with should know their diagnosis, the implications of their prognosis, and their treatment plan, regardless of care setting, so that they did not have to keep repeating the situation or explaining things. They wanted to be listened to, have their opinions respected and their questions answered. Patients and FCs felt they should be treated as individuals, with empathy, and with an appreciation of their particular situation.

HCP participants felt services should be adequately staffed to provide people with rapid access to testing and result reporting and processes that would allow for rapid decision making about treatment plans. They wanted to be able to better support people in their care by having the time to undertake a comprehensive assessment of their needs and to subsequently be able to make referrals to a range of supportive care services that were adequately staffed to rapidly meet these needs. They wanted to have the time to support people when they needed advice or information and they wanted to be able to proactively review patients. HCPs themselves needed access to the right information and support in order to care for this cohort of patients to the best of their ability. Ultimately, they wanted to treat people with compassion and kindness.

8.3 Conceptualisations of supportive care

So much of what patients and FCs felt they needed for supportive care to be optimal was about their experience overall, rather than specific interventions. It is suggested that the original intention of Fitch's Framework – the conceptualisation of an approach to care delivery which considers the entirety of a patient's experience, has been eroded over time, so that supportive care has become fragmented and disparate with a focus instead on discrete interventions to address specific health outcomes (Krishnasamy et al., 2023). The quality of the patient and FC experience of care is therefore largely considered in relation to whether certain interventions happen or are effective, i.e. whether a patient sees a specialist dietician, or whether a psychological intervention helps improve anxiety or depression. While these separate components of care are clearly important for symptom control and improving QoL, a compartmentalised way of thinking neglects overarching components of care such as efficient care coordination, a sense of urgency in responding to patients and their FCs, and empathetic communication – all issues which are highlighted in the preceding case assertions in Chapter 7.

A response to this fragmentation has been offered by Krishnasamy et al.'s reframing of supportive cancer care (2023). Their framework moves away from a conceptualisation of supportive care as a component of cancer care to a conceptualisation where all cancer care takes place within a supportive care framework. Krishnamsamy et al. recognise the complexity of supportive care in their attention to multiple domains, and the incorporation of the ‘inputs’ which enable supportive care to be delivered, the ‘processes’ which supportive care may involve, and the ‘outputs’ which supportive care may achieve. However, they do not explicitly articulate the importance of the patient experience, referring instead to overarching imperatives of supportive care service delivery e.g. care that is evidence-based, comprehensive, integral, timely, and multi-speciality.

Patient experience frameworks

A number of generic patient experience frameworks have been developed for use in healthcare systems (e.g. WHO, 2003 and IOM, 2001), including the Department of Health’s NHS patient experience framework (DH, 2011), based on work previously undertaken on the principles of person-centred care by The Picker Institute (1987). NICE also published Patient Experience Guidance (CG138), (subsequently revised in 2021), informed by the Warwick Patient Experience Framework (Staniszewska et al. 2014). Though the frameworks differ in detail, there are common themes or domains which are seen as critical to a high quality patient experience, such as physical comfort, emotional support, continuity of care, effective communication, the provision of appropriate information and the treatment of the patient as an individual, respecting their preferences and treating them with dignity and compassion.

A cancer specific patient experience framework - the Comprehensive Cancer Experience Measurement Framework (CEMF) (Loiselle et al., 2019), has also been developed to guide the assessment of person-centred experiences and cancer care system performance. It is a comprehensive presentation of four inter-related aspects – the patient perspective, the family perspective, the shared patient and family perspective and interactions with the healthcare system. This latter aspect is described by the authors as denoting ‘individuals’ experiences with healthcare settings that represent the system’s ability to contribute to person-centered care,’ (Loiselle et al., 2019 p2582). The CEMF demonstrates the complexity of the cancer patient experience framework and emphasises interactions with HCPs, and communication, as key features.

Communication as a fundamental aspect of patient and FC experience

Communication is recognised as a core clinical skill and therefore a core curriculum element in medical curricula (Gilligan et al, 2020), and curricula for nursing and other students pursuing clinical careers. Advanced Communication Skills Training (ACST) is also available for HCPs who are regularly involved in complex, difficult or challenging conversations with patients or FCs. CNSs would be expected to complete this advanced training while doctors continue to develop their communication skills in practice as part of their ongoing training, once qualified. Indeed, they are examined on communication skills as part of their Practical Assessment of Clinical Examination Skills (PACES) for membership of a Royal College i.e. MRCP (Membership of the Royal College of Physicians).

In spite of the instruction provided during training, and additional training provided post-qualification, the need to improve interpersonal communication in general between HCPs and patients and FCs has been the subject of much debate in the literature (e.g. McDonald, 2016), and continues to be debated as shortfalls in practice continue to be highlighted (Brunton-Douglas et al, 2023).

There is also a well-established body of literature which relates to the challenges of communicating with people who are terminally ill e.g. Clayton et al.'s systematic review of literature regarding the sustenance of hope when communicating with terminally ill patients and their families (2008) and Daugherty and Hlubocky's survey of oncologists in the US (2008) which reported that doctors found prognosis discussions challenging. Almost three-quarters of respondents (73%) noted that education in prognosis communication was either absent or inadequate during their training, yet almost all (96%) believed it should be part of cancer care training.

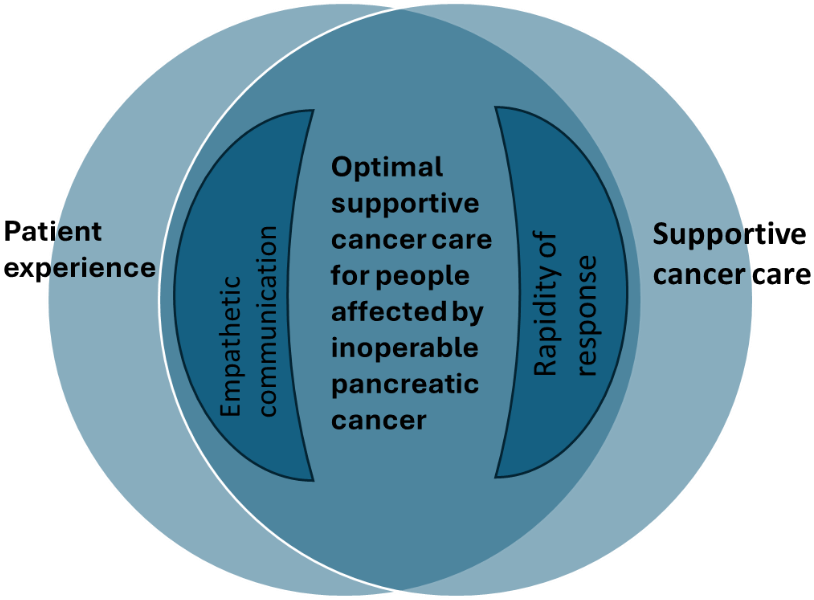
Clayton et al. (2008) note that initiating conversations about prognosis requires skill and sensitivity, in order for the HCP to clarify the understanding of the patient and FC about the situation, and to gauge how much information they want to know. Their study also highlights the importance of the patient's relationship with the HCP to facilitate these difficult conversations. The challenge however is how to establish these relationships in practice when such a conversation may happen at the first meeting between a specialist and a patient with inoperable pancreatic cancer , when no relationship has yet been established, or when there is a lack of continuity of care and patients are seeing different HCPs at appointments.

A model of optimal supportive care for inoperable pancreatic cancer

A conceptual framework for optimal supportive care should incorporate domains considered relevant to the provision of an optimal patient and FC experience, in addition to domains relevant to the provision of supportive cancer care to meet specific needs. This could be conceptualised as shown in Figure 5 below. While there is an almost complete overlap, there are some aspects of supportive cancer care which are not relevant for people affected by inoperable pancreatic cancer such as cancer survivorship support and some aspects of patient experience which may not be as relevant for this cohort.

To refine the conceptualisation, components of supportive cancer care and patient experience frameworks such as the service imperatives from Krishnasamy et al.'s supportive care framework (2023) and interactions with the health system from Loiselle et al.'s CEMF (2019) need to be accentuated to recognise the distinct needs of this cohort of people for a rapid response from healthcare and compassion.

Fig 5: A model of optimal supportive care for inoperable pancreatic cancer



The recommendations that follow later in this chapter therefore address both those case assertions which comment on specific supportive care needs for people affected by inoperable pancreatic cancer such as the provision of better support to manage PEI and those that address more fundamental aspects of patient experience such as effective care coordination and empathetic communication.

8.4 Sharing findings with stakeholders and development of recommendations

As noted in Chapter 4, the extended recruitment period for the study meant the workshops originally intended to be used as fora for discussing the findings and potential recommendations with study participants had to be reviewed.

Instead, a summary of the findings was produced to ‘sense test’ with various stakeholders. The summary was published in PCUK’s RIN newsletter in late February 2024 with an invitation for people to provide feedback if they wished to do so (see Appendix A23). In addition, the summary was sent to the three FCs who had wanted to take part in the study but who had not been eligible. These individuals had previously been offered the opportunity to see a summary as a means to involve them in the study in some way, and they had expressed an interest in doing so. The summary was also sent to one of the participating FCs who had indicated a specific interest in the outcomes, as well as a number of clinicians at the participating NHS sites who were not in the CAG, and the specialist nurse team at PCUK.

Feedback on the findings was subsequently received by email from three FCs and two HCPs. Of these respondents, two of the FCs were female and one was male.

One of the FCs was the daughter of a patient who had died, one was the wife of a patient who had died and one was the son of a patient who was still receiving treatment at the time. One of the FCs responded following the publication of the summary in the PCUK newsletter, one responded to an email from the researcher inviting their comments as they had previously expressed an interest in taking part in the study but were not eligible to do so, and one of the FCs who responded was a study participant. It is not possible to provide further demographic details regarding the age or ethnicity of the two female FCs as these details were not requested, as this activity was deemed PPIE and not research. The approximate age of the FC who was a study participant is provided in Table 5 but due to the small number of participants, ethnicity has not been shown at the individual level in Table 5 as this may have risked the participant being identified. Both of the HCPs who responded were female specialist nurses.

The comments from respondents indicated that the findings resonated well with their experiences and that they felt all the key issues and concerns had been captured well and presented sensitively. The key issues that were highlighted i.e. speed of response, care co-ordination, information provision and communication were agreed as being priority areas. The HCPs provided feedback on the variations in service provision and the inequity of access to services for inoperable patients within the findings. They also commented on the inability to address people’s holistic needs satisfactorily, and the difficulties in making a business case for additional capacity for this patient cohort. This feedback provided the researcher with reassurance regarding the salience of the findings and reinforced priority areas for developing recommendations.

It is possible that had the demographic profile of these stakeholder respondents been different, alternative comments may have been provided. For example, if patients had responded rather than FCs, or if doctors had responded rather than specialist nurses. However, given the common issues that were raised by patients and FCs alike and by all HCPs, it is unlikely that there would have been significant differences in opinion.

Draft recommendations were subsequently shared with the CAG, a representative of a national network of HPB CNSs, and a number of other contacts within the pancreatic cancer community. A series of Zoom meetings were convened with these individuals to discuss the draft recommendations in person. In addition, feedback was received by email from one of the CAG members who could not attend a meeting.

In total, ten stakeholders responded with comments - six HCPs, including three CNSs, one oncologist and two HPB Clinical leads, one FC and three individuals with national roles promoting quality improvement within the delivery of pancreatic cancer services. This feedback has been helpful in providing another ‘sense check’ of feasible solutions to incorporate into practice, and in some instances highlighting potential implementation challenges. Stakeholders also indicated examples of good practice and resources they were aware of which could be incorporated, and these are included below.

8.5 Recommendations

Table 8 provides a summary of the recommendations before each is described in detail. The table also highlights the relevant case assertion for each recommendation and provides illustrative data from interviews, and feedback from stakeholders on the research findings and recommendations, providing further support for the inclusion of each recommendation. Where relevant, supporting policy documents and strategic developments are also indicated.

Table 8: Summary of recommendations

ID	Recommendation	Case Assertion	Illustrative data from interviews	Illustrative data from feedback on findings and recommendations	Supporting Policy and strategic developments
1	Timely access to specialist CNS support	Patients and FCs require an urgent response from health services Significant gaps exist in care co-ordination	*'The only contact details we were given were for the gastroenterologist's PA. The consultant just said, ' You'll get a clinic letter'. 'It felt like we were left in limbo, we didn't know what the next steps would be.' - FC* *'… it would be so amazing if those clinicians could contact (CNS name) team and say to them, 'Look, I have this patient…I've given them a diagnosis, can you give them a ring before they see an oncologist?' … Because what happens is I don't hear about these patients until they get to the MDT so that could be a delay of another week, or even two weeks and then by the time I see the patient after the MDT, it's another week…' - HCP*	'The CNS sits in on the consultation and then takes them to another room for a long chat. The problem is the consultants see the patients much quicker than the nurses, so some people won't get seen [by CNS] in the clinic.' - HCP	National Pancreatic Cancer Audit PCUK Optimal Care Pathway (See Chapter 2 sections 2.2 and 2.4)

ID	Recommendation	Case Assertion	Illustrative data from interviews	Illustrative data from feedback on findings and recommendations	Supporting Policy and strategic developments
2	Introduction of fast-track referrals and pathways for services	Patients and FCs require an urgent response from the health service Unmet physical needs exist specifically in relation to PEI and PERT Unmet psychological and emotional needs exist particularly at diagnosis	'*...we do have access to clinical psychology here, but they're not easy to access...often months in advance, (for) newly diagnosed patient who's struggling with a diagnosis, it's just not practical, it's really not helpful actually*.' – HCP *'there's no pathway that we can try and avoid ED when patients are unwell, because it's the only thing we've got....they do end up having to sit in A&E for hours, ... before we can get them a bed, and when someone is in a situation like our pancreatic cancers are it's not great for them.'* -HCP	'The on-call surgeon is alerted and will try and see them quickly and there is an overspill ward.' – HCP	Digestive Cancers Europe Call for Action NICE Guideline for EoL Care (See Chapter 2 sections 2.5 and 2.11
3	Provision of information on Pancreatic Enzyme Insufficiency (PEI)	Unmet physical needs exist specifically in relation to PEI and PERT	*I wasn't told to go to your doctor once they've gone [PERT tablets] because I've always got to take them. … [consultant oncologist's name] – she said, 'Well you should have been taking them.' And I said, 'Well they didn't say that to me. They never said a word.' - Patient*	I think the conclusion needs to reiterate the need for better coordination in the timely provision of effective practical treatments such as nutrition and digestion advice. - FC	NICE Guidelines NG85 PCUK Patient Charter (see Chapter 2 sections 2.7 and 2.8)

ID	Recommendation	Case Assertion	Illustrative data from interviews	Illustrative data from feedback on findings and recommendations	Supporting Policy and strategic developments
4	Optimise the functionality of existing hospital-based IT systems	Significant gaps exist in care coordination	*'…she sometimes had to wait hours for pain relief and once she rang me in agony late at night asking me if I could ring the ward and ask them to give her, her medication!'- FC*	'The emergency alert on EPR is useful. At the [name of hospital]they get an email for every emergency admission.'- HCP 'All interactions are written here [Somerset Cancer Registry] but it doesn't get pulled into EPR.' - HCP	Digestive Cancers Europe Call for Action NICE Guideline for EoL Care (See Chapter 2 sections 2.5 and 2.11
5	Early introduction of Community Palliative Care Services and Advanced Care Planning	Significant gaps exist in care co-ordination	*'But you know at this point, apart from the paramedic [999 call response], she hadn't seen a doctor, she hadn't, no doctor had come to the house, no nurse had come to the house, it was really a lot of being left to sort of get on with it a bit.'* –FC	'The CNS only has a quick chat if they're going on the palliative route, then we don't see them again. We don't provide any leaflets about the community palliative service – do Macmillan do a leaflet?' - HCP	PCUK Patient Charter NICE Guidance for EoL Care NG142 Cancer Care Reviews Gold Standards Framework (See Chapter 2 sections 2.7, 2.11, 2.14 and 2.15)
6	Facilitate primary care access to specialist support	Significant gaps exist in care co-ordination	*'… there are lots of interim condition-specific questions that actually there's no-one to turn to and no-one to get advice from, and personally, I think that there's quite a big communication void.'* - HCP	'The clinical letter [to the GP] needs to include CNS details.' - HCP 'The CNS number was taken off the clinical letter – they used to be on there – usually it's just the secretary's number now.' - HCP	PCUK Patient Charter NICE Guidance for Eol Care NG142 Cancer Care Reviews Gold Standards Framework (See Chapter 2 sections 2.7, 2.11, 2.14 and 2.15)

ID	Recommendation	Case Assertion	Illustrative data from interviews	Illustrative data from feedback on findings and recommendations	Supporting Policy and strategic developments
7	Promotion of existing resources and support to patients and FCs	Unmet information needs exist across the cancer trajectory	*'And Pancreatic UK have got some great resources that we can ask people to have a look at but that's not something that I do that regularly… There's no reason why I couldn't utilise those resources more.' - HCP*	'People get too many bits of paper. We use the PCUK operable and inoperable packs and we also have a stand in clinic in a prominent place with information leaflets.' - HCP '…the powerful contribution that PCUK can make in supporting patients with practical advice.' - FC	NHS England Timed HPB Cancer Diagnostic Pathway Digestive Cancers Europe Call to Action PCUK Patient's Charter NICE Guidance for Carers NG150 (See Chapter 2 sections 2.4, 2.5, 2.7 and 2.16)
8	Introduction of information checklist	Unmet information needs exist across the cancer trajectory	*'… the first day when he came home after his first chemo, again cause I couldn't be there, he had this bag of medication, but he had no idea when he was supposed to take it, how he was supposed to take it.' - FC*	'The summary [participant research summary] brings together all the three factors (communication, care co-ordination, information provision) that patients, their family or carers and HCP face when dealing with inoperable pancreatic cancer.' - FC	NHS England Timed HPB Cancer Diagnostic Pathway Digestive Cancers Europe Call to Action PCUK Patient's Charter NICE Guidance for Carers NG150 (See Chapter 2 sections 2.4, 2.5, 2.7 and 2.16)

ID	Recommendation	Case Assertion	Illustrative data from interviews	Illustrative data from feedback on findings and recommendations	Supporting Policy and strategic developments
9	Review additional ways of supporting FCs, other than the provision of information and resources	Family carers experience significant unmet needs	*'I think there needs to be something a bit different to a sicknote, that just says please be aware, employer, this individual is currently working through this domestic responsibility, which has come upon them and is quite all-intensive…' - FC*	'Though the health system is under stress, it would be helpful if the HCPs were aware of how the lack of coordinated services has impacted on the patient and their carers.'- FC	PCUK Patient Charter Gold Standards Framework NICE Guideline for carers (NG150) (See chapter 2 sections 2.7, 2.15, 2.16)
10	Review communication skills training	Poor patient and FC experiences exist across the cancer trajectory	*'…but I did get a feel from him, not that I was complaining, but you know, 'you're 71, you've had life, you know, this is what you've got left sort of thing! It did sort of down you a little…'- patient*	'Our experience of mum receiving the news of her stage 4 cancer after a 10hr wait in A&E was mitigated by the kindness and compassion of the Medical Consultant who broke the news to us in a private area.' - FC	NHS ACCEND Programme (nurses, and AHPs only) Advanced Communication Skills Training GMC revalidation - Domain 2 - Patients, partnerships and communication
11	Review HCP wellbeing support	Significant emotional work is required from HCPs supporting people with inoperable pancreatic cancer	*'And we do often speak about the patients after clinic, so you know we do share an office and it's really helpful to just kind of talk it through with each other particularly if it has been difficult.'* - HCP	"*nor indeed that showing vulnerability was culturally acceptable as a healthcare professional*" does really strike a chord with me as a medical professional as well as being on the other side as patient-carer, how do they (HCP) cope with their work and work load. - FC	NHS England – Health and wellbeing framework NHS Employers – mental health first aiders and wellbeing champions

Recommendation 1 – Timely access to specialist CNS support

The findings from the study clearly indicate variation at what point people have contact with a specialist CNS, and a perceived gap in support for patients and their FCs between the point of diagnosis and their first appointment with a specialist.

The recent Timed HPB Cancer Diagnostic Pathway guidelines indicate that patients should have access to a HPB CNS by a specific point within the pathway, depending on the route to diagnosis and the specific tests that the patient requires to confirm a diagnosis. Organisations should therefore review their own processes for the provision of this kind of specialist support as early as possible in the pathway after their initial diagnosis.

The Bridging Clinic at Norfolk and Norwich Hospital is an example of how one organisation has addressed the early provision of specialist support. The clinic was set up to provide support for people between diagnosis and the start of treatment and focuses on assessment, early symptom management and referral to supportive therapies (Sreedharan et al, 2018). This model of care could be formally evaluated and if the evaluation shows positive outcomes for patients and FCs, it could be replicated more widely.

Recommendation 2 - Introduction of fast-track referrals and pathways for services

Organisations should explore the feasibility of introducing fast-track pathways and referrals to supportive care services such as specialist dieticians, psychosocial support and palliative care for people with inoperable pancreatic cancer. People do not have time to wait days, weeks or in some cases months to access services that may be beneficial.

Fast-track pathways to surgery exist in order to avoid delays through potential complications of pre-operative biliary draining procedures for those patients who are operable (Yannoulias et al, 2021). There is therefore a precedent for establishing pathways that acknowledge the speed of disease progression with pancreatic cancer patients, though surgical outcomes have been given preference in this regard over symptom management and enhancing quality of life. This inequity in approach should be challenged.

Consideration should also be given to implementing pathways for patients who need to access healthcare in an emergency, where these are not already in place and where the emergency is not sepsis related. (Arrangements already exist for people to contact their acute oncology team in the event of suspected sepsis while on treatment.)

Cancer Urgent Assessment Pathways (CUAC) enable patients to be seen and assessed quickly, avoiding the need to wait in A&E departments. An evaluation of an emergency department avoidance model of care (Haugstetter et al, 2022) implemented in Australia, initially in response to the COVID-19 pandemic, demonstrated that the CUAC model was an efficient and potentially cost-saving model of care for the management of cancer patients with treatment-related concerns.

Recommendation 3 - Provision of information on Pancreatic Enzyme Insufficiency

There are existing, reputable resources for patients and FCs on the management of PEI and PERT dosing – these include the leaflets and YouTube videos produced by PCUK as well as materials produced by other organisations such as the free recipe book, launched by Pancreatic Cancer Action. Patients should be given or signposted to these resources as standard.

In addition, clinic letters could be reviewed to ensure that GPs receive clear information on PERT prescriptions and dosage for their patients, with signposting to specialist advice, if required.

Recommendation 4 – Optimise the functionality of existing Hospital IT systems

Electronic Patient Records (EPRs) have the potential to facilitate more personalised care and better care coordination for patients. Currently, 90% of Hospital Trusts have introduced electronic patient records (https://digital.nhs.uk/news). Two specific opportunities have been identified from the findings presented here – firstly, for more personalised care, the system could be used to record 'soft' patient information i.e. a reminder that a patient is hard of hearing. Secondly, functionality within the EPR, if activated, should allow for routine alerts to be sent to CNS teams, if a patient known to the team has been admitted to the hospital as an emergency. This would allow for a more co-ordinated approach to their care while in hospital.

Organisations may also use additional systems to record patient data. For example, organisations currently use a web application called the Somerset Cancer Register which helps to track and manage the patient pathway. The application is used to manage MDT meetings and includes the ability to record CNS activity including HNAs. The system may also enable the recording of ‘soft’ intelligence.

HPB teams should therefore review their use of hospital-based IT systems to assess the feasibility of recording ‘soft’ patient information to provide more personalised care and to ensure information input into one system is visible across all systems used in the organisation.

Recommendation 5 – Early introduction of community palliative care services and Advanced Care Planning

There is a need to improve patient and FC understanding of what community palliative care services can offer, to ensure that people are not missing the opportunity to benefit from their service because of misconceptions about the terminology and associations with EoL care.

A simple leaflet ‘What is palliative care’ such as that produced by Leeds Palliative Care Network, may help to dispel some of the misconceptions people have and can help people to begin conversations about ACP.

In addition, the referral protocols for community palliative care services should be reviewed so that as a minimum patients who are not receiving chemotherapy are referred to their community palliative care services with an ‘open referral’. This would enable them to initiate support themselves when needed, rather than waiting for a re-referral from an HCP at a point of crisis.

Recommendation 6 – Facilitate primary care access to specialist support

GPs interviewed for the study noted the lack of effective mechanisms to access specialist information and support, when needed.

Specific advice and support from a patient's hospital-based care team might be facilitated by reviewing what contact instructions are included in clinical letters to GP practices. Feedback from HCPs on the findings and recommendations noted that while it would be usual practice for the contact details of a consultant's secretary to be included in clinical letters, it might not be standard practice to include the contact number for the CNS team. It was suggested that this could be easily remedied through discussions with medical secretaries.

In addition, it might be possible for clinical letters to also signpost GPs to other sources of support. For example, for general advice and support, GPs could be signposted to Gateway C - an online cancer education platform that already exists for primary care. Gateway C is part of The Christie Foundation Trust and is funded by the NHS. It was introduced to facilitate earlier and faster diagnosis of cancer within primary care (https://www.gateway.org.uk). Within the database, primary care staff can access a range of resources, including a podcast specifically on pancreatic cancer, a training module, and links to PCUK resources.

The existence of the platform was not mentioned by study participants. This may suggest that it has not yet been rolled out through the participants' Cancer Alliance, or it may suggest low awareness. It is therefore a potentially useful resource for Cancer Alliances to promote.

Recommendation 7 – Promotion of existing resources and support to patients and FCs

Further work is required to encourage specialist HCPs to promote the existence of current resources and support available from third sector organisations such as

PCUK's nurse-led Helpline, and Macmillan Cancer Support's Helpline, along with the extensive written resources available through these organisations.

In addition, organisations should review their information provision for people diagnosed with suspected pancreatic cancer in A&E departments and other non-cancer specific pathways or generic suspected cancer pathways. This could include appropriate generic literature which would at least provide people with the information about next steps and what they can expect to happen in terms of further tests and appointments. In addition, PCUK already has a handy pocket sized Z-card with its website address and Helpline telephone number on which could be provided as a minimum in settings where the provision of anything more specialised is logistically difficult.

Specialist HCPs should also be encouraged to remind patients and FCs of the support available from third sector organisations such as Macmillan Cancer Support and PCUK on an ongoing basis, as a means of supporting people with their emotional needs. Particular attention needs to be given to the signposting of FCs to existing resources.

Recommendation 8 – Introduction of information checklist

Patients and their FCs should receive information tailored to their specific diagnosis, treatment, and circumstances. A checklist could be used as a prompt for HCPs to ensure all relevant information is provided. The checklist could be adapted with the inclusion of relevant additional local services and other support such as third sector organisations like PCUK. It might also include prompts for activities such as arranging an orientation visit to the chemotherapy unit for those patients who will have chemotherapy.

The checklist could also facilitate better engagement between the patient and primary care. Though it is usual for a CNS looking after a patient who is inoperable to contact the patient's GP practice and advise them that their registered patient is eligible for the Gold Standards Framework (or equivalent quality standards for managing patients within the last year of life), HCPs could encourage people to make contact with their GP proactively. HCPs could also encourage FCs to ask their GP for a carer's assessment if the practice provides them.[12] This might enable FCs to access additional support through the practice.

In addition, FCs may be expected to undertake technical tasks to support their family member e.g. administering medication and injections. HCPs need to consider the burden of these roles, and provide structured information, as required, to facilitate the FC's role.

In general, more thought should also be given to providing information to patients, or signposting them to information provided in different formats i.e. infographics, videos, podcasts etc. For example, there are already various Youtube videos related to the management of PEI and taking PERT, while an infographic setting out the different tests required, treatment timescales i.e. chemotherapy cycles, and follow-up scans etc. may also be helpful.

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[12] This is not the same process as a carer's assessment carried out by a carer's local adult social services department which might determine what help the individual might qualify for from the council such as help with benefits and caring costs.

Recommendation 9 – Review additional ways of supporting FCs, other than the provision of information and resources

The significant needs of FCs for better information are addressed by Recommendations 7 and 8 above. This recommendation addresses other unmet needs – such as those for psychological, emotional or practical support (while recognising that better information provision could signpost FCs to advice and sources of support for these needs i.e. Macmillan's information on a carer's rights at work).

There are existing initiatives, services and guidance in place within secondary care organisations to support FCs in general (i.e. not specifically FCs of cancer patients). These include services such as the carer's support service and carer's charter at University Hospitals Birmingham and the guidance, 'Supporting carers in general practice' (NHS England and NHS Improvement, 2019). The latter contains a range of practical ideas for how carers can be supported by general practice, including maintaining registers of carers and carer reviews and having a carer's champion within the practice. The existence of these could be included in the information checklist referred to in Recommendation 9 above to bring them to the attention of patients and FCs. This could help to encourage FCs to consider their needs in relation to a period of time off work, for example.

In addition, secondary care organisations might consider introducing an adapted HNA for FCs, in addition to the patient's HNA.

Recommendation 10 - Review communication skills training

Given the fundamental contribution that empathetic communication makes to a patient's experience, organisations should develop and maintain HCP communication skills as a priority.

Wessex Cancer Alliance recently undertook a scoping project to identify the need for support for CNSs and other HCPs working with cancer patients, to maintain and develop their communication skills, once they had completed an advanced communication skills course (HEE, 2023). The findings suggest that further support is needed by HCPs to embed their skills in practice, as skills learnt during their training became diluted over time. In addition, the project found that changes to the skill mix of the CNS workforce and an increasing emphasis on task rather than skills has moved the focus away from effective communication. The project also found that the non-CNS oncology workforce may have limited opportunities to access advanced communication skills courses. The project recommends the introduction of a communication skills portfolio for HCPs and formal mentorship opportunities for less experienced HCPs (HEE, 2023).

Other simple interventions could also prove helpful. For example, a study by Taylor et al. (2016), explored interventions to improve clinical skills in supporting the emotional and psychological well-being of patients with end-stage renal disease. One intervention involved consultants asking patients a direct question about how they were feeling. A short, focused training session using cognitive and behavioural techniques was provided to consultants to enable them to handle any emotional issues raised in subsequent consultations once the interventions were introduced.

The intervention was found to be feasible and acceptable in practice by consultants and patients, and the training was found to be helpful. The intervention was reported as having a positive effect on discussions about the emotional and psychological well-being of the patient.

Opportunities for self-reflection on the skills HCPs possess and their development needs are offered through the revalidation process, which takes place every five years for doctors and every three years for nurses. However, it is unlikely that a senior practitioner with years of experience would acknowledge a deficit in their skills unless the impact of this deficit is brought to their attention by some means. Unless people feel strongly enough to complain about the care they have received, the poor communication styles of some HCPs are likely to go unchallenged. Peer-to-peer challenge with team or departmental 'learning events' may therefore provide a different kind of opportunity for HCPs to reflect in a constructive way, perhaps by asking a simple question, 'Could we have done that better?'

Recommendation 11 – Review HCP wellbeing support

Though much has already been written about health and wellbeing support for HCPs and many recommendations have already been made for appropriate interventions (e.g. West et al., 2020), cancer service managers and provider organisations should nonetheless review their practices for supporting HCPs who care for patients with terminal cancer specifically. Specific regard should be given to ensuring HCPs have opportunities to raise concerns or issues and discuss demanding situations with peers in a safe and supportive environment, without risk of censure or judgement. In addition, organisations should review their arrangements for providing appropriate further support for those HCPs who require additional resources to draw on to maintain their wellbeing.

8.6 Implementation challenges

Given that this research is aligned with pragmatism and the overarching criterion for this paradigm is whether the research makes a difference to the problem(s) identified, or not, the following section considers the specific challenges that might arise in relation to the implementation of these recommendations, and the challenges inherent in implementing change in general.

The recommendations above vary in the ‘scale’ of change required from HCPs and organisations and the feasibility of implementation. Some would require a minor change to current practice - such as the inclusion in clinical letters of CNS’s contact numbers. Others would require a more significant change to practice such as the introduction of fast-track pathways. And while a recommendation such as the introduction of an information checklist may not be a particularly significant change to practice, it would require time to develop the checklist and it is probable that using the checklist would require some additional time spent with patients, impacting further on existing capacity constraints. Time may be ‘saved’ at other points on the cancer trajectory if people are provided with comprehensive information at the outset, but this would be difficult to evidence and quantify, making the ‘business case’ to invest time in this challenging.

Workforce capacity

An IT alert system to know when patients have been admitted as an emergency, is technically feasible to implement and is in force in some organisations, but an HCP who provided feedback on the recommendations noted that though her Trust had this in place capacity constraints meant that her team could not respond proactively to these alerts (it was not unusual to receive 10 plus alerts a week). Instead, the team could only manage their regular weekly visit to the wards, or to visit the ward when specifically requested to do so by a colleague.

Increasing capacity within the workforce is a significant challenge to address and requires national investment and policy solutions. It is estimated that the number of people in the UK diagnosed with cancer is set to rise by a third by 2040, taking the number of new cases every year from 384,000 to more than half a million for the first time (Cancer Research UK, 2023).

While capacity has increased in some areas, it is not necessarily keeping pace with the growth in demand, or compensating for staff who are leaving the NHS. For example, the Nursing and Midwifery Council (NMC) reports that while there was a 3.3% increase in the number of nurses joining the register in the year to March 2022, there was an increase in the numbers of nurses leaving the register with 13.37% doing so in the same period (NMC, 2023).

If HCPs feel they are unable to care for their patients in the way they would wish to because of environmental factors such as vacancies, short-staffing and heavy workloads, this could lead to ‘moral injury’ - a form of psychological distress resulting from actions, or the lack of them, which violate an individual’s moral or ethical code (Maffoni, et al., 2019). This can lead to HCPs feeling overwhelmed, demoralised and burnt out – the result of which may be further increases in HCPs leaving their profession (Rodney, 2017).

The concept of emotional labour is also highly relevant when considering the current pressures on staff. The concept was originally coined by Hochschild in her 1983 work - The Managed Heart. It has been developed as a concept in nursing care by the likes of Smith (1992, 2001, 2012) and Theodosius (2008) and extended to other HCPs (Riley and Weiss, 2016). Emotional Labour is the process of managing or suppressing natural feelings and emotions in order to present an 'acceptable demeanour' in the workplace. HCPs are expected to be emotionally caring, calm, and immune to the unpleasantness and scariness inherent in much healthcare work, but this suppression of natural emotions takes emotional effort which may become unsustainable over time (Menzies, 1960).

A strong evidence base linking the health and wellbeing of HCPs with the quality of care they are able to provide to patients and their ability to act with compassion, was set out in the Boorman Review for the NHS in 2009 (DH, 2009). The report set out a series of recommendations for NHS organisations regarding their responsibility for taking care of staff health and wellbeing. Many initiatives such as Schwartz Rounds© - when staff share and reflect on the emotional, social, and ethical challenges of their work (Maben et al, 2018), wellbeing champions and/or mental health first aiders https://www.nhsemployers.org/articles/mental-health-workplace were introduced subsequently as a means to support staff, in addition to the standard support offered by workplace occupational health departments.

However, these initiatives while helpful, can only go so far in supporting staff who are exposed to workloads that are unsustainable. Ultimately, the lack of capacity in the system is a vicious circle which needs to be broken, if staff are to be truly supported to deliver the care that patients deserve.

There are examples of what can be achieved for patients when investment is forthcoming. The HPB team at East Lancashire Hospitals NHS Trust secured funding from Macmillan Cancer Support to double its CNS workforce, employ patient support workers and a specialist dietician. As a consequence, the team is able to run a range of new clinics and services to better meet patient needs - these include a weekly nurse-led MTD clinic, twice weekly HNA clinics, a daily telephone clinic for patients and a weekly clinic for all palliative patients (Vicki Stevenson-Hornby, HPB CNS, East Lancashire Hospitals NHS Trust, personal communication, 19.10.23).

The psycho-oncology service referenced in Chapter 5, where all cancer patients are screened for psychological distress on an ongoing basis, was also made possible following significant financial investment from Macmillan Cancer Support.

The publishing of the new timed HPB cancer diagnostic pathway is a positive development but stakeholders acknowledge that the implementation of the pathway will require sustained and additional funding from the Government. There are therefore already urgent calls by stakeholders for the Government to carry out a workforce review as a priority (Alice Clarkson, PCUK, personal communication, 02.05.24).

The Getting it Right First Time (GIRFT) Programme is also examining the workload of CNSs to determine a better means of calculating the minimum number of CNSs required for each unit. This work is also exploring the potential of cancer support workers to supplement CNS capacity (Claire Pearce, CNS, GIRFT Programme, personal communication, 02.05.24).

The ACCEND programme, (Aspirant Cancer Career and Education Development programme) will also be scoping the current situation regarding the number and role of HPB CNSs and will be looking at the competencies required of this role, in the near future (Lynne McCallum, specialist HPB nurse, PSBGI, personal communication, 27.03.24). In addition, the Programme has a workstream specifically focused on developing a competency and capability framework for cancer support workers and to map core training requirements and additional training requirements, depending on the exact nature of the role.

The introduction of alternative posts such as the cancer support worker could help to alleviate some of the pressure on CNS teams and the potential for this type of role within HPB CNS teams or Upper GI teams should be explored further.

Information provision

Though the promotion of existing resources and information seems straightforward, the information needs and preferences of cancer patients is a complex topic spawning a large body of literature e.g. Butow et al. (1997), Jenkins et al. (2001), Rutten et al. (2005), and Maddock et al. (2011). There is also a large body of literature on information provision in general which explores universal concepts such as health literacy[13] and absorptive capacity i.e. the ability for people to take in the information that is being presented to them. Absorptive capacity is affected by factors such as the patient's physical health status and their psychological and emotional states (e.g. Beaver et al, 2007 and Kessels, 2003) – factors which are highly likely to affect people with inoperable pancreatic cancer.

A patient's or FC's informational needs is therefore highly individualised depending on their preferences for written or visual information, the level of detail desired, their level of health literacy, their state of mind and their ability to retain information. Meeting each individual's information needs optimally, requires a truly person-centred approach which is tailored to the individual – one of the key components of patient experience frameworks. In practice this is difficult to achieve in a setting where there is limited time to explore people's preferences and little capacity to review the nature of the information provided. These challenges could potentially be addressed in part through the additional capacity that a patient cancer support worker might bring to a CNS team and through greater patient and FC involvement in determining what information is helpful to have and how and when it should be presented – perhaps encouraged through co-design activities (Bate and Robert, 2006).

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[13] defined by the World Health Organisation as "…the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health." (NHS England » Enabling people to make informed health decisions)

Determinants of healthcare professional practice

As presented in Chapter 2, there are already a range of clinical guidelines and standards in place that should inform the level of care and support provided to people with inoperable pancreatic cancer, but their implementation is variable – for example in the rate of PERT prescribing or the availability of opportunities to undertake ACP.

There is a body of literature regarding barriers to implementing clinical guidelines e.g. Francke et al., (2008). Barriers are reported as including environmental characteristics i.e. time and staff, peer support and senior buy-in; patient characteristics i.e. some patients might not 'fit the profile' of the patients the guidelines are intended for; characteristics of the guidelines themselves i.e. are they clear and easy to understand and are they based on a sound scientific rationale; and professional characteristics i.e. are HCPs aware of the guidelines and their content (Francke et al., 2008).

While insufficient time and staff are suggested to be the main impediments to guideline implementation (Francke et al., 2008), determinants of healthcare professional practice are nonetheless key factors to consider in relation to the successful implementation of change. For example, a recent study highlighted the challenges of using decision aids in consultations with pancreatic cancer patients, where the clinicians involved felt the decision aid was impractical and constrained conversations with patients (Dengsø et al., 2024).

The concept of clinical judgement is relevant when considering how HCPs practice their profession and thus how far it is possible to codify and standardise aspects of clinical practice (e.g. Weed and Weed, 1999; Downie and Macnaughton, 2000; White and Stancombe, 2003; Kienle and Kiene, 2011; and Clemett and Raleigh, 2021). For example, in a patient consultation, HCPs will be drawing on their practical experience to determine how they conduct a consultation and what information is shared and discussed. This was demonstrated in the findings presented in Chapter 6 when HCPs talked about using their clinical judgment to gauge if someone was 'in the right place' or frame of mind to have a conversation about their prognosis, or about the progression of their disease or a referral to palliative care. This assessment, based on clinical judgement, is likely to trump a guideline that suggested for example that all patients should receive an HNA following their first appointment with a specialist.

Thus recommendations are made in acknowledgement that clinical judgement will still be applied to determine how they are implemented in practice.

Meeting FC needs

Help-seeking behaviour is an important concept when exploring why it may be challenging for HCPs to identify people's needs at times. In simple terms, help-seeking behaviour refers to the actions individuals take to seek support for their health concerns. There is an extensive body of literature relating to help-seeking behaviour for cancer symptoms in general (e.g. O'Mahoney and Hegarty, 2009), and literature relevant to pancreatic cancer symptoms specifically (Mills et al., 2017). There is also a body of literature related to help-seeking behaviour for side effects of treatment, or other concerns or needs during treatment for cancer (e.g. Steginga et al. 2008). The literature is limited however in relation to help-seeking behaviour among the FCs of people with cancer, and no studies could be found in relation to help seeking behaviour among FCs of people with pancreatic cancer.

It is possible that an adapted HNA, if undertaken with FCs, in an environment that is focused solely on the FC, may encourage them to articulate their needs. It is highly unlikely that this could be managed within CNS teams' existing capacity, given what is already known about capacity constraints. However, this could be a role that a cancer support worker could undertake, or this could be a role undertaken within the Macmillan hubs operating in provider units. Alternatively, this could be undertaken by a social prescriber or care navigator within primary care.

Providing optimal support to FCs is not only about meeting their needs however. It is also about providing them with a positive experience of healthcare – in the same way as providing optimal supportive care to patients is not just about meeting their supportive care needs but also ensuring a positive care experience. Al-Janabi et al.'s work on the effects of healthcare delivery on carer wellbeing (2019) is instructive in relation to FC experiences of healthcare, even though the authors were not focused on cancer care. The authors identify six mechanisms that can affect the wellbeing of FCs positively, or negatively. These mechanisms are the provision of good information (the arguments for which have already been made), the management of care and where the locus of responsibility for this lies, patient outcomes, alienation, compliance, timing, and location.

Al-Janabi et al. (2019) suggest that FCs may feel they are shouldering the responsibility of care inappropriately at times, a situation likely to cause FCs stress and anxiety, as noted in Chapter 5. When their family member does not receive care delivered in a person-centred way, the authors suggest this can reinforce feelings of alienation in FCs while the opposite occurs if care is delivered in a person-centred way. The negative impact on FCs of care that was not person-centred was also evident in the findings (for example when HCPs did not take into account that a patient was deaf), as was the impact of the timing of care – when there were delays in pathways, or aspects of care were delivered late (such as pain relief or chemotherapy), or not at all. There were also issues with the location of care – for example when FCs were trying to organise travel to appointments.

The empirical findings therefore accord with Al Janabi et al.'s assertion that mechanisms of healthcare delivery can have a detrimental impact on FC's wellbeing and their general experience of healthcare. There was no explicit recognition of this however among HCPs and no sense that any measures were in place to actively mitigate for these potential effects.

The range of issues that may arise as a consequence of the mechanisms of healthcare delivery are potentially extensive and beyond the scope of this research to address. However, it is important that HCPs and organisations recognise the consequences of mechanisms of healthcare delivery on FCs as well as patients. Where possible, they should take steps to minimise any additional stress and anxiety these mechanisms may cause e.g. by preventing FCs' feelings of alienation through improved communication.

Context and variation

Much has been written in the social sciences literature about the importance of context on the successful implementation of change (Rogers et al, 2020) and there is an extensive body of literature on ‘the implementation’ gap in healthcare policy (Braithwaite et al, 2018).

Contextual issues were raised by patients and FCs as either contributing to a positive or negative experience, and by HCPs as being reasons why things happened or didn’t happen in practice. On a very local scale, one CNS noted that when her team had been based in an office co-located with her organisation’s HPB ward, visiting patients who had been admitted as an emergency was straightforward. A subsequent move to an office in a building some distance from the wards affected the team’s ability to provide the level of support they would have done so previously for these patients.

On a larger scale, the mixed economy in provision of community palliative care services with some very small, local charitably run organisations and other larger NHS-run services, means that people in different parts of the country will have access to different services – a ‘postcode lottery’ effectively. This variation and fragmentation of services makes the implementation of change difficult to standardise in different operating environments.

Simple contextual factors such as the space available within clinic areas might affect the implementation of the recommendations made here i.e. if there is limited storage space for patient literature, or limited space for a carousel for patient leaflets to be prominently displayed.

The implementation of these recommendations may therefore be managed more readily within some organisations than others because of the local context.

To conclude the discussion on the challenges of implementing the recommendations presented in this thesis, Table 9 below shows the change required for implementation and indicates which body, organisation or individual might need to assume responsibility for implementation. The table also includes an assessment of the feasibility of implementation based on the likely resources required to make the change, the likelihood of changing clinical practice in this area and the support already in place for making the change from existing bodies or policy. The assessments range from high feasibility of implementation, to low to medium feasibility. In spite of this assessment, the recommendations assessed as having lower feasibility are still considered important enough to include as they address fundamental aspects of care, such as communication.

Table 9: Assessment of feasibility of implementation for recommendations

No	**Recommendation**	**Change required**	**Feasibility**	**Loci of responsibility for implementation**
1	Timely access to specialist CNS support	Organisational review of practice Implementation of NHS HPB Timed diagnostic pathway	Medium (moderate cost as may require additional workforce capacity, medium change to practice, strong existing policy support)	National (NHS England, PCUK, GIRFT, Audit) Regional (Integrated Care Boards (ICB) and Cancer Alliances) Organisation, team and individual

No	Recommendation	Change required	Feasibility	Loci of responsibility for implementation
2	Introduction of fast-track referrals and pathways for services	Existing fora such as the Acute Oncology Expert Advisory Group are already vehicles for promoting urgent assessment pathways through Cancer Alliances and Integrated care Boards. Work is already underway in some geographical areas on rapid access pathways and admission avoidance i.e. North Mersey Macmillan project. Work needs to be published/promoted and spread through Cancer Alliances and ICBs	Low-medium (cost of investment in staffing to deliver fast-track services as increased capacity is likely to be required, minor change to practice for referring HCPs, some policy/practice support)	National (Acute Oncology Expert Advisory Group), Macmillan Regional (Cancer Alliances and ICBs, Organisation, team
3	Provision of information on Pancreatic enzyme insufficiency (PEI)	This could be addressed by implementing recommendations 6,7 and 8 and including specific information on PEI and PERT dosing on clinical letters	High (low cost, small change to practice, strong support from clinical guidelines and strategic programmes such as audit)	National (NHS England, GiRFT Programme, Regional (ICBs, Cancer Alliances) Organisation, team and individual
4	Optimise the functionality of existing hospital-based IT systems	This would require organisations to ensure this functionality is 'switched on' and process for alert emails to relevant team – this could be requested by HPB CNS teams of their IT Departments, and could be encouraged by GiRFT Programme	Medium (low IT cost, medium CNS cost to respond to alerts, medium change to practice, potential policy/practice support)	Organisation (individual Trust IT Departments) Team (HPB CNS team) Individual (individual CNSs to respond to alerts)
5	Early Introduction of Community Palliative Care Services and ACP	Organisations could co-produce patient information with patients, FCs and HCPs on the role of community palliative care services and ACP to facilitate conversations and referrals	Medium (low cost to make referral, medium change to practice – higher cost in community to respond to referral as increased capacity required. Strong support from existing policies)	National i.e. Cancer charities Regional – Cancer Alliances and ICBs, Organisations - Community palliative care services, CNS teams and individual HCPs

No	Recommendation	Change required	Feasibility	Loci of responsibility for implementation
6	Facilitate primary care access to specialist support	GiRFT Programme could be a vehicle by which the inclusion of CNS contact details are mandated in primary care clinic letters, together with signposting of GPs to specialist resources through charities and existing GP resources i.e. Gateway C	High (low cost, small change to practice)	National (NHS England, GiRFT Programme, Regional (ICBs, Cancer Alliances) Organisation Team and individual
7	Provision of existing resources and support to patients and FCs	Raising awareness of available resources and support, accessing stocks of leaflets etc.	High (low cost, small change to practice, strong support from existing policies and guidelines re: information provision)	National (PCUK, Macmillan, GiRFT team) Organisation Team and individual
8	Introduction of information checklist	Development of checklist potentially by PCUK, or national HPB Network and roll out of checklist nationally through GiRFT Programme, or undertaken by individual organisations for local relevance but either approach to incorporate a co-design approach.	Medium-High (low cost, small change to practice)	National (PCUK, HPB Network, GiRFT) Team and individual
9	Review additional means of supporting FCs, other than the provision of information and resources	Recommendations 7, 8 and 9 should contribute to supporting FCs. The development of an adapted HNA for FCs could be led by a national entity such as PCUK, through its research involvement network, incorporating a co-design approach.	Medium-High (modest cost to develop HNA for FCs but implementation would require a moderate change to practice – issues with capacity could be addressed by cancer support workers undertaking FC HNAs. Policy support re: carers assessments)	National (PCUK, HPB Network, GiRFT, ACCEND programme) Team and individual
10	Review Communication skills training	The ACCEND Programme is due to look at competencies required of CNSs and cancer support workers in due course. It	Low to medium (low cost to review needs but medium cost to implement	National i.e. Health Education England, ACCEND programme Organisational

No	Recommendation	Change required	Feasibility	Loci of responsibility for implementation
		is anticipated that this will incorporate communication skills. A review of communications skills of other HCPs such as doctors is unlikely to feature any national body but is instead most likely to be addressed at a local level with teams undertaking peer to peer review and challenge.	training where needs identified. Moderate change to practice for some HCPs i.e. CNSs, potentially more significant for other HCPs i.e. medical staff, support from existing policies i.e. validation)	Team (peer reflection) and individual
11	Review HCP wellbeing support	Organisational recognition of emotional labour of cohorts of HCPs working with specific groups of patients and FCs and internal review of arrangements for their support. This could be driven by national policy. Subsequent changes are likely to be context specific.	Low to medium (low cost to review but more significant cost to implement appropriate support, potentially more significant change to culture and practice required. Strong support from existing policies on staff wellbeing and reports linking wellbeing to quality care.)	National – NHS Organisational – Director of HR, Nursing and Medical Directors, Cancer Services Managers and Lead Cancer nurses, CNS team and individual HCPs

8.7 Future research

In addition to the recommendations set out above, there are two areas highlighted by the research which may benefit from further research. These are as follows:

Models of supportive care delivery

The role of the cancer support worker may help to fill some of these gaps in care identified in this research. Cancer support workers have been a regular feature of cancer nursing teams for more than a decade since their introduction by Macmillan

Cancer Services. Their purpose initially was to enable people living with cancer with non-complex needs to self-manage (Macmillan, 2015b). Over time however, their role has been adapted to suit local needs.

A survey of HPB nurses (n=38) in 2022 indicated that 25 of the respondents had such roles within their team – this included respondents from specialist surgical centres and DGHs. Respondents were unanimous in their support for such roles but identified a number of training and development needs for these individuals, including; understanding the disease and its rapid progression and when to escalate concerns, understanding their role and their contribution to the team as a whole, and developing post-holders' confidence in communicating with patients to enable them to provide emotional support and to undertake specific tasks such as HNAs (Lynne, McCallum, specialist nurse, PSGBI, personal communication, 27.03.24).

Work planned on the competencies required for the HPB CNS role, in combination with work that is already underway on the competencies required by the support worker role more generally, through the ACCEND Programme (see Section 7.7.1), may indicate areas to focus on for future research in relation to the contribution cancer support workers can make.

A number of areas where cancer support workers may be able to assist in the implementation of the above recommendations have been highlighted above.

Patient information provision

Though patients and FCs identified significant unmet information needs throughout the cancer trajectory, it is unclear what information people would find most helpful, at what point, and in what format. A future research study could therefore explore the timing, content, and format of information specifically for this cohort of people. As part of this research, the feasibility of producing an infographic or visualisation of a likely patient trajectory could be explored. An infographic might include diagnostic tests, follow-up appointments, treatment timescales, and review appointments, with indications of who is responsible for a patient's care at each stage of the trajectory, and who to contact for advice and support, at each stage. The research should incorporate co-design activities with patients and FCs (Bate and Robert, 2006).

8.8 Summary of chapter

This chapter has considered the implications of the case assertions made in Chapter 7 in terms of policy, practice, education and research. The case assertions have been examined through the lens of patient (and FC) experience, in addition to frameworks of supportive cancer care, in order to determine what optimal supportive care could look like for people affected by inoperable pancreatic cancer and to subsequently develop a conceptual model of optimal supportive care for this cohort of people.

In keeping with the research's underpinning theoretical paradigm of pragmatism and its embrace of plural forms of knowledge, the findings were shared with a range of stakeholders and subsequent discussions with stakeholders explored how the gaps and shortfalls identified in supportive care might be addressed. These discussions have informed the development of a series of recommendations including; timely access to specialist CNS support, fast-track pathways to supportive care services and urgent assessment pathways, steps to improve care coordination within the acute and community settings and actions to improve the provision of information to patients and FCs. In recognition of the impact of HCPs' skills and wellbeing on patients and FCs, two recommendations have been made specifically addressing these issues.

The challenges inherent in implementing these recommendations have been acknowledged, and an assessment has been provided on the feasibility of implementation based on the change required and the presence of potential 'driving forces' for change (Lewin, 1951), such as the existence of existing fora or strategic developments that can influence change i.e. the GiRFT Programme.

The chapter concludes by proposing two areas for future research.

Chapter 9 – Conclusion

9.1 Summary of study

The aim of OPTIMISTIC, an intrinsic case study, was to explore how the care and support of people with inoperable pancreatic cancer and their FCs could be optimised. Chapter 1 of the thesis provides the background to pancreatic cancer as a disease and provides a clear rationale for exploring this topic. It also provides a rich description of the 'case' – the provision of supportive care to people with inoperable pancreatic cancer and their FCs in the English NHS.

Chapter 2 provides an overview of current policy relevant to the provision of care for this patient group, together with an overview of other recent strategic developments that are likely to have an impact on the provision of care in the short to medium term. This chapter contributes to the case study findings as a source of contextual data.

Findings from the academic literature regarding the supportive care needs of people with inoperable pancreatic cancer and their FCs is summarised in Chapter 3. The literature identifies a range of unmet needs for patients and FCs and provides insights into potential causes and possible solutions. A full explanation of the methodology is provided in Chapter 4. In brief, a qualitative intrinsic case study with a longitudinal element was employed. This involved 60 semi-structured interviews with 13 patients and 12 FCs (some of whom were interviewed more than once) and 24 HCPs. Data from the interviews were analysed thematically using the Framework Method (Gale et al., 2013). Fitch's Framework, (1994), for conceptualising patient and FC’s supportive care needs was subsequently used as an organising framework to present the findings and to inform the discussion of the main themes.

The first objective of the OPTIMISTIC study was to explore the supportive care needs of people recently diagnosed with inoperable pancreatic cancer, and their FCs, and how these change over time, and to assess the extent to which patients and their FCs felt their needs were being met. These findings, presented in Chapter 5, show that the domains of greatest need among patients are the physical and emotional domains, with information needs also reported as high. The findings also show that people feel their experiences of care are affected by poor care co-ordination and poor communication – both interpersonal communication between the patient and HCPs and the wider family unit and HCPs, and the exchange of information between parties. The findings show that there are significant limitations in the health and care system’s ability to respond to this cohort of patients’ needs, given the often rapid deterioration in their health status, due to the progression of their disease.

The findings also highlight the relentless nature of the FC role, supporting their family member and helping to co-ordinate their care, while in many cases, continuing to combine this with existing responsibilities and commitments. Everything the FCs experienced in their role was amplified by the complications of their family member’s disease and its often rapid progression. The findings suggest that FCs’ needs are often not identified, let alone adequately addressed.

The study’s second objective was to explore the experiences of HCPs to identify the challenges in providing optimal care and support to people. The findings presented in Chapter 6 paint a picture of complex patient pathways set within a context of a service under extreme pressure with reduced workforce capacity, constrained resources, and increasing workloads. HCPs expressed dissatisfaction at the limitations of services for patients such as dietetic and psychological support and palliative care services. In particular, participants highlighted gaps in support for people not receiving active treatment but not yet requiring EoL care. HCPs acknowledged that they are not always able to deliver the care and support that they wish to provide.

While a few participants highlighted examples of excellent care, the study concludes that people are not always receiving the care and support that they need and should expect, and that these shortfalls are exacerbated at particular points in their cancer trajectory. By exploring these issues, the research has highlighted gaps and areas for improvement in the provision of supportive care, as presented in a series of case assertions in Chapter 7. These case assertions emphasise that the fundamentals of a good patient experience must also be in place in order for supportive care to be considered optimal.

How these gaps might be addressed has been explored through discussions with stakeholders, resulting in a series of recommendations as set out in Chapter 8 which address aspects of patient experience as well as specific supportive care needs. These recommendations include; timely access to specialist CNS support, the introduction of fast-track pathways to supportive care services, the early introduction of community palliative care services and Advanced Care Planning, better communication of sources of support and advice for GPs, the promotion of existing resources and support to patients and FCs, and additional support to HCPs to manage challenging conversations and to maintain their overall wellbeing.

Two areas for future research have been identified. These are exploring the contribution that cancer support worker roles could make to the care and support of people affected by inoperable pancreatic cancer and exploring how the information needs of patients and FCs could best be met.

9.2 Strengths of research

This research presents insights into the experiences of people solely with inoperable pancreatic cancer, and their FCs. In this regard, the research provides accounts which represent the majority of pancreatic patients and their FCs. This research also provides a longitudinal element which has generated insights into changes in needs over time, and the response of the health and care service to these changes, as well as highlighting the rapidity of deterioration in health for some patients.

This research is also unique in its exploration of the care and support provided to people from a broad range of geographical locations within England and from across the health and care system continuum, including hospital-based care (both specialist and DGH), primary care and community care, and the care and support provided by the non-statutory sector, including charitable organisations. The study therefore has wide reach and transferability.

In addition, the research includes the perspectives of HCPs alongside patients and FCs, rooting the research contextually. This inclusion of multiple sources of empirical data, characteristic of a case study approach, and the involvement of additional stakeholders in the 'testing' of findings, has enabled the development of recommendations for change which are rooted in the reality of everyday practice and which are anticipated as being acceptable to patients, FCs and HCPs.

The research has also allowed for a detailed critique of Fitch's seminal Supportive Cancer Care Framework (1994). While Fitch's Framework allows for an holistic assessment of needs at different stages of the cancer trajectory, provides standards of clinical care to be measured against, and an assessment of scale of need at different levels, it is now 30 years' old and there are limitations in its use, as noted below in section 9.4.

9.3 Limitations of the research

A number of minor limitations to the research have been identified as follows.

Participant sample

The sample of patients included a range of ages and an almost equal split between genders. The FCs comprised a balance between adult child carers and spousal carers though the gender split was overwhelmingly female (83%). There was however little ethnic or cultural diversity among participants - only one of the patients and one FC were non-white and two of the patients and one FC did not speak English fluently. There was some evidence of diversity with regards to health literacy with some patients and FCs highly literate and engaged while others appeared less confident in their knowledge and understanding of the disease.

It is possible that had more participants been recruited from diverse ethnic backgrounds or for whom English was not their first language, other issues may have arisen, or assumed greater prominence in the findings. However, the researcher is confident that the identification of the main themes related to the provision of care and support has been achieved.

As regards HCP participants, there was variation with regards to professional background, location, and length of experience and seniority. It was, however not possible to recruit a gastroenterologist, despite requests. The inclusion of a gastroenterologist may have provided further insightful accounts of routes to diagnosis and the experience of gastroenterologists in providing care to this cohort of patients.

There was less variation with regards to gender and ethnicity. Of the 24 HCPs interviewed, only two were male (both consultant physicians) and only three were non-white (all female physicians). It is possible that had more participants been male, or from diverse ethnic backgrounds, other issues may have arisen. However, in the context of their experience of providing care to this cohort of people, the researcher is confident that these would not have been significantly different issues to those presented in Chapter 6.

Methodology

Due to the speed of disease progression, and the fact that some FCs were recruited after their family member had died, multiple interviews with participants were not always possible, or appropriate. It was therefore not possible to undertake a detailed longitudinal analysis of the data and instead a few broad observations have been offered regarding changes in needs over time. The longitudinal aspect has, however, enabled a clear sense of the often rapid progression of the disease for patients, as demonstrated in Table 6, in Chapter 5.

Joint interviews with dyad participants

As noted in Chapter 4, both joint and separate interviews with participants have advantages and disadvantages. Joint interviews with dyads may enable one person to dominate the conversation, or may lead to tension between the dyad, while separate interviews might be logistically difficult to arrange or foster an unwarranted sense of secrecy between dyads (Morris, 2001). Though the researcher did not observe any tension in joint interviews, nor concerns over secrecy in separate interviews, the latter type of interview did yield a qualitatively different kind of data, as explained in Chapter 5.

It is possible that had all interviews been conducted separately, participant accounts may have been more emotional. This may have been more significant if the intention of the research had been to focus on the emotional response of participants to their situation and certainly if the research had been a phenomenological study, this would have been an important consideration.

This aspect of study design requires careful consideration for further studies but given the aims of this study, the quality of the data did not appear to be compromised by the approach of incorporating joint interviews with some dyads. In addition, it was felt that giving due regard to people's preferences was of prime importance for this group of participants.

Testing out findings and recommendations

As noted in Chapter 4, the extended recruitment period for patient and FC participants meant that it was not possible to test study findings and recommendations out with participants through workshops, as originally envisaged. The use of workshops would theoretically have allowed more people to be involved in providing feedback on the findings and potential recommendations and this may have provided alternative views on the salience of the findings and subsequent recommendations. Given the commonality of the views expressed by those who did provide feedback however, the researcher is confident that alternative views would not have altered the development of the recommendations significantly.

9.4 Limitations of theoretical model

The limitations of the theoretical model used are dealt with separately here, as the researcher attests that they do not constitute a limitation of the research per se.

The first limitation of Finch's Framework relates to the absence of a domain or overarching construct relating to 'how' care is being delivered or how the needs of patients and FCs are met, or not, in relation to their experience as patients and FCs. The explicit inclusion of such a domain is important in order to understand that optimal supportive care incorporates the entirety of the caring experience and not just access to discrete interventions or services to manage specific supportive care needs and whether these interventions or services are effective or not in meeting needs. The second limitation of the Framework is that it does not explicitly acknowledge the specific temporal needs of people. This is of great significance to people with inoperable pancreatic cancer who require their needs to be met rapidly.

Fitch's conceptualisation of levels of need (2004) is also limited as the model's estimated proportions of patients requiring a service or intervention are based on an average across all cancer types. For example, Fitch suggests that approximately 30-40% of patients 'will require specialized or expert professional intervention for symptom management and psychosocial distress'. The proportion of inoperable pancreatic cancer patients requiring such interventions is likely to be significantly higher and therefore this conceptualisation of an inverted triangle of needs with smaller numbers of patients requiring more intense support is not compatible for inoperable pancreatic cancer and not useful for service planning purposes.

A further minor point in relation to Fitch is that she doesn't include health literacy or educational attainment as a characteristic to be considered when ensuring that supportive care is relevant to people's needs and sensitive to their characteristics. However, there were examples in this research of people's needs not being met as a consequence of their level of education and health literacy. This occurred firstly, in relation to the provision of printed information - reported as being difficult to take in by one patient who classed himself as a poor reader; and secondly, by the unwillingness shown by some HCPs to engage fully with people who had clearly undertaken a significant amount of their own research and were 'knowledgeable' patients or FCs. This certainly seemed to be the case with one of the patients and one of the FCs who participated in the research.

9.5 Contributions to knowledge

The experiences of people with inoperable pancreatic cancer have been overlooked in previous research and compromised by cancer patient experience surveys which do not disaggregate data between all GI cancer patients. This research also focuses on the experiences of FCs of people with inoperable pancreatic cancer – another area which has received less attention in the literature. This research has therefore made important contributions to knowledge by providing in-depth accounts of the experiences of care of people affected by inoperable pancreatic cancer.

Conducting multiple interviews over time has enabled a layering of knowledge about people's experiences over the course of their disease trajectory, highlighting how their needs change over time and whether or not the health and care system was able to respond.

In particular, the findings have highlighted how many patients experience a rapid deterioration in health, whether as the result of the progression of their disease, or as the result of complications of treatment. While it is well known that the prognosis for inoperable patients is poor – supportive care services are often not organised in such a way as to respond to people's needs in a timely manner, let alone urgently. Thus, there may be a delay in people being prescribed PERT following diagnosis, or receiving inadequate instructions about dosage, leading to some patients rapidly losing weight and becoming too nutritionally compromised to be considered for treatment. There was also no evidence of any fast-track referral pathway for access to supportive care services such as psychological and emotional support, leaving many people struggling to cope with their diagnosis and prognosis. Beyond diagnosis, patients experienced challenges accessing their GPs and were often not afforded a priority response for appointments or prescriptions. While a rapid deterioration in a patient's health can lead to failure to refer to, or delays in referral to community palliative care services, leading in some cases to patients feeling isolated and helpless without adequate professional support.

Some of the issues raised by patients and FCs may be common across different cancer types – for example deficits in interpersonal communication with HCPs and lapses in care coordination. However, the shock of diagnosis, the rapid speed of deterioration, the high symptom burden and the high mortality rate faced by people affected by inoperable pancreatic cancer, are distinctive features of their experience. These factors arguably combine to amplify the impact of these issues for this cohort of people.

This research therefore helps to establish a case for patients to receive care and support which is far more time sensitive and for FCs to be given specific attention and support, not only to enable them to fulfil their caring role but also to support their own health and wellbeing.

These contributions to knowledge allow for a modification of Fitch's Framework (1994) which reflects the experiences and needs of today's inoperable pancreatic cancer patients and their FCs, and indeed, the experiences and needs of all cancer patients and FCs. This modification would see the addition of two domains. An eighth domain would relate to the need for a high quality patient experience. This domain might be defined as ‘experiential needs’ and a definition could be provided which draws on patient experience frameworks, thus: ‘Needs for a high quality experience that is person-centred, respectful of individual preferences, dignified and prioritises continuity of care and compassionate communication.’ A ninth domain would relate to the need for efficiency in the provision of care. This domain might be defined as ‘efficiency needs’ and a definition could be provided which draws on the concept of Krishnasamy et al.’s service imperatives (2023) thus: ‘Needs for timely, efficient and responsive care.’

When considering Fitch’s five basic clinical standards for supportive care of cancer patients and their FCs (1994), a sixth standard relating to timely supportive care could also be added as follows: ‘People receive supportive care within a timescale which is appropriate to their needs,’. And, for Fitch’s conceptualisation of levels of need to be useful in practice, they should be cancer specific, as the need for services will vary in magnitude depending on cancer type.

In summary, while overarching frameworks and models of supportive cancer care are helpful in thinking about the complexity of supportive cancer care and what may be involved in its delivery at a general level, they do not represent the totality of people’s experiences, and are conceptually weakened if they do not acknowledge the centrality of patient experience and the need for efficiency in care delivery. They are also more practically beneficial when adapted to be cancer specific.

Finally, this research has also included the experiences of HCPs. This highlights the nature of the emotion work involved in caring for this cohort of people, and while emotional labour may be a feature of professional life for all HCPs, the distinctness of the experience of caring and supporting people affected by inoperable pancreatic cancer, may help to establish a case for specific attention and support to be given to the wellbeing of these HCPs.

In combination, these three perspectives have allowed a unique multi-dimensional picture of the issues faced by people affected by inoperable pancreatic cancer and the challenges the healthcare system faces responding to their needs.

9.6 Impact activities

Elements of the findings and recommendations from the study have already been disseminated within the pancreatic cancer community - through clinical networks, PCUK, and through conference presentations. Other opportunities to present the findings and recommendations are expected to arise later in the year and beyond, including the dissemination of a summary and briefing to members of the National Pancreatic Cancer Research Group, and presentations to palliative care specialists. Dissemination will also continue through the publication of journal articles and conference posters and presentations.

9.7 Concluding remarks

This research has highlighted significant gaps in the provision of supportive care to people with inoperable pancreatic cancer and their FCs. The nature of the disease gives rise to complex and urgent supportive care needs, which the system is not always able to respond to adequately. There are some intransigent systemic issues at play such as the adequate funding of the health and care service to meet population needs, but there are also areas where reasonably minor changes, at modest cost, could make significant impacts on patients and FCs.

I have been shown much goodwill and encouragement regarding the aims of this study from patients, FCs, HCPs, and the wider pancreatic cancer community. With the impact activities already undertaken from this project, and the strategic developments referenced in Chapter 2, there are reasons to feel cautiously optimistic that the experience of people with inoperable pancreatic cancer and their FCs may be improved in the future.

It has been the privilege of my career to undertake this research.

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Appendices Contents Table

Appendix 1A. Scoping review protocol

Title

Best practice interventions in the provision of supportive care for patients with pancreatic cancer – a scoping review.

Secondary objectives are as follows:

- To explore what is known about the most appropriate way to support patients with pancreatic cancer, and their family carers with a specific focus on patients with inoperable pancreatic cancer
- To explore which patients and family carers have access to which supportive care interventions/services/practices, when they receive such care, how it is delivered and whether it is valued by the patient and or family carer
- To explore the effectiveness of supportive care interventions/services/practices i.e. how is their impact on patients and family carers measured? There might be different ways in which impact is measured including QoL scores, PROMS etc.
- To identify gaps in supportive care for patients with pancreatic cancer and their family carers (i.e. who is not receiving specific interventions, services and care who might benefit from such care) with a specific focus on inoperable pancreatic cancer, in order to inform the empirical work of the study
- To inform the development of a best practice model for supportive care for patients with inoperable pancreatic cancer
- To clarify key concepts/ definitions – i.e. how is supportive care defined in the literature and what interventions/services/practices are included within this definition?

INTRODUCTION

Rationale

Pancreatic cancer is the tenth most common cancer in the UK with approximately 10,000 people diagnosed each year (1). Survival rates are low, only 1 in 4 (25.4%) people diagnosed with pancreatic cancer in England survive their disease for one year or more (according to figures for the period 2013-2017). Only slightly more than 5 in 100 (7.3%) people diagnosed with pancreatic cancer in England survive their disease for five years or more (2013-2017), while just 1 in 20 (5%) of patients survive for 10 or more years (2013-2017) (1).

Surgery is the only curative treatment for pancreatic cancer but is usually only possible when patients are diagnosed with localised cancer i.e. where their cancer has not spread to other parts of the body. At present, less than 1 in 10 (10%) of patients are deemed eligible for surgery at diagnosis (2) If the cancer has spread to other parts of their body, then the patient is likely to be deemed ‘unresectable’ or unsuitable for surgery and would be described as being on a non-curative pathway. Management then consists of ‘best supportive care' or 'palliative care' to manage symptoms and maintain optimal quality of life. Such care might address symptoms such as pain, digestive discomfort, or depression (3).

A survey (4) exploring experiences and supportive care needs of patients with pancreatic cancer, found that many patients have unmet information and cancer support needs – almost a third of respondents reported that they did not receive enough information at diagnosis, while 1 in 10 people (10%) felt they were not involved in decisions about their treatment. Almost half of respondents (49%) reported one or more moderate to high unmet need within the month prior to them completing the survey. Psychological support and physical support were reported as leading to the biggest gaps in care. The survey also highlighted that experiences were generally poorer, and unmet supportive care needs greater, in patients with unresectable disease (4).

The first Priority Setting Partnership (PSP) addressing the treatment of pancreatic cancer was established in Germany in 2017 in cooperation with the James Lind Alliance (5). The PSP generated the top 10 research priorities for pancreatic cancer with two priorities directly relating to aspects of Quality of Life (QoL) as follows: 'Does nutrition influence the survival or QoL of patients with pancreatic cancer?'; and 'How can patients with pancreatic cancer be offered a holistic treatment package to improve Quality of Life?'

A literature review published in 2019 (3) of the supportive care needs of patients with pancreatic cancer notes that identifying the needs of people with pancreatic cancer is a neglected area of research and service provision. The authors of the review suggest that more could be done to explore potential interventions and models of care that would optimise people's QoL for as long as possible.

Given the poor prognosis and the inevitable distress caused by a diagnosis of pancreatic cancer, enhancing the quality of life for people, through high quality supportive care, is of prime importance.

Aim and Objectives

This scoping review will explore what constitutes best practice in the provision of supportive care for patients with pancreatic cancer, with a specific focus on patients with inoperable pancreatic cancer.

- To explore what is known about the most appropriate way to support patients with pancreatic cancer, with a specific focus on patients with inoperable pancreatic cancer
- To explore which patients, have access to which supportive care interventions/services/practices, when they receive such care, how it is delivered and whether it is valued by the patient and or family carer
- To explore the effectiveness of supportive care interventions/services/practices i.e. how is their impact on patients measured? There might be different ways in which impact is measured including QoL scores, PROMS etc.
- To identify gaps in supportive care for patients with inoperable pancreatic cancer (i.e. who is not receiving specific interventions, services and care who might benefit from such care) in order to inform the empirical work of the study

- To inform the development of a best practice model for patients with inoperable pancreatic cancer
- To clarify key concepts/ definitions – i.e. how is supportive care defined in the literature and what interventions/services/practices are included within this definition?

Information sources

Studies will be identified by systematically searching electronic databases and scanning reference lists of articles identified in the search. Four electronic bibliographic databases will be searched for relevant material for inclusion in the review with publication dates from April 2004 (following the publication of the NICE guidelines on Improving supportive and palliative care for adults with cancer published in March 2004 (6)) up to the end of December 2021. The search will be applied to CINAHL and adapted as necessary for MEDLINE, PsychInfo and Academic Search Complete. The search will be limited to studies in the English language.

Grey literature such as patient management guidelines or reports will be included in this review but only from the UK. Only UK grey literature will be included as the international corresponding organisations are too numerous to follow a dedicated search of each organisations' publications.

Sources of relevant grey literature will include the following:

- The charities involved in pancreatic cancer research, care and support in the UK i.e. Pancreatic Cancer UK, Cancer Research UK, Pancreatic Cancer Action.
- NHS Improvement (prior to 1st April 2019 when the organisation merged with NHS England)
- NHS England
- National Institute for Clinical Excellence (NICE)
- The Royal Colleges – Royal College of Surgeons of England, Royal College of Surgeons of Edinburgh, Royal College of Psychiatrists, Royal College of Physicians and Surgeons of Glasgow, Royal College of Physicians of Edinburgh, Royal College of Physicians, Faculty of Pharmaceutical Medicine, Royal College of General Practitioners, Royal College of Nursing, Royal College of Occupational Therapists
- The professional organisations for Allied Health Care Professionals (AHCPs) where a Royal College does not exist - The British Dietetic Association, The British Psychological Society, The Chartered Society of Physiotherapy

Types of study to be included

All studies i.e. review, qualitative, quantitative and mixed method studies will be included. In addition, quality improvement initiatives and service evaluation reports from the grey literature will be included.

Condition or domain being studied

Supportive care services, interventions or practices.

A definition of supportive care is taken from the Multinational Association of Supportive Care in Cancer (MASCC) 2015 http://www.mascc.org/ as follows

‘Supportive care in cancer is the prevention and management of the adverse effects of cancer and its treatment. This includes management of physical and psychological symptoms and side effects across the continuum of the cancer experience from diagnosis, through anticancer treatment, to post-treatment care.’

Participants/population

Adult (over 18 years of age) pancreatic cancer patients and their family carers.

Intervention(s), exposure(s)

Supportive care interventions, services or practices are wide-ranging and can include physical, psychological and social aspects of care. Examples may include pain management, nutritional support, the provision of information, counselling, or any other interventions that helps to prevent or manage the adverse effects of cancer and its treatment.

Comparator(s)/control

Not applicable

Main outcome(s)

1. Identification of the interventions, services and practices used to address the supportive care needs of patients with pancreatic cancer, and their family carers, with a specific focus on inoperable pancreatic cancer
2. Identification of the gaps in supportive care for patients with pancreatic cancer, and their family carers, with a specific focus on inoperable pancreatic cancer
3. Assessment of the effectiveness of these interventions, services and practices i.e. the impact on patients and family carers; with an assessment of what works for who and in what circumstances, with a specific focus on inoperable pancreatic cancer
4. Clarification of key concepts and definitions such as ‘supportive care intervention’

METHODS

JBI guidance recommends a 3 step strategy to searching as follows:

1. An initial limited search using at least two online databases – this will allow for the analysis of text words used in the title and abstract for use in step 2
2. A search using all identified keywords in all included databases
3. A search of reference lists of identified reports and articles

Search strategy for Stage 2 above (to be adapted depending on database)

The following strategy has been determined using the SPIDER framework:

S (Sample) ‘pancreatic cancer’ or ‘pancreatic neoplasm’ or ‘pancreatic carcinoma’ or ‘pancreatic tumor/tumour’

AND

S (Sample) terminal or advanced or inoperable or incurable

AND

PI (Phenomenon of Interest) supportive care OR support OR care OR need OR information OR emotional OR psychological OR psychosocial OR psychosexual OR social OR sexual* OR relationship OR spiritual OR existential OR cultural OR physical OR daily living OR functional)** OR practical *** OR pain OR fatigue OR anorexia OR early satiety OR sleeplessness OR weight loss OR dyspepsia OR fat malabsorption OR cachexia OR sarcopenia OR malnutrition OR nausea OR vomiting OR bloating OR wind OR itchiness OR loss of appetite OR diarrhoea OR depression OR anxiety OR fatigue OR panic OR distress OR stress OR worry OR fear OR despair OR hopelessness OR mental health OR fatalism OR quality of life OR wellness OR wellbeing

But NOT

PI (Phenomenon of Interest) EUS-guided percutaneous coeliac plexus block OR image-guided percutaneous coeliac plexus block OR pancreatin OR creatin OR Creon OR biliary obstruction OR duodenal obstruction OR stents OR biliary bypass OR chemotherapy OR gemcitabine or capecitabine

AND

D (Design) all types of study

AND

E (Evaluation) support OR care OR intervention OR service OR practice OR effectiveness OR experience OR satisfaction OR views OR attitudes OR patient reported outcomes OR quality of life

AND

R (Research type) reviews, quantitative, qualitative, mixed methods studies, quality improvement initiative and service evaluation

Eligibility criteria

Studies, guidelines, reports or articles published From April 2004 up to the end of December 2021 that report on the nature of supportive care interventions, services or practices for patients with inoperable pancreatic cancer, access to these interventions or services, and/or their effectiveness.

Literature will be included that relates to heterogenous cancer patients providing the results for those with pancreatic cancer are clearly identified and analysed separately.

Literature will be included that relates to supportive care interventions, services or practices for inoperable pancreatic cancer patients and their families or informal carers.

Exclusion criteria

Literature would be excluded as follows, ranked according to prime reason for excluding:

1. Literature must be available in the English language in order to avoid any mistakes or omissions in translation. Articles not written in the English language will be excluded.
2. Literature relating to interventions covered by NICE guidance for the management of pancreatic cancer - this includes the following: pain management using EUS-guided or image-guided percutaneous coeliac plexus block; the use of pancreatin in nutritional management; the relief of biliary or duodenal obstruction whether through the use of stents to relieve obstruction, or surgical bypass; the provision of chemotherapy either as a systemic combination or gemcitabine only
3. Studies, guidelines, reports or articles will be excluded that relate to heterogenous cancer patients where the results for those with pancreatic cancer are not clearly identified and analysed separately
4. Literature relating to neuroendocrine tumours only – as these are different kinds of tumours to the usual ductal carcinomas and are not always malignant
5. Literature relating to supportive care for post-operative patients only
6. Literature relating to supportive care for patients with curable pancreatic cancer only
7. Case studies of individual patients, or family carers
8. Editorials and opinion pieces.
9. Interventions, services and practices that do not meet the definition of supportive care taken from the Multinational Association of Supportive Care in Cancer (MASCC) 2015 http://www.mascc.org/

Study records:

Data management

Raayan will be used for screening purposes across the team while EndNote reference management software will be used to manage all data and references throughout the review.

Charting the data (Data extraction - selection and coding)

Initial search results from all databases will be screened for duplicates through Raayan and these will be eliminated. Titles and abstracts will then be screened and excluded if they are not considered relevant to the review topic. Double screening will be undertaken by two other reviewers, double reviewing half each. Subsequently, the full text of potentially eligible studies, guidelines, reports or articles will be located for further reading and 20% will be screened to confirm eligibility for inclusion by two other reviewers i.e. 10% each. In addition, the reference list of articles retained for inclusion will be searched for additional relevant literature.

Screening, eligibility decisions and data charting (collected into a table) will be conducted by a primary researcher (the PhD student) with a percentage independently checked by a second and third reviewer as described above. A data charting table will include the following variables:

Citation - Journal (or equivalent for grey literature), title, author, volume, page numbers, year of publication

Objective – Description of the study, guideline, report or article objective as stated by the authors

Sample - Demographic detail of the participants in the study, where applicable

Research type - Study Type / Design – e.g. Quantitative, Qualitative, mixed methods, systematic review; or where grey literature – quality improvement initiative or service evaluation

Phenomenon of Interest – how has the study, guideline, report or article identified supportive care interventions, services or practices designed to meet supportive care needs for patients with pancreatic cancer?

Design – what methods have been used – questionnaires, interviews, focus groups etc.?

Evaluation – does the study, guideline, report or article explore the nature of interventions/services or practices to support the supportive care needs of patients with pancreatic cancer, or evaluate the effectiveness of interventions/services/practices to support these needs?

Outcomes - What are the results or outcomes of the study, guideline, report or article?

Comments – Assessment of usefulness of the study, guideline, report, article in terms of meeting the objectives of the review

Two additional researchers (PhD supervisors) will assess 20% of studies, guidelines, reports or articles through each of these phases of the review. Any disagreement will be resolved by discussion and if a consensus cannot be reached, a third independent reviewer will make the final decision. If further information than that contained in the publication is required, attempts to contact the original authors will be made. A summary of the identification of, screening of, and eligibility decisions regarding articles will be made into a flow diagram following the PRISMA design.

Outcomes and prioritization

1. Identification of the interventions, services and practices used to address the supportive care needs of patients with pancreatic cancer, with a specific focus on inoperable pancreatic cancer
2. Identification of the gaps in supportive care for patients with pancreatic cancer, with a specific focus on inoperable pancreatic cancer
3. Assessment of the effectiveness of these interventions, services and practices i.e. the impact on patients; with an assessment of what works for who and in what circumstances
4. Clarification of key concepts and definitions such as ‘supportive care intervention’

Risk of bias in individual studies

As this is a Scoping Review, included literature will not be critically appraised to assess the reporting of methodological quality using an appropriate JBI Critical Appraisal Checklist (i.e. for Qualitative research) (8). Instead, the included literature will be appraised to determine its usefulness in addressing the review objectives as the purpose of a scoping review is not to come up with an answer or to test a hypothesis – rather the purpose of the scoping review is exploratory.

Two additional researchers (PhD supervisors) will assess a randomly selected quota of the studies, guidelines, reports or articles – either 10% of the total papers included, or a minimum of five papers whichever is the greater of the two, on the same basis. Any differences of opinion will be resolved through discussion and consensus with a third researcher if necessary.

A description will be provided however of the following in terms of prevalence in the literature, where available: Geographical setting (by country or region within country); demographics of study participants (by gender, age, ethnicity, socio-economic status, educational attainment); presence of specific social factors (by caring and non-caring responsibilities); relevant clinical factors (by prognosis and treatment pathway); relevant organisational factors (by specialist and non-specialist sites).

Strategy for data synthesis

A descriptive, qualitative, content analysis will be undertaken. A thematic analysis will not be undertaken as this is beyond the remit of a scoping review.

The findings will also be charted in three tables as follows:

1. The summary data charting table - a summary of all the literature included, as noted in the data extraction section above
2. A mapping of the interventions against the following: types and descriptions of interventions/strategies etc; population receiving the interventions; when delivered, mode of delivery and duration of delivery; aims of the intervention; whether and how effectiveness is measured; which of Fitch's seven domains of supportive care for cancer patients (9) - physical, informational, emotional, psychological, practical, social and spiritual are covered by the intervention.
3. A realist review of the interventions and services provided to patients and their family carers - what works best for whom and in what circumstances

Meta-bias(es)

An assessment will be made of the following potential meta bias(es): Geographical (by country or region within country); demographic (by gender, age, ethnicity, socio-economic status, educational attainment); social factors (by caring and non-caring responsibilities); clinical factors (by prognosis and treatment pathway); organisational factors (by specialist and non-specialist sites).

In addition, an assessment will be made as to the focus of the supportive care interventions/services or practices and whether there is a bias in the literature towards one type of intervention/service or need, or one domain of need i.e. psychological support needs, or nutritional support needs.

Confidence in cumulative evidence

The strength of the body of evidence will be assessed by following the process outlined above for a critical appraisal of the papers.

It is possible that there will still be some definitional ambiguities that might hamper the endeavour such as the definition of supportive care needs.

References

1. Cancer Research UK (2020) https://www.cancerresearchuk.org/aboutcancer/pancreaticcancer/about. – accessed 01/03/2021 (last reviewed 14th July 2020)

2. National Institute for Health and Care Excellence (NICE). (2018) Pancreatic cancer: diagnosis and management in adults. NICE Clinical Guideline CG32. https://www.nice.org.uk/guidance/cg32; 2018.

3. Scott, E and Jewell, A. (2019) 'Supportive care needs of people with pancreatic cancer: A literature review'. Cancer Nursing Practice doi:10.7748/cnp2019.e.1566

4. Watson, E.K., Brett, J., Hay, H. et al (2019) 'Experiences and supportive care needs of UK patients with pancreatic cancer: A cross-sectional questionnaire survey'. BMJ Open 2019,9:e032681

5. Klotz, R. et al (on behalf of the Priority Setting Partnership Pancreatic Cancer) (2020) Top ten research priorities for pancreatic cancer therapy. The Lancet Vol 21 June 2020

6. NICE (2004) Improving Supportive and Palliative Care for Adults with Cancer (The Manual)

7. NICE (2018) Pancreatic cancer in adults: diagnosis and management

8. Lockwood C, Munn Z, Porritt K. Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. Int J Evid Based Healthc. 2015;13(3):179–187.

9. Fitch, M.I. (1994). Providing supportive care for individuals living with cancer (Task Force Report). Toronto: Ontario Cancer Treatment and Research Foundation

A2. Introductory letter to study

IRAS Project ID: 302097

NHS REC Name: South Central – Oxford B Research Ethics Committee

REC Reference: 22/SC/0013

TITLE OF STUDY: Optimising the care and support for patients with inoperable pancreatic cancer and their families and carers

Hello, my name is Hilary Brown, and I am a Health Services Researcher and PhD student at Oxford Brookes University. I am researching the support and care needs of people recently diagnosed with inoperable pancreatic cancer. The study will aim to highlight any areas for improvement in the provision of support and care to patients and their family carers, such as the help and information people might need.

I know this must be a very difficult time for you and your family members, but I would like to ask you to consider taking part in this study, in order to help other people like you.

Briefly, I would like to interview (informal conversation) people who have recently been diagnosed with inoperable pancreatic cancer and their family carers up to three times over the next few months, approximately once every two-three months.

I have asked your consultant to pass on this introductory letter in order to let you know that the study is going on and that your cancer nurse will be discussing this with you in more detail shortly to see if you would be interested in taking part. There is absolutely no obligation to take part in this study and you can tell your consultant now if you do not wish to find out more.

Thank you very much for taking the time to read this letter.

Yours sincerely,

Hilary Brown (PhD Student)

Email: 19154077@brookes.ac.uk

A3. Participant Information Sheet – Patients

IRAS Project ID: 302097
NHS REC Name: South Central – Oxford B Research Ethics Committee
REC Reference: 22/SC/0013

Optimising the care and support for patients with inoperable pancreatic cancer and their families and carers

You are being invited to take part in a study that is being undertaken by Ms. Hilary Brown – a health services researcher and a PhD student at Oxford Brookes University. Participation in the study is completely voluntary.

Before you decide, it is important that you understand why the study is being carried out and what it would involve. If there is anything that is not clear, or if you would like more information, please ask.

What is the purpose of the study?

Receiving a diagnosis of inoperable pancreatic cancer is very distressing and overwhelming for people and their family members. People will experience a range of diverse physical, emotional, and practical needs when they are diagnosed, while those closest to the patient will also experience a range of different emotions and needs as they come to terms with the diagnosis and provide support to their family member.

This study will explore the support and care needs of people recently diagnosed with inoperable pancreatic cancer, and their family members, and how these needs might change over time. It will also consider people's experiences of receiving care or services to help identify or address these needs.

In addition, the study will explore the experience of healthcare professionals who routinely provide care and support to people with pancreatic cancer to identify the challenges they might face in providing the best care and support to patients and their family carers.

The study will aim to highlight any gaps in the provision of support and care to patients and their family carers and explore how these gaps might be addressed.

Why have I been invited to participate?

You have been invited to take part in the study because you have recently received a diagnosis of inoperable pancreatic cancer. I will be recruiting a maximum of 25 patient and family carer pairs through Oxford University Hospitals, University Hospitals Birmingham, Worcestershire Acute Hospitals NHS Trust and Walsall Healthcare NHS Trust.

What will happen to me if I take part?

If you decide to take part, the study will involve you and your nominated family carer (closest supportive person) taking part in three interview sessions. Your family carer might be a spouse or partner, family member, or close friend. Ideally, you and your family carer would be interviewed separately each time, but you could be interviewed together if that is your preference.

Please note that if you do not have a close supportive person to nominate, or you do not wish to do so for whatever reason, this does not prevent you from participating in the study on your own.

The interviews will take place with me either in person in a place of your choosing (and Covid restrictions permitting), by telephone or by a video platform like Zoom, whichever you prefer and at a time that is convenient for you.

The interviews will last around 45 minutes to an hour but could be shorter if that feels too long. The first interview will take place ideally within a month of your diagnosis, the second interview three months after diagnosis, and the third interview six months after diagnosis.

With your permission, the interviews will be audio or visually recorded and prior to starting each interview I will ask you to reaffirm your verbal consent to participate in the study. The audio/video recording will be conducted through a secure and confidential platform. Once transcribed and checked for accuracy, recordings from the interviews will be destroyed, unless you specifically give your permission for the recording to be used at a future event (see below). If this is the case, the recording would be destroyed within a week of the event taking place.

The interviews will involve me asking you questions about the sort of support and care needs you are experiencing, and if these needs are being met.

I have a produced a simple diary or log sheet to help you remember what appointments you have had and which health professionals you may have seen, as this might be useful to refer to in the interviews. You do not have to use this, but it is included in the pack, in case you might find it useful. The questions I will ask you in the first interview are also included in the pack, as it might be helpful for you to know in advance the questions I will be asking, so you can have a think about your answers beforehand.

You will also be invited to attend an event when potential ideas to improve care and support will be discussed and recommendations for changes can be suggested. There will be two half-day events – one in Oxford and one in Birmingham and they will take place as soon as possible after the interviews have been completed.

Everyone who has taken part in the interviews will be invited to an event, but participation is entirely voluntary. Neither you nor your family carer has to commit to attend an event to take part in the interviews. You could also contribute to these events without having to attend in person, for example through a recording of you talking about your experiences.

There are no personal financial costs associated with participation. If you decide to be interviewed in a location which is not your home, travel expenses will be reimbursed. The discussion event will be arranged for the daytime and with a start time to allow for people to travel. Should you decide to take part in this event in person any travel costs to do so will be reimbursed.

Do I have to take part?

It is up to you to decide whether to take part in this research study. If you do decide to take part, you will be asked to give your consent to take part and to provide the name of your nominated family carer, with their permission.

If you decide to take part, you are still free to withdraw at any time and without giving a reason. If you do choose to or are forced to withdraw from the study due to personal circumstances, any unprocessed data collected from you will be withdrawn but data that has been processed cannot be withdrawn. However, in this situation I would not use your direct quotes in the thesis or any publications.

Choosing to either take part or not take part in the study will have no impact on your current or future treatment or care. However, if you choose not to take part, recruitment of your nominated family carer to the study will not be undertaken.

If you are unable to continue with the study for any reason at some future point, it is possible for your nominated family carer to continue in the study if they wish to do so, as they may have ongoing needs to discuss. However, there is absolutely no obligation whatsoever for them to continue in the study and they are free to withdraw at any point.

What are the possible benefits of taking part?

The study will help us understand gaps in the provision of care to address the support and care needs of people with inoperable pancreatic cancer and their family carers. Though taking part may not directly benefit you, I hope that the study will lead to longer term improvements in how healthcare professionals are better able to support people diagnosed with inoperable pancreatic cancer, and their family carers.

What are the possible disadvantages and risks of taking part?

The main disadvantage of taking part in this study is the possible distress that the interview could provoke. Some negative feelings about your experience and some sensitive or emotional issues may arise during the interviews. You would also be giving up your time to participate.

The interview can be stopped at any point, if you felt you would like to take a break and it can be concluded at any point if you do not wish to continue at the time. Withdrawing from the study will not affect your care in any way. If the interview causes you any distress, or raises questions about the care you are receiving, I would be able to signpost you to sources of support such as the Patient Advice Liaison Service and the team of healthcare professionals who care for you at the hospital.

How will we use information about you?

We will need to use information from you for this research project.

This information will include your:

- Name
- Contact details
- Sex
- Age
- Ethnicity

All personal data will be held by Oxford Brookes University. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, the anonymised interview data will be kept for a period of 10 years, in accordance with the University's policy on academic integrity. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study in a specialised database.

Where can you find out more about how your information is used?

You can find out more about how we use your information at www.hra.nhs.uk/information-about-patients, from the leaflet available from www.hra.nhs.uk/patient-dataandresearch or by sending an email to infosec@brookes.ac.uk or the Data Protection Officer (BrookesDPO@brookes.ac.uk).

What will happen to the results of the research study?

The findings from the research will initially be shared with participants at the events where potential recommendations for changes to how care and support is provided will be discussed. They will then be published within my PhD thesis. A copy of the thesis will be stored in the University library and will be available electronically.

Findings will also be published in academic journal articles and presented as conference papers or presentations. They may also be used by other relevant organisations such as Pancreatic Cancer UK in their publications.

Who is organising and funding the research?

I am conducting the research as a PhD student at Oxford Brookes University. I am based within the Oxford Institute of Nursing, Midwifery and Allied Health Research, Faculty of Health and Life Sciences.

Who has reviewed the study?

To protect your safety, rights, wellbeing, dignity and interests, this study has been reviewed and given a favourable opinion by South Central Oxford B Research Ethics Committee. The study reference is: 22/SC/0013

What should I do if I want to take part?

If you would like to take part in the study, please speak to the person you would choose to nominate as your family carer to ask if they would also be interested in taking part in the study.
If you are both happy to proceed, please contact me by email 19154077@brookes.ac.uk. Or you can use the tear off slip at the bottom of this sheet to reply by post.

I would ideally like to undertake the first interview with you and your family carer within the first month following your diagnosis, so if you would like to participate, please bear this in mind when making contact.

Contacts for further information/support

If you feel you would like some additional support in relation to your situation, the following contacts may be helpful.

Cancer Nurse Specialist Team at Oxford Brookes University Hospitals – telephone 01865 235130 (answerphone out of hours)

Patient Advisory Service at Oxford University Hospitals: Email: PALS@ouh.nhs.uk or telephone: 01865 221473

Pancreatic Cancer UK Helpline's nurses are specialists in pancreatic cancer and can help with managing symptoms, questions about your diagnosis, treatment options or just to talk about how you are feeling. You can call them free on 0808 801 0707 (Open Mondays, Tuesdays, Thursdays, and Fridays between 9am and 4pm, and open Wednesdays between 10am and 6pm.)

Marie Curie can provide practical and clinical information and emotional support for patients and their family and friends. You can call them free on 0800 090 2309 (open 8am-6pm Monday to Friday and 11am-5pm on Saturdays).

The **Macmillan** Support Line can help with clinical, practical, and financial information. You can call them free on 0808 808 00 00 (7 days a week, 8am-8pm)

If you have any queries about the study, please contact me 19154077@brookes.ac.uk or my supervisor Professor Eila Watson ewatosn@brookes.ac.uk

If you have any complaints about the way you are dealt with during this study, please contact the Chair of the University Research Ethics Committee on ethics@brookes.ac.uk

Thank you for taking the time to read this information sheet and for your consideration of taking part in this study.
Version Number V3.0

……………………………………………………………………………………………………

I am interested in participating in the study and would like to arrange a time to discuss this further with you.

I have spoken to the person I would nominate as my family carer, and they have also expressed an interest in taking part in the study. (delete as applicable)

I do not have someone I wish to nominate as my family carer. (delete as applicable)

Name:

Contact details:

Home phone:

Mobile:

Email address:

Home address:

Please return this slip in the stamped and addressed envelope to:
Hilary Brown
PhD Student
Supportive Cancer Care Research Group
Oxford Institute of Nursing, Midwifery and Allied Health Research
Faculty of Health and Life Sciences
Oxford Brookes University
Jack Straws Lane
Marston
Oxford OX3 0FL

A4. Consent Form – Patients

PATIENT CONSENT FORM
Optimising the care and support for patients with inoperable pancreatic cancer and their families and carers

IRAS Project ID: 302097
NHS REC Name: South Central – Oxford B Research Ethics Committee
REC Reference 22/SC/0013

Name, position and contact details of Researcher:
Hilary Brown, MPhil / PhD student,
Email: 19154077@brookes.ac.uk

		Please initial box
1.	I confirm that I have read and understand the information sheet (version 3.0 dated 22nd February 2022) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, and without my medical care or legal rights being affected.	
3.	I understand that the interview will be audio-recorded, with an option of video recording if online and where consent is specifically given verbally.	
4.	I understand that confidentiality can only be maintained within the limits of the law and that in exceptional circumstances confidentiality may need to be broken if the safety of individuals is at risk.	
5.	I understand that my personal data will be kept until the end of the PhD study and that research data generated by the study will be kept for a period of ten years.	
6.	I agree to the use of pseudonymised quotes in publications i.e. where my real name is not used.	
7.	I agree that an anonymised data set*, gathered for this study may be stored electronically in a specialised database for future research. *(This means that no-one can be identified from the data that is stored)	
8.	I agree to take part in the above study.	

Name of Participant Date Signature

Name of Researcher Date Signature

A5. Participant Information Sheet – Family Carers

IRAS Project ID: 302097
NHS REC Name: South Central – Oxford B Research Ethics Committee
REC Reference: 22/SC/0013

Optimising the care and support for patients with inoperable pancreatic cancer and their families and carers

You are being invited to take part in a study that is being undertaken by Ms. Hilary Brown – a health services researcher and a PhD student at Oxford Brookes University. Whether or not you take part in the study is entirely up to you.

Before you decide, it is important that you understand why the study is being carried out and what it would involve for you. If there is anything that is not clear, or if you would like more information, please ask.

What is the purpose of the study?

Receiving a diagnosis of inoperable pancreatic cancer is very distressing and overwhelming for people and their family members. People will experience a range of diverse physical, emotional, and practical needs when they are diagnosed, while those closest to the patient will also experience a range of different emotions and needs as they come to terms with the diagnosis and provide support to their family member.

This study will explore the support and care needs of people recently diagnosed with inoperable pancreatic cancer, and their family members, and how these needs might change over time. It will also consider people's experiences of receiving care or services to help identify or address these needs.

In addition, the study will explore the experience of healthcare professionals who routinely provide care and support to people with pancreatic cancer to identify the challenges they might face in providing the best care and support to patients and their family carers.

The study will aim to highlight any gaps in the provision of support and care to patients and their family carers and explore how these gaps might be addressed.

Why have I been invited to participate?

You have been invited to take part in the study because you have been nominated as the family carer of someone who has recently received a diagnosis of inoperable pancreatic cancer. I will be recruiting a maximum of 25 patient and family carers through Oxford University Hospitals, University Hospitals Birmingham, Worcestershire Acute Hospitals NHS Trust and Walsall Healthcare NHS Trust.

What will happen to me if I take part?

If you decide to take part, the study will involve you and your family member taking part in three interview sessions. Ideally, you and your family member would be interviewed separately each time, but you could be interviewed together if that is your preference. 22/02/2022

The interviews will take place with me either in person in a place of your choosing (and Covid restrictions permitting), by telephone or by a video platform like Zoom, whichever you prefer and at a time that is convenient for you.

The interviews will last around 45 minutes to an hour but could be shorter if that feels too long. The first interview will take place ideally within a month of your family member receiving their diagnosis, the second interview three months after diagnosis, and the third interview six months after diagnosis.

With your permission, the interviews will be audio or visually recorded and prior to starting each interview I will ask you to reaffirm your verbal consent to participate in the study. The audio/video recording will be conducted through a secure and confidential platform. Once transcribed and checked for accuracy, recordings from the interviews will be destroyed, unless you specifically give your permission for the recording to be used at a future event (see below). If this is the case, the recording would be destroyed within a week of the event taking place.

The interviews will involve me asking you questions about the sort of support and care needs you are both experiencing, and if these needs are being met.

I have a produced a simple diary or log sheet to help you remember what appointments your family member has had and which health professionals they may have seen, as this might be useful to refer to in the interviews. You do not have to use this, but it is included in the pack, in case you might find it useful. The questions I will ask you in the first interview are also included in the pack, as it might be helpful for you to know in advance the questions I will be asking, so you can have a think about your answers beforehand.

You will also be invited to attend an event when potential ideas to improve care and support will be discussed and recommendations for changes can be suggested. There will be two half-day events – one in Oxford and one in Birmingham and they will take place as soon as possible after the interviews have been completed.

Everyone who has taken part in the interviews will be invited to an event, but participation is entirely voluntary. Neither you nor your family member has to commit to attend an event to take part in the interviews. You could also contribute to these events without having to attend in person, for example through a recording of you talking about your experiences.

There are no personal financial costs associated with participation. If you decide to be interviewed in a location which is not your home, travel expenses will be reimbursed. The discussion event will be arranged for the daytime and with a start time to allow for people to travel. Should you decide to take part in this event in person any travel costs to do so will be reimbursed.

Do I have to take part?

It is up to you to decide whether to take part in this research study. If you do decide to take part, you will be asked to give your consent. If you decide to take part, you are still free to withdraw at any time and without giving a reason. If you do choose to or are forced to withdraw from the study due to personal circumstances, any unprocessed data collected from you will be withdrawn but data that has been processed cannot be withdrawn. However, in this situation I would not use your direct quotes in the thesis or any publications.

Choosing to either take part or not take part in the study will have no impact whatsoever on the current or future treatment or care of your family member.

If your family member is unable to continue with the study for any reason at some future point, it is possible for you to continue in the study if you wish to do so, as you may have ongoing needs to discuss. However, there is absolutely no obligation whatsoever for you to continue in the study if this is the case and you are free to withdraw at any point.

What are the possible benefits of taking part?

The study will help us understand gaps in the provision of care to address the support and care needs of people with inoperable pancreatic cancer and their family carers. Though taking part may not directly benefit you, I hope that the study will lead to longer term improvements in how healthcare professionals are better able to support people diagnosed with inoperable pancreatic cancer, and their family carers.

What are the possible disadvantages and risks of taking part?

The main disadvantage of taking part in this study is the possible distress that the interview could provoke. Some negative feelings about your experience and some sensitive or emotional issues may arise during the interviews. You would also be giving up your time to participate.

The interview can be stopped at any point, if you felt you would like to take a break and it can be concluded at any point if you do not wish to continue at the time. Withdrawing from the study will not affect the care of your family member in any way. If the interview causes you any distress or raises questions about the care your family member is receiving, I would be able to signpost you to sources of support such as the Patient Advice Liaison Service and the team of healthcare professionals who care for your family member at the hospital.

How will we use information about you?

We will need to use information from you for this research project.
This information will include your:

- Name
- Contact details
- Sex
- Age
- Ethnicity

All personal data will be held by Oxford Brookes University. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, the anonymised interview data will be kept for a period of 10 years, in accordance with the University's policy on academic integrity. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study in a specialised database.

Where can you find out more about how your information is used?

You can find out more about how we use your information at www.hra.nhs.uk/information-about-patients, from the leaflet available from www.hra.nhs.uk/patientdataandresearch or by sending an email to infosec@brookes.ac.uk or the Data Protection Officer (BrookesDPO@brookes.ac.uk).

What will happen to the results of the research study?

The findings from the research will initially be shared with participants at the events where potential recommendations for changes to how care and support is provided will be discussed. They will then be published within my PhD thesis. A copy of the thesis will be stored in the University library and will be available electronically.

Findings will also be published in academic journal articles and presented as conference papers or presentations. They may also be used by other relevant organisations such as Pancreatic Cancer UK in their publications.

Who is organising and funding the research?

I am conducting the research as a PhD student at Oxford Brookes University. I am based within the Oxford Institute of Nursing, Midwifery and Allied Health Research, Faculty of Health and Life Sciences.

Who has reviewed the study?

To protect your safety, rights, wellbeing, dignity and interests, this study has been reviewed and given a favourable opinion by South Central - Oxford B Research Ethics Committee. The study reference is: 22/SC/0013.

What should I do if I want to take part?

If you would like to take part in the study, please contact me by email 19154077@brookes.ac.uk. Or you can both use the tear off slip at the bottom of this sheet to reply by post.

I would ideally like to undertake the first interview with you and your family member within the first month following your diagnosis, so if you would like to participate, please bear this in mind when making contact.

Contacts for further information/support

If you feel you would like some additional support in relation to your situation, the following contacts may be helpful.

Cancer Nurse Specialist Team at Oxford University Hospitals: telephone 01865 235130 (answerphone out of hours)

Patient Advisory Service at Oxford University Hospitals: Email: PALS@ouh.nhs.uk or telephone: 01865 221473

Pancreatic Cancer UK Helpline's nurses are specialists in pancreatic cancer and can help with managing symptoms, questions about diagnosis, treatment options or just to talk about how you're feeling. You can call them on 0808 801 0707 (Open Mondays, Tuesdays, Thursdays, and Fridays between 9am and 4pm, and open Wednesdays between 10am and 6pm.)

Marie Curie can provide practical and clinical information and emotional support for patients and their family and friends. You can call them free on 0800 090 2309 (open 8am-6pm Monday to Friday and 11am-5pm on Saturdays).

The **Macmillan** Support Line can help with clinical, practical, and financial information. You can call them on 0808 808 00 00 (7 days a week, 8am-8pm)

If you have any queries about the study, please contact me at 19154077@brookes.ac.uk or Professor Eila Watson ewatosn@brookes.ac.uk

If you have any complaints about the way you are dealt with during this study, please contact the Chair of the University Research Ethics Committee on ethics@brookes.ac.uk.

Thank you for taking the time to read this information sheet and for your consideration of taking part in this study.

Version Number 3.0

We are interested in participating in the OPTIMISTIC study and we would like to arrange a time to discuss this further with you.

Names: (please indicate if you are the person with pancreatic cancer, or their family carer)

Contact details:

Home phone:

Mobile:

Email address:

Home address:

Please return this slip to:
Hilary Brown
PhD Student
Supportive Cancer Care Research Group
Oxford Institute of Nursing, Midwifery and Allied Health Research
Faculty of Health and Life Sciences
Oxford Brookes University
Jack Straws Lane
Marston
Oxford OX3 0FL

A6. Family Carer Consent Form

OXFORD BROOKES UNIVERSITY

FAMILY CARER CONSENT FORM

Optimising the care and support for patients with inoperable pancreatic cancer and their families and carers

IRAS Project ID: 302097
NHS REC Name: South Central - Oxford B Research Ethics Committee
REC Reference 22/SC/0013

Name, position and contact details of Researcher:
Hilary Brown, MPhil / PhD student,
Email: 19154077@brookes.ac.uk

		Please initial box
1.	I confirm that I have read and understand the information sheet (version 3.0 dated 22nd February 2022) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, and without the medical care of my family member, or my legal rights being affected.	
3.	I understand that the interview will be audio-recorded, with an option of video recording if online and where consent is specifically given verbally.	
4.	I understand that confidentiality can only be maintained within the limits of the law and that in exceptional circumstances confidentiality may need to be broken if the safety of individuals is at risk.	
5.	I understand that my personal data will be kept until the end of the PhD study and that research data generated by the study will be kept for a period of ten years.	
6.	I agree to the use of pseudonymised quotes in publications i.e. where my real name is not used.	
7.	I agree that an anonymised data set*, gathered for this study may be stored electronically in a specialised database for future research. *(This means that no-one can be identified from the data that is stored)	
8.	I agree to take part in the above study.	

Name of Participant　　Date　　Signature

Name of Researcher　　Date　　Signature

A7. Diary Sheet/Log Form for patients and Family Carers

APPOINTMENT LOG

Optimising the care and support for patients with inoperable pancreatic cancer and their families and carers study

This log sheet is for you record the appointments and contacts you have with health and social care professionals in order to help you recall information during interviews. Its completion is entirely voluntary – please only use it if you find it helpful. The researcher will not ask to see this log, so anything you write in here is entirely confidential and for your own records.

Date What was the date of the appointment, activity or contact with a healthcare professional?	**Appointment/Activity** What happened on this date? This might be a routine clinic appointment at the hospital, an appointment with your GP, a diagnostic test like a scan or a blood test or a phone call with someone from your care team asking for advice or support. You might also include any attendances at A&E for urgent care, if required.	**Outcome/Result, if relevant** What happened at the appointment/activity and what will happen next, if anything?	**Reflection (optional)** How did I feel about this?
Examples:	***Examples:***	***Examples:***	***Examples:***
1. 31st January 2022	Clinic appointment with Dr Khan	Went through test results	Felt I was listened to and could ask questions
2. 12th February 2022	Phone call with Sheila – Cancer Nurse at PCUK helpline to talk about digestive problems	Sheila suggested I should adjust my CREON dosage, so I'll make an appointment to see my GP	Seems quite straightforward - wish I'd called sooner – just hope I can get an appointment quickly!
3. 31st March 2022	Phoned Maggie Hospital Cancer Nurse about my ongoing pain	Appointment made to see doctor	Anxious that I've got to wait for a few days before I can get this sorted

When completing this log, please feel free to add additional lines, when required.

Date	Appointment/Activity	Outcome/result	Reflection

A8. Participant Information Sheet for Healthcare Professionals

IRAS Project ID: 302097
NHS REC Name: South Central – Oxford B Research Ethics Committee
REC Reference: 22/SC/0013

Optimising the care and support for patients with inoperable pancreatic cancer and their families and carers

You are being invited to take part in a study that is being undertaken by Ms. Hilary Brown – a health services researcher and a PhD student at Oxford Brookes University. Whether or not you take part in the study is entirely up to you.

Before you decide, it is important that you understand why the study is being carried out and what it would involve for you. If there is anything that is not clear, or if you would like more information, please ask me.

What is the purpose of the study?

Receiving a diagnosis of inoperable pancreatic cancer is very distressing and overwhelming for people and their family members. People will experience a range of diverse physical, emotional, and practical needs when they are diagnosed, while those closest to the patient will also experience a range of different emotions and needs as they come to terms with the diagnosis and provide support to their family member.

This study will explore the support and care needs of people recently diagnosed with inoperable pancreatic cancer, and their family members, and how these needs might change over time. It will also consider people's experiences of receiving care or services to help identify or address these needs.

The study will also explore the experience of healthcare professionals who routinely provide care and support to people with inoperable pancreatic cancer to identify the challenges they might face in providing the best care and support to patients and their family carers.

The study will therefore highlight gaps or areas for improvement in the provision of care to address the supportive care needs of patients and their family carers, and through discussion with everyone taking part in the study, explore how these gaps might be addressed.

Why have I been invited to participate?

You have been invited to take part in the study because you have been identified as a healthcare professional who routinely provides care and support to people with inoperable pancreatic cancer and their family carers. I will be recruiting a maximum of 25 healthcare professionals from two geographical areas - Oxford and the West Midlands.

What will happen to me if I take part?

If you decide to take part, the study will involve you committing to one (30-45 minute) interview with me either in person (Covid restrictions permitting), by telephone or by a video platform like Zoom, whichever you prefer and at a time that is convenient for you.

With your permission, the interview will be audio or visually recorded and prior to starting the interview you will be asked to reaffirm your verbal consent to participate in the study. The audio/video recording will be conducted through a secure and confidential platform. Once transcribed and checked for accuracy, recordings from the interviews will be destroyed, unless you specifically give your permission for the recording to be used at a future event (see below). If this is the case, the recording would be destroyed within a week of the event taking place.

The interview will involve me asking you questions about the sort of support and care needs you have seen patients with inoperable pancreatic cancer and their family carers experiencing and whether and how you have felt able to address these needs.

I will also be interviewing people diagnosed with inoperable cancer and their family carers about their experiences of having supportive care needs and their experiences of receiving any interventions or services to address these needs.

You will also be invited to attend an event when potential ideas to improve care and support will be discussed and recommendations for changes can be suggested. There will be two half-day events – one in Oxford and one in Birmingham and they will take place as soon as possible after the interviews have been completed.

Everyone who has taken part in the interviews will be invited to an event, but participation is entirely voluntary. You do not have to commit to attend an event to take part in the interview. You could also contribute to these events without having to attend in person, for example through a recording of you talking about your experiences.

Do I have to take part?

It is up to you to decide whether to take part in this research study. If you decide to take part, you are still free to withdraw at any time and without giving a reason. If you do choose to withdraw from the study any unprocessed data collected from you will be withdrawn but data that has been processed cannot be withdrawn. However, in this situation the researcher would not use your direct quotes in the thesis or any publications.

Choosing to either take part or not take part in the study will have no impact whatsoever on your employment.

What are the possible benefits of taking part?

The study will help us understand gaps or areas for improvement in the provision of care to address the supportive care needs of people with inoperable pancreatic cancer and their family carers. Though taking part may not directly benefit you, we hope that the study will lead to longer term improvements in how healthcare professionals are better able to support patients diagnosed with inoperable pancreatic cancer, and their family carers.

What are the possible disadvantages and risks of taking part?

The main disadvantage of taking part in this study would be giving up your time. There are no personal financial costs associated with participation. The interview will be held at a time that is convenient for you and the discussion event will be arranged for the daytime with a start time to allow for people to travel.

Withdrawing from the study will not affect your employment in any way. If the interview causes you any distress or raises questions about the care you are able to provide patients and their family carers with, <u>I would be able to signpost you to sources of support such as the Occupational Health services in your own Trust.</u>

Occupational Health at Oxford University Hospitals: Occupational Health is based at the John Radcliffe Hospital, at the Centre for Occupational Health and Wellbeing.
Tel: 01865 223325
Monday to Friday 8.00am - 4.00pm
Email: OccupationalHealthJR@ouh.nhs.uk

It is possible that during this study that poor practice, unmet needs, or other service issues are identified. These findings will be shared in presentations and my thesis but if you make any comments on these issues, you will not be identifiable.

How will we use information about you?

We will need to use information from you for this research project.
This information will include your:

- Name
- Contact details
- Professional background
- Place of work

<u>All personal data will be held by Oxford Brookes University</u>. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

<u>Once we have finished the study, the anonymised interview data will be kept for a period of 10 years, in accordance with the University's policy on academic integrity</u>. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study in a specialised database.

Where can you find out more about how your information is used?

You can find out more about how we use your information at www.hra.nhs.uk/information-about-patients, from the leaflet available from www.hra.nhs.uk/patient-dataandresearch or by sending an email to infosec@brookes.ac.uk or the Data Protection Officer (BrookesDPO@brookes.ac.uk).

What will happen to the results of the research study?

The findings from the research will initially be shared with participants at the events where potential recommendations for changes to how care and support is provided will be discussed. They will then be published within my PhD thesis. A copy of the thesis will be stored in the University library and will be available electronically.

Findings will also be published in academic journal articles and presented as conference papers or presentations. They may also be used by other relevant organisations such as Pancreatic Cancer UK in their publications.

Who is organising and funding the research?

I am conducting the research as a PhD student at Oxford Brookes University. I am based within the Oxford Institute of Nursing, Midwifery and Allied Health Research, Faculty of Health and Life Sciences.

Who has reviewed the study?

To protect your safety, rights, wellbeing, dignity and interests, this study has been reviewed and given a favourable opinion by South Central – Oxford B Research Ethics Committee. The study reference is: 22/SC/0013.

What should I do if I want to take part?

If you would like to take part in the study, please contact me by email 19154077@brookes.ac.uk

Contacts for further information/support

If you have any queries about the study, please contact me at 19154077@brookes.ac.uk or Professor Eila Watson ewatosn@brookes.ac.uk

If you have any complaints about the way you are dealt with during this study, please contact the Chair of the University Research Ethics Committee on ethics@brookes.ac.uk.

Pancreatic Cancer UK Helpline's nurses are specialists in pancreatic cancer and as well as supporting patients and their family members can also support healthcare professionals with advice on caring for someone with pancreatic cancer. You can call them on 0808 801 0707 (Open Mondays, Tuesdays, Thursdays, and Fridays between 9am and 4pm, and open Wednesdays between 10am and 6pm.)

Thank you for taking the time to read this information sheet and for your consideration of taking part in this study.

Version Number
V3.0

A9. Healthcare Professional Consent Form

Optimising the care and support for patients with inoperable pancreatic cancer and their families and carers

IRAS Project ID: 302097
NHS REC Name: South Central – Oxford B research Ethics Committee
REC Reference 22/SC/0013

Name, position and contact details of Researcher:
Hilary Brown, MPhil / PhD student,
Email: 19154077@brookes.ac.uk

		Please initial box
1.	I confirm that I have read and understand the information sheet (version 3.0 dated 22nd February 2022) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, and without my employment, or my legal rights being affected.	
3.	I understand that the interview will be audio-recorded, with an option of video recording if online and where consent is specifically given verbally.	
4.	I understand that confidentiality can only be maintained within the limits of the law and that in exceptional circumstances confidentiality may need to be broken if the safety of individuals is at risk.	
5.	I understand that my personal data will be kept until the end of the PhD study and that research data generated by the study will be kept for a period of ten years.	
6.	I agree to the use of pseudonymised quotes in publications i.e. where my real name is not used.	
7.	I agree that an anonymised data set*, gathered for this study may be stored electronically in a specialised database for future research. *(This means that no-one can be identified from the data that is stored)	
8.	I agree to take part in the above study.	

____________________ ____________ __________________

Name of Participant Date Signature

____________________ ____________ __________________

Name of Researcher Date Signature

A10. Patient Topic Guide – Interview 1

IRAS Project ID: 302097
NHS REC Name: South Central – Oxford B Research Ethics Committee
REC Reference: 22/SC/0013

Optimising the care and support for patients with inoperable pancreatic cancer and their families and carers

Patient Interview Guide – Interview 1

Introduction

Hello, it's Hilary Brown - we've spoken before – I'm the PhD student at Oxford Brookes University who is undertaking this research study. I really appreciate you giving up your time - the interview should take about 45 minutes to an hour, is that still ok for you today? We can stop any time you like though.

When we spoke before we went through the Participant Information Sheet and Consent Form. Have you been able to agree to each statement and are you happy to proceed today?

When I begin the interview, I will start the recording and ask you to verbally give your consent to take part. I will need to do this at the start of each interview. After you have verbally given your consent, I will stop that recording and start a new recording for the interview. This is so we can keep the consent conversation which contains your personal details separate from your interview data. So, just to reiterate that your participation is completely voluntary, and you can choose not to answer any questions, or stop the interview at any point.

As well as recording our conversation, I will also be taking my own notes to help me remember what you say.

So, just to summarise, the purpose of the interview today is to understand your experiences with receiving help and support for managing your symptoms and any other cancer-related issues or concerns. By gaining an understanding of this, our aim is to better inform the type of support that patients receive in the future.

Do you have any further questions before we begin?

(Please note that these are the topic areas I will cover - the questions as listed here may not be followed exactly and will depend on the participant's responses.)

1. Could you start by telling me how you came to be diagnosed with pancreatic cancer?
2. What was your experience of the diagnosis?
    - How was the news given to you?
    - Did you have the time you needed to ask questions?
    - Can you remember what happened in the days afterwards? i.e., Were you referred to anyone else to discuss the diagnosis and its implications for you?
3. How have you been feeling since receiving the diagnosis?

    - Have you felt able to talk about the situation with your family and friends?

4. Have you had treatment options explained to you? Can you tell me about these?
5. Who is looking after your care and treatment at the moment?
    - Do you have a Cancer Nurse Specialist?
    - Have you seen a dietician?
    - Who else have you seen so far?
6. Do you feel there is effective communication from the healthcare professionals you are seeing?
    - Do you feel you are being listened too?
7. Can you tell me about your physical symptoms and how they are currently affecting you?
    - What help or support have you had for managing these symptoms?
    - Do you feel as though your physical needs are being met at the moment?
8. What help or support have you had for managing your emotional needs?
    - Do you feel as though your emotional needs are being met at the moment?
9. What practical concerns do you have – for example are you worried about household finances, or insurance policies or other practical things like shopping, or looking after relatives?
    - What help or support have you had for managing these practical concerns?
    - Do you feel as though your practical needs are being met at the moment?
10. Have you been in touch with any charities for help and support?
    - If so, how did you find out about the charity?
11. You have nominated xxxxxxxx as your main family carer – do you have any concerns about how they are managing through this?
    - What sort of help or support do you think they might need at the moment?

Those are all the questions I had for you but before we end the interview, is there anything else you would like to talk about that we haven't covered today?

Thank you so much for your time and for sharing your experiences. I really appreciate it. If this interview has raised any issues for you that you would like to talk to someone about, please call the Pancreatic Cancer UK free Support Line. The support line is staffed by specialist nurses and is open Mondays, Tuesdays, Thursdays, and Fridays between 9am and 4pm, and open Wednesdays between 10am and 6pm. The number to call is 0808 801 0707, or you can go onto their website and fill out an online form to contact a nurse over email. The website address is https://www.pancreaticcancer.org.uk

A11. Patient Topic Guide – Interview 2

IRAS Project ID: 302097
NHS REC Name: South Central – Oxford B Research Ethics Committee
REC Reference: 22/SC/0013

Optimising the care and support for patients with inoperable pancreatic cancer and their families and carers

Patient Interview Guide – Interview 2

Introduction

Hello, it's Hilary here. I really appreciate you giving up your time again today - the interview should take about the same amount of time as before, is that still ok for you today?

As I did last time when I begin the interview, I will start the recording and ask you to verbally give your consent to take part and again, I'll start a new recording for the actual interview.

So, just to summarise, the purpose of the interview today is to see how your support and care needs might have changed since the last time we spoke and whether you feel you are getting the right support of support and care to manage these needs.

Do you have any further questions before we begin?

Questions

(Please note that these are the topic areas I will cover - the questions as listed here may not be followed exactly and will depend on the participant's responses.)

1. How have you been managing since we last spoke?
2. What sort of symptoms and concerns are you currently experiencing and have these changed since we spoke previously?
3. Do you think you are getting the right help or support at the moment to manage your symptoms or address these concerns?
4. Have you seen or been referred to any other service or healthcare professional since the last time we spoke? (Please feel free to refer to the diary or appointment log if you have been using it.)
5. What sort of additional help or support do you think would be most beneficial for you at this point in time?
6. How do you think xxxxxxx has been managing?
7. What sort of help or support do you think xxxxxxx needs most at this point in time?

Those are all the questions I had for you today but before we end the interview, do you have any comments you would like to make on any issues that we haven’t covered today?

Thank you so much for your time and for sharing your experiences. I really appreciate it. If this interview has raised any particular issues for you that you would like to talk to someone about, please call the Pancreatic Cancer UK free Support Line. The support line is staffed by specialist nurses and is open Mondays, Tuesdays, Thursdays and Fridays between 9am and 4pm, and open Wednesdays between 10am and 6pm. The number to call is 0808 801 0707, or you can go onto their website and fill out an online form to contact a nurse over email. The website address is https://www.pancreaticcancer.org.uk

A12. Patient Topic Guide – Interview 3

IRAS Project ID: 302097
NHS REC Name: South Central – Oxford B Research Ethics Committee
REC Reference: 22/SC/0013

Optimising the care and support for patients with inoperable pancreatic cancer and their families and carers

Patient Interview Guide – Interview 3

Introduction

Hello, it's Hilary here. I really appreciate you giving up your time again today - the interview should take about the same amount of time as before, is that still ok for you today?

As I did last time when I begin the interview, I will start the recording and ask you to verbally give your consent to take part and again, I'll start a new recording for the actual interview.

So, just to summarise, the purpose of the interview today is to see how your support and care needs might have changed since the last time we spoke and whether you feel you are getting the right support of support and care to manage these needs.

Do you have any further questions before we begin?

Questions

(Please note that these are the topic areas I will cover - the questions as listed here may not be followed exactly and will depend on the participant's responses.)

1. How have you been managing since we last spoke?
2. What sort of symptoms and concerns are you currently experiencing and have these changed since we spoke previously?
3. Do you think you are getting the right help or support at the moment to manage your symptoms or address these concerns?
4. Have you seen or been referred to any other service or healthcare professional since the last time we spoke? (Please feel free to refer to the diary or appointment log if you have been using it.)
5. What sort of additional help or support do you think would be most beneficial for you at this point in time?
6. How do you think xxxxxxx has been managing?
7. What sort of help or support do you think xxxxxxx needs most at this point in time?

Those are all the questions I had for you today but as this is our last interview for the study, please feel free to comment on anything that you think is important to you that we haven't covered already, or that you would like to say more about.

Thank you so much for your time and for sharing your experiences. I really appreciate it. If this interview has raised any particular issues for you that you would like to talk to someone about, please call the Pancreatic Cancer UK free Support Line. The support line is staffed by specialist nurses and is open Mondays, Tuesdays, Thursdays and Fridays between 9am and 4pm, and open Wednesdays between 10am and 6pm. The number to call is 0808 801 0707, or you can go onto their website and fill out an online form to contact a nurse over email. The website address is https://www.pancreaticcancer.org.uk

A13. Family Carer Topic Guide – Interview 1

IRAS Project ID: 302097
NHS REC Name: South Central Oxford B research Ethics Committee
REC Reference: 22/SC/0013

Optimising the care and support for patients with inoperable pancreatic cancer and their families and carers

Family-carer Interview Guide – Interview 1

Introduction

Hello, it's Hilary Brown - we've spoken before – I'm the PhD student at Oxford Brookes University who is undertaking this research study. I really appreciate you giving up your time - the interview should take about 45 minutes to an hour, is that still ok for you today?

When we spoke before we went through the Participant Information Sheet and Consent Form. Have you been able to agree to each statement and are you happy to proceed today?

When I begin the interview, I will start the recording and ask you to verbally give your consent to take part. I will need to do this at the start of each interview. After you have verbally given your consent, I will stop that recording and start a new recording for the interview. This is so we can keep the consent conversation which contains your personal details separate from your interview data. So, just to reiterate that your participation is completely voluntary, and you can choose not to answer any questions, or stop the interview at any point.

So, just to summarise, the purpose of the interview today is to understand your experiences with receiving help and support for any issues or concerns you may have, either for yourself as a family-carer, or for your family member managing their symptoms and concerns. By gaining an understanding of this, we will hopefully be able to better inform the type of support that patients and their family-carers receive in the future.

Do you have any further questions before we begin?

Questions

(Please note that these are the topic areas I will cover - the questions as listed here may not be followed exactly and will depend on the participant's responses.)

1. Could you perhaps start by telling me how xxxxxxx came to be diagnosed?
2. What was your experience of the diagnosis?
    - How was the news given to you?
    - Did you have the time you needed to ask questions?
    - Can you remember what happened in the days afterwards? i.e. Was xxxxx referred to anyone else to discuss the diagnosis and its implications? Were you able to talk to anyone about the implications of the diagnosis?

3. How have you been feeling since the diagnosis?
    - Have you felt able to talk about the situation with xxxxxxxx?
    - Have you felt able to talk about the situation with family and friends?
4. Has xxxxxxx had any treatment options explained to him/her?
    - What do you understand about them?
5. Who is looking after xxxxxx care and treatment at the moment?
    - Does xxxxxx have a Cancer Nurse Specialist?
    - Has xxxxx seen a dietician?
    - Who else has xxxxxx seen so far?
    - Have you attended appointments with xxxxxx?
6. What sorts of physical symptoms is xxxxxxxx experiencing at the moment?
    - What help or support has xxxxxx had for managing these symptoms?
7. Has xxxxxx had any help or support for managing their emotional needs?
8. Do you feel as though xxxxxxx needs are being met at the moment?
9. How satisfied do you feel with the care and treatment that xxxxxx has received to date?
10. And what about you? What sort of help and support do you feel you need at the moment?
    - Do you feel as though your needs are being met at the moment?
11. Have you been in touch with any charities for help and support?
    - If so, how did you find out about the charity?

Those are all the questions I had for you today but before we end the interview, is there anything else that you would like to talk about that we haven't covered today?

Thank you so much for your time and for sharing your experiences. I really appreciate it. If this interview has raised any particular issues for you that you would like to talk to someone about, please call the Pancreatic Cancer UK free Support Line. The support line is staffed by specialist nurses and is open Mondays, Tuesdays, Thursdays and Fridays between 9am and 4pm, and open Wednesdays between 10am and 6pm. The number to call is 0808 801 0707, or you can go onto their website and fill out an online form to contact a nurse over email. The website address is https://www.pancreaticcancer.org.uk

A14. Family Carer Topic Guide – Interview 2

IRAS Project ID: 302097
NHS REC Name: South Central – Oxford B Research Ethics Committee
REC Reference: 22/SC/0013

Optimising the care and support for patients with inoperable pancreatic cancer and their families and carers

Family-carer Interview Guide – Interview 2

Introduction

Hello, it's Hilary here. I really appreciate you giving up your time again today - the interview should take about the same amount of time as before, is that still ok for you today?

As I did last time when I begin the interview, I will start the recording and ask you to verbally give your consent to take part and again, I'll start a new recording for the actual interview.

So, just to summarise, the purpose of the interview today is to see how your needs as a family carer might have changed since the first time we spoke and what sort of help and support you're getting at the moment.

Do you have any questions before we begin?

Questions

(Please note that these are the topic areas I will cover - the questions as listed here may not be followed exactly and will depend on the participant's responses.)

1. How have you been managing since we last spoke?
2. What sorts of issues and concerns have you been experiencing?
3. Do you think you are getting the right help or support at the moment to manage these issues?
4. What sort of additional help or support do you think would be most beneficial for you at this point in time?
5. How do you think xxxxxxx has been managing?
6. What sort of help or support do you think xxxxxxx needs most at this point in time?

Those are all the questions I had for you today but before we end the interview, is there anything else that you would like to talk about that we haven't covered today that we haven't covered today?

Thank you so much for your time and for sharing your experiences. I really appreciate it. If this interview has raised any particular issues for you that you would like to talk to someone about, please call the Pancreatic Cancer UK free Support Line. The support line is staffed by specialist nurses and is open Mondays, Tuesdays, Thursdays and Fridays between 9am and 4pm, and open Wednesdays between 10am and 6pm. The number to call is 0808 801 0707, or you can go onto their website and fill out an online form to contact a nurse over email. The website address is https://www.pancreaticcancer.org.uk

A15. Family Carer Topic Guide – Interview 3

OXFORD BROOKES UNIVERSITY

IRAS Project ID: 302097
NHS REC Name: South Central – Oxford B Research Ethics Committee
REC Reference: 22/SC/0013

Optimising the care and support for patients with inoperable pancreatic cancer and their families and carers

Family carer Interview Guide – Interview 3

Introduction

Hello, it's Hilary here. I really appreciate you giving up your time again today - the interview should take about the same amount of time as before, is that still ok for you today?

As I did last time when I begin the interview, I will start the recording and ask you to verbally give your consent to take part and again, I'll start a new recording for the actual interview.

So, just to summarise, the purpose of the interview today is to see how your needs as a family carer might have changed since the first time we spoke and what sort of help and support you're getting at the moment.

Do you have any further questions before we begin?

Questions

(Please note that these are the topic areas I will cover - the questions as listed here may not be followed exactly and will depend on the participant's responses.)

1. How have you been managing since we last spoke?

2. What sorts of issues and concerns have you been experiencing?

3. Do you think you are getting the right help or support at the moment to manage these issues?

4. What sort of additional help or support do you think would be most beneficial for you at this point in time?

5. How do you think xxxxxxx has been managing?

6. What sort of help or support do you think xxxxxxx needs most at this point in time?

Those are all the questions I had for you today but as this is our last interview for the study, please feel free to comment on anything that you think is important to you that we haven't covered already, or that you would like to say more about.

Thank you so much for your time and for sharing your experiences. I really appreciate it. If this interview has raised any particular issues for you that you would like to talk to someone about, please call the Pancreatic Cancer UK free Support Line. The support line is staffed by specialist nurses and is open Mondays, Tuesdays, Thursdays and Fridays between 9am and 4pm, and open Wednesdays between 10am and 6pm. The number to call is 0808 801 0707, or you can go onto their website and fill out an online form to contact a nurse over email. The website address is https://www.pancreaticcancer.org.uk

A16. Healthcare Professional Topic Guide

IRAS Project ID: 302097
NHS REC Name: South Central – Oxford B research Ethics Committee
REC Reference: 22/SC/0013

Optimising the care and support for patients with inoperable pancreatic cancer and their families and carers

Healthcare Professional Interview Guide

Introduction

Hello, it's Hilary Brown - we've spoken before – I'm the PhD student at Oxford Brookes University who is undertaking this research study. I really appreciate you giving up your time - the interview should take about 30 to 45 minutes, is that still ok for you today?

When we spoke before we went through the Participant Information Sheet and Consent Form. Have you been able to agree to each statement and are you happy to proceed today?

When I begin the interview, I will start the recording and ask you to verbally give your consent to take part. This will be in addition to you signing and returning the consent form. After you have verbally given your consent, I will stop that recording and start a new recording for the interview. This is so we can keep the consent conversation which contains your personal details separate from your interview data. So, just to reiterate that your participation is completely voluntary, and you can choose not to answer any questions, or stop the interview at any point.

So, just to summarise, the main purpose of the interview today is to understand your experiences providing support and care to patients with inoperable pancreatic cancer and their family carers. By gaining an understanding of this, we will hopefully be able to better understand the type of support that patients and their family carers might need and how they can receive this in the future.

Do you have any further questions before we begin?

Questions

(Please note that these are the topic areas I will cover - the questions as listed here may not be followed exactly and will depend on the participant's responses.)

1. Could you perhaps start by telling me how long you've been in your current role?
    - What previous experience have you had of caring for patients with pancreatic cancer before starting this role?
2. Can you tell me what your usual kind of contact would be with patients with inoperable pancreatic cancer?

    - Clinics?
    - Telephone calls, emails?
    - On the wards?
    - Other settings?

3. What are the sorts of problems and concerns that inoperable patients have, and how might these change over time?
4. Do you use a Holistic Needs Assessment in your routine contact with these patients?
5. How easy do you think these patients find it to articulate their concerns to you?
    - Is there a difference in how these patients might talk about their physical needs versus their emotional needs?
6. To what extent do you feel able to help with both their physical and emotional concerns?
7. Have you ever felt that you were unable to offer the kind of help and support that these patients need?
8. To what extent are you able to refer these patients on to other healthcare professionals or services to meet any needs that you feel you are unable to address?
9. How do you see your role in supporting the family carers of these patients?
10. What are the sorts of issues and concerns that family carers have, and how might these change over time?
    - Firstly, in relation to the patient's needs?
    - Secondly, in relation to their own needs?
11. How easy do you think family carers find it to articulate their concerns?
    - Is there a difference in how easy family carers might find it to talk about their own needs versus their family member's needs?
12. To what extent do you feel able to offer the help or support that family carers might need?
13. To what extent are you able to refer family carers on to other healthcare professionals or services to meet any needs that you feel you are unable to address?
14. Do you think there are any gaps in care or areas for improvement in the care and support of patients with inoperable pancreatic cancer and their family-carers?
    - Do you have any thoughts as to how these gaps or areas for improvement could be addressed?

Those are all the questions I had for you today but before we end the interview, is there anything else you would like to talk about that we haven't covered today?

Thank you so much for your time and for sharing your experiences. I really appreciate it.

A17. Distress protocol for all participants

Distress protocol for OPTIMISTIC – "OPTIMISing the care and support for patients with inoperable pancreaTIC cancer and their families and carers.

This protocol applies to patient, family carers and healthcare professional participants

Patients and Family carers

It is possible that some patient participants or family carer participants may become distressed during interviews, or may bring up issues which raise concerns about, or warrant a change, in their clinical management. Should this be the case then the following steps will be undertaken by the researcher.

1. If the participant appears to require additional support to manage their distress, the researcher will signpost them to an appropriate source of assistance. For patients and family carers this may be a suitable member of their clinical team such as a Cancer Nurse Specialist or a third-party organisation that provides emotional and psychological support to cancer patients and their family carers. For example, Pancreatic Cancer UK's Support Helpline, or Macmillan Cancer Support. Or depending on the nature of the issue causing distress, it may be appropriate to signpost the participant to the Patient Advisory and Liaison Service (PALS) at the relevant NHS provider organisation.

   If a participant discloses any ideation of self-harm or suicide, this must be dealt with by the researcher as an urgent matter and discussed with the Principal Supervisor and a senior member of the clinical care team.

2. Where concerns are raised regarding the clinical management of the patient, the researcher will gain verbal consent from the participant to discuss these matters with a relevant member of the patient's clinical care team.
   Once consent has been obtained, then the researcher must hand over any clinically relevant details to the clinical care team as soon as possible and ensure that an appropriate plan is put in place to address the concern raised.

Healthcare professionals

'Caring for patients with cancer generates significant work-related stress, dissatisfaction and exhaustion in healthcare professionals.' (Ferrens, 1990). It is possible that healthcare professionals may themselves become anxious or distressed during interviews regarding their ability to care for patients as they might wish. Moral injury which is defined as the psychological distress which results from actions, or the lack of them, which violate an individual's moral or ethical code can lead to moral distress for healthcare professionals (Maffoni M, Argentero P, Giorgi I, et al., 2019).

1. Healthcare Professionals with any needs for support that arise as a result of participation, would be encouraged to speak to their professional or management lead at their organisation, or to access any welfare support services that exist within their organisations, or through their professional bodies.

Role of the Principal Supervisor

- The Principal Supervisor, Professor Eila Watson, must be informed immediately when the Distress Protocol is activated at ewatson@brookes.a.c.uk. Any action and the outcome must be discussed with the Principal Supervisor.

- Steps will be undertaken to ensure that the researcher will have access to the Principal Supervisor or another member of the supervisory team, when undertaking field work.

References

Ferrans, C. (1990). Quality of life: Conceptual issues. Seminars in Oncology Nursing, 6, 248. doi: 10.1016/0749-2081(90)90026-2

Maffoni M, Argentero P, Giorgi I, et al. Healthcare professionals' moral distress in adult palliative care: a systematic review. BMJ Supportive & Palliative Care 2019; 9:245-254.

A18. Distress protocol for researcher and supervisory team

Distress protocol for OPTIMISTIC – "OPTIMISing the care and support for patients with inoperable pancreaTIC cancer and their families and carers.

This protocol applies to the research team, including the researcher and supervisory team.

Researcher

It is possible that the researcher may hear some distressing experiences while conducting interviews with participants, particularly with patients and family carers.

1. In the first instance, steps will be undertaken to ensure that the researcher will have access to the Principal Supervisor or another member of the supervisory team, when undertaking field work in order to ensure the opportunity for an immediate debrief after interviews, if required.

2. In addition, informal weekly debriefs will be scheduled with a member of the supervisory team during the data collection period.

3. Should the researcher require additional support to manage their anxiety or distress, a range of student wellbeing services are available to access through Oxford Brookes University. These include providing help with developing coping strategies and offering practical support (eg helping a student access an external agency) or simply offering a listening ear.

Supervisory team

It is possible that members of the supervisory team may be affected by reading or hearing the experiences shared in interviews.

1. In the first instance, the supervisory team members will provide peer support to each other.

2. Should a member of the supervisory team require additional support to manage their anxiety or distress, a range of services are available to access through the Occupational Health Departments of both Oxford Brookes University and University of Birmingham.

Role of the Principal Supervisor

- The Principal Supervisor, Professor Eila Watson, must be informed immediately when the Distress Protocol is activated at ewatson@brookes.a.c.uk. Any action and the outcome must be discussed with the Principal Supervisor.

A19. Discontinuation Protocol

Discontinuation protocol for OPTIMISTIC – "OPTIMISing the care and support for patients with inoperable pancreaTIC cancer and their families and carers.

This protocol applies to the researcher.

Rationale

Given the longitudinal nature of the research study, it is necessary to consider the evolving nature of the relationship between the researcher and the patient and family carer participants over time and to take steps to prevent the development of an emotionally dependent attachment. This may be a particular risk for this study as given the context of the research i.e. speaking to people affected by a terminal diagnosis of pancreatic cancer and in order to develop a relationship of trust and to put participants at their ease, it will be important for the researcher to adopt an empathetic approach to participants rather than a neutral approach. The researcher may also be the only person that the patient and/or family carer is able to talk with freely and candidly about their experiences of the disease and the care they or their loved one has received.

It is anticipated that the provision of clearly worded participant information at the outset and clear communication of the nature of the relationship at all stages of contact between the researcher and participants will help to mitigate for a dependent attachment developing but to provide an additional reinforcement of the nature of the relationship, the following steps will be undertaken.

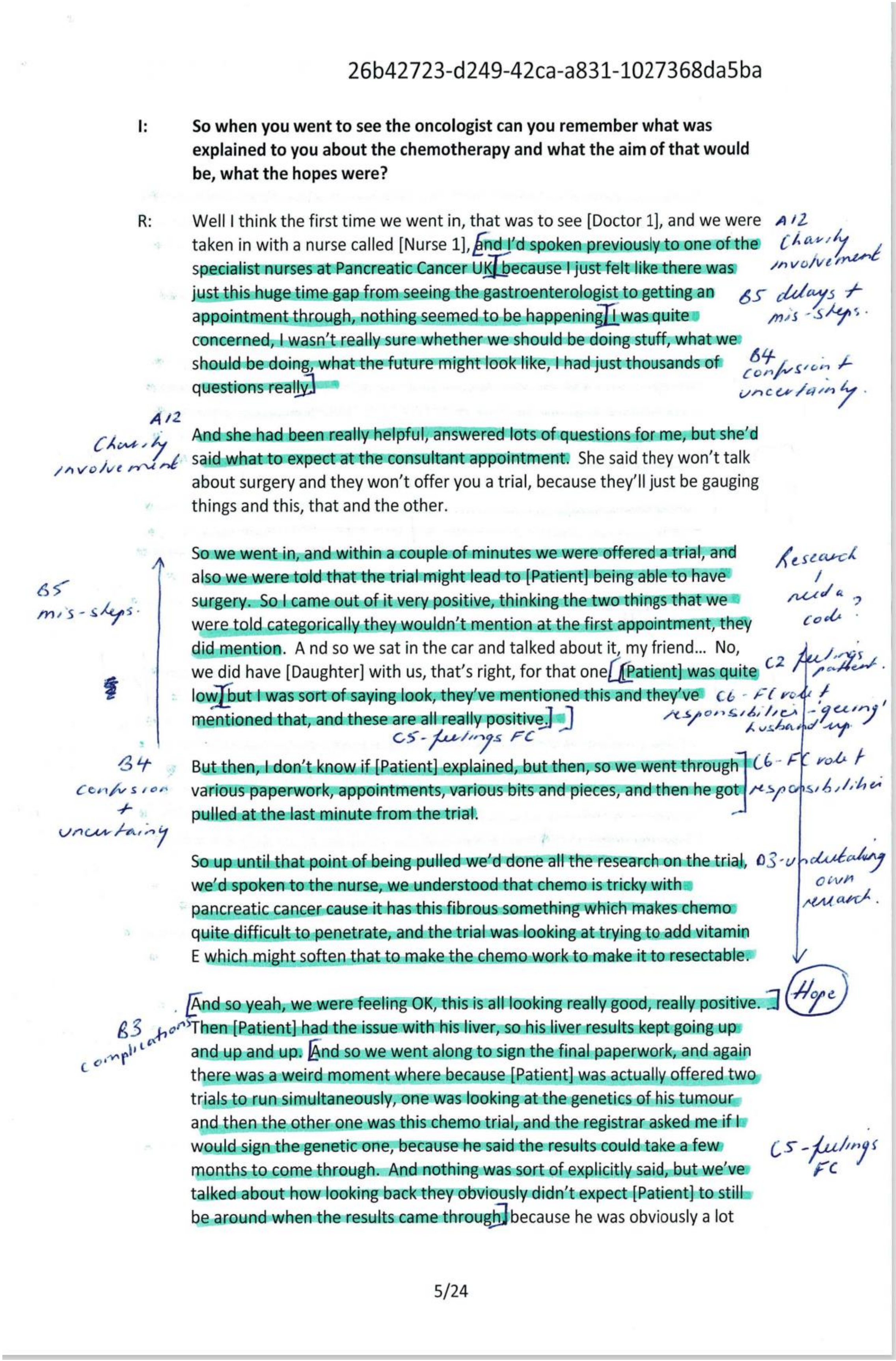
Procedure

At the conclusion of the third and final interview with the patient and family carer participant (where three interviews are conducted), the researcher will provide the participant with a thank you card to demonstrate their appreciation of their contribution to the research and a ‘Goodbye’ letter (Appendix E) which will make a further statement about the nature of the relationship between the researcher and participant as being one of enabling the collection of rich data for research purposes. The letter will also set out the next steps for the study i.e. that the participant can expect an invitation to attend an Experience Based Co-design event in due course, with a final dissemination event planned beyond that.

The letter will include a statement asking the participant or their family carer to email the researcher if the situation of either changes and they are no longer in a position to contribute to or attend either Experience-based Design events or the final dissemination event.

Finally, the letter will reiterate the support that is available to pancreatic cancer patients and their family carers through Pancreatic Cancer UK’s Helpline and other cancer charities such as Macmillan Cancer Support and Cancer Research UK.

A20. Extract of Coded Family Carer Transcript



26b42723-d249-42ca-a831-1027368da5ba

I: So when you went to see the oncologist can you remember what was explained to you about the chemotherapy and what the aim of that would be, what the hopes were?

R: Well I think the first time we went in, that was to see [Doctor 1], and we were taken in with a nurse called [Nurse 1], and I'd spoken previously to one of the specialist nurses at Pancreatic Cancer UK because I just felt like there was just this huge time gap from seeing the gastroenterologist to getting an appointment through, nothing seemed to be happening I was quite concerned, I wasn't really sure whether we should be doing stuff, what we should be doing, what the future might look like, I had just thousands of questions really.

A12 Charity involvement

B5 delays + mis-steps.

B4 confusion + uncertainty.

And she had been really helpful, answered lots of questions for me, but she'd said what to expect at the consultant appointment. She said they won't talk about surgery and they won't offer you a trial, because they'll just be gauging things and this, that and the other.

A12 Charity involvement

So we went in, and within a couple of minutes we were offered a trial, and also we were told that the trial might lead to [Patient] being able to have surgery. So I came out of it very positive, thinking the two things that we were told categorically they wouldn't mention at the first appointment, they did mention. A nd so we sat in the car and talked about it, my friend... No, we did have [Daughter] with us, that's right, for that one [Patient] was quite low but I was sort of saying look, they've mentioned this and they've mentioned that, and these are all really positive.

B5 mis-steps.

Research / need a code?

C2 feelings patient.

C6 - FC role + responsibilities - 'geeing' husband up.

C5 - feelings FC

But then, I don't know if [Patient] explained, but then, so we went through various paperwork, appointments, various bits and pieces, and then he got pulled at the last minute from the trial.

B4 confusion + uncertainty

C6 - FC role + responsibilities

So up until that point of being pulled we'd done all the research on the trial, we'd spoken to the nurse, we understood that chemo is tricky with pancreatic cancer cause it has this fibrous something which makes chemo quite difficult to penetrate, and the trial was looking at trying to add vitamin E which might soften that to make the chemo work to make it to resectable.

D3 - undertaking own research.

Hope

And so yeah, we were feeling OK, this is all looking really good, really positive. Then [Patient] had the issue with his liver, so his liver results kept going up and up and up. And so we went along to sign the final paperwork, and again there was a weird moment where because [Patient] was actually offered two trials to run simultaneously, one was looking at the genetics of his tumour and then the other one was this chemo trial, and the registrar asked me if I would sign the genetic one, because he said the results could take a few months to come through. And nothing was sort of explicitly said, but we've talked about how looking back they obviously didn't expect [Patient] to still be around when the results came through because he was obviously a lot

B3 complications

C5 - feelings FC

poorlier at that point than any of us… Well than me or [Patient] realised, because they were concerned about what was happening with his liver.

B11 - attitude of staff.

And then he got a sort of emergency appointment within about three days I think, it was over the Easter holidays, to go in and have this stent fitted, and this doctor rang him on Easter Sunday and said you're coming in on Tuesday and you're gonna have this stent fitted, you do know this is what's happening, da de da de da. And again looking back we were thinking gosh, that was quite exceptional that we were contacted on a Sunday.

B3 treatment

B4 confusion

So yeah, so he had the stent fitted, and then I dropped him off for what we thought was a routine scan and some bloods, and then about an hour or so later I got a message saying come and pick me up, and when I went to pick him up he was very sort of flustered and I couldn't really work out what was going on he was very sort of distressed, but not crying but just agitated, really agitated, and he wouldn't really tell me what's going on. And eventually he began to tell me that he'd gone in to have the scan and been whisked off into a room where they'd… He'd met with [Doctor 1] again, the top consultant, and she'd basically said the trial's off and we need to get you on chemo on Thursday, this was on the Monday or the Tuesday, Monday maybe, and you need to decide between these two options, and you need to sign now. A3 Chemo

C2 Patient feelings

B9 decision-making

C7 dynamic patient + FC.

And luckily, in hindsight luckily, [Patient] had the sort of… Well the bravery really to say no, I'm not signing anything without my partner being here, because we then, he brought both of the documents home and I contacted the specialist nurse straight away and she sort of went through what the two options were and what they meant, and in retrospect we know now that there would have been no chance of [Patient] being eligible for surgery if he'd gone with one of the options as opposed to the other, but none of that was explained to him, he was really distressed because he thought the reason he'd been pulled from the trial was because he was iller than they were telling him he thought there was something else going on, none of that was explained. I got this very brief e-mail from one of the specialist nurses, [Nurse 1], who said I'm really sorry that you weren't there and so we weren't able to explain, we'll try and ring you tomorrow and go through everything.

A2 CNS + C6 FC role.

B10 communication poor.

C2 patient feelings

I sent them quite a long e-mail, to her and also to our specialist nurse from the charity, saying you know, what's going on, is there more, is he iller than we thought, explain.

A2 - CNS & A12 - Charity support.

And then we then over the next sort of 48 hours we understood why he'd been pulled from the trial, and it wasn't because he was ill, wasn't anything to do with him but obviously we had this period of time where we were just in turmoil really. B4 confusion + uncertainty.

And then he started the chemo the next day, and it was just… So bless him, he was in just such a complete state that week well you know, we were both in a complete state but I mean he was in a complete state, he hadn't eaten, he'd got himself into such a frenzy thinking that he was really really ill. I mean he is really really ill, but iller than we even…

C2 - patient feelings

C5 FC feelings

I: **Yes, I understand.**

R: Thought he was.

And so he started chemo in quite a weakened position and had just the most awful experience on that first round. And yeah, looking back I just think oh my goodness, everything was stacked up against him.

A3 - Chemo

B3 treatment Challenges.

We've spoken to other people in other countries and in other authorities, and particularly in other countries, they sit you down beforehand, you have an hour sitting with a specialist nurse who explains what chemo is, what will happen, what the line will look like, what that will feel like going in, how that's managed, how you look after it, how you're gonna feel, what you should be eating and drinking, all of that, we weren't given any of that, we had nothing, we had to figure it all out ourselves.

B10 - lack of communication + info D1.

And actually the first day when he came home after his first chemo, again cause I couldn't be there, he had this bag of medication, but he had no idea when he was supposed to take it, how he was supposed to take it. I ended up googling the names of all the different medication to work out what it all was and how he was supposed to have it. I mean it was just, it was diabolical, it really was.

A16 medication

FC role C6.

B10 - lack of communication

I: **So [Partner], just to sort of go back a step, when…**

R: Sorry, yeah.

I: **No no no, not at all, with the liver results, was it the bilirubin levels that were highly? Can you remember if that's what they called?**

R: Yeah, so…

I: **Bilirubin.**

R: That was high, and also his alkaline phosphates or phosphorates or something, they were also very high.

B3 complication

And I mean at that point I didn't… I was still learning all of this so I didn't really, I didn't know what any of that meant.

B15 health literacy

I: **No, of course not.**

R: But I could see that one or two of the numbers were high, higher than they recommended. Well we get this screenshot that shows what it should be, the normal range, and then what the results are, and there was two on there that were really quite high, and one in particular, and I can't remember without looking, but that was rising sort of rapidly, so that should have been… I can't remember if it should have been in the thirties or forties, and it was sort of 160 or 170 or something.

B10
communication
of results
without
explanation

But obviously I'm a layman so I didn't know whether that was really really bad or just slightly bad. But obviously it was really really bad.

B15
health
literacy

And then he had the stent fitted and they did bloods, I don't think they did bloods the day he had the stent fitted but I think within a couple of days, and that's when we went back in, and at that point we still thought he was going on the trial, and so we were signing all the paperwork and they were sort of saying yeah, your bloods are looking better, a lot better than they were [so we're on track to carry on to start the trial next week, and you know, so we were feeling quite sort of relieved by that.]

Hope - FC + patient feelings
C5 C2

He never went yellow.

I: No.

R: Which I know is an indicator, for lots of people that's how they often get diagnosed, isn't it.

I: That's right.

R: He never went yellow, his eyes didn't go yellow, so he obviously hadn't reached that peak point that a lot of people do, but he must have been heading towards that, but obviously he was diagnosed before the point that a lot of people are diagnosed, so they caught it through the blood test rather than through his skin colour.

I: So just thinking about starting chemotherapy and the lack of information, so lack of information about side effects, and as you say what the PICC line would look like etcetera.

Was it… I suppose you didn't really have much chance to, if it was the next day, to contact PCUK or his nurse, it was just sort of happened so quickly.

R: I think it was two days later. So I can't remember exactly, it was either the Monday and he was due to start on the Thursday, or it was the Tuesday and was due to start on the Thursday, and they were adamant he must start on the Thursday.

A21. Codes added and amended to the Analysis Framework

Participant	**Code(s) added or amended**
FC 1	C7 – wider family involvement C8 – FC roles and responsibilities F4 – genetic counselling A21 – hospice provision
FC 3	C9 – FC support network C10 – dynamic between FC and patient C11 – FC coping strategies A22 – feedback on quality of care and care provision A1 – *care co-ordination* and continuity of care - amended C4 - Patient *needs* and concerns - amended C5 - FC *needs* and concerns - amended C6 - HCP *needs* and concerns – amended
Patient 3 and FC 2	B7 – treatment options C12 – patient support network B3a – delays in pathway
Patient 1	A23 – Pharmacy and medication C13 – patient coping strategies C13a – self-efficacy and self-care B4 - *side effects* and symptoms – amended
Patient 2	C1 – *response to* diagnosis - amended C2 – *response to* diagnosis - amended F4 – *genetic testing and* counselling – amended
Patient 4	A4a – dynamic between patient and HCPs

A22. Illustrative example of coding matrix for patients and FCs

Case	Code A4 = Dietetics/Nutrition	Code A7 = primary care	Code B4 = confusion and uncertainty	Code B5 = delays and mis-steps	Code C5 = FC feelings, needs and concerns	Code C6 =FC roles and responsibilities
P3 and FC 2 - interview 1	Was given CREON tablets when discharged after second stent fitted but no information about need to continue taking them for life, so they ran out as didn't know she would need a repeat prescription. Was later given a book about nutrition and tips re: foods to try and felt they had access to a dietician if needed. Also given some nutritional supplements.	GP is excellent. Had to go to GP when discharged after second stent to get CREON prescription - had to insist on not budging until she got prescription P7:165	Not clear what options would be after diagnosis P4:95 - uncertainty. When advised inoperable, offered chemo and an innovative alternative but couldn't remember what it was - stereotactic ablation?	Experience of first round of chemo being postponed was frustrating, having driven there and waited around and then having to go back again when sorted out the right dose. P14:316 Why didn't chemo unit know oncologist wasn't around on the Friday to page? and why wasn't it clear what the infusion dose should be from the records?	Worried about stress of diagnosis and a long day for 80 yo mum - repeat stent procedure - was in hospital from 9-6.30 and had to cope with the diagnosis being given. FC is still working. They don't feel that they need any help or assistance at the moment but they know where to go if they do need anything. Small stressors build up, 'You don't need it, you're trying to manage people's expectations, your own worries, trying to get Mum through the day.' Stress of parking.	Taking Mum to appointments and waiting for her. Visiting her as an inpatient and talking to doctors to find out information. Going to GP and insisting Mum got CREON prescription. Getting parking permit for hospital sorted. Ringing to rebook chemo appointment
P3 and FC 2 - interview 2	Tried nutritional supplements - didn't get on with them	GP checked swollen leg - feels GP was on the ball and very responsive from initial presentation	Weren't told how many cycles and rounds she would have at the outset - was that so as not to scare her and put her off? P24:555 and P25:567	Gap between scan on 12th December and appointment with oncologist on 23rd January and 7 week delay from scan being undertaken and chemo starting - tumour had increased in size and oncologist said it was result of not being on treatment P29:670	Was concerned about Mum's weight loss and loss of appetite but otherwise no needs - they're quite self-sufficient but know where to go if they need any support	Monitoring patient weight and reminding staff about Mum's needs - i.e. hard of hearing and needs hand warmed for 10 minutes before cannula inserted etc. and has infusion over 45 minutes - become the expert on her mother's treatment needs P18: 418 and keeping patient company at appointments and during treatment - there's a lot of hanging around
Patient 6 and FC 4 Interview 1	Was told by surgeon after RAMPS procedure that he would have to take CREON and would always have issues with his digestion - started losing weight with first round of chemo around Christmas- raised concerns - had phone call with dietician and sent some supplements? Saw dietician in February and only started taking CREON then. Weight had stabilised. Needed more information on how to take CREON. Has subsequently seen dietician at DGH.	Poor ongoing experience of GP practice - can't get appointments easily though needs regular diabetes checks and issues with prescriptions being sent through to pharmacy - they have made an official complaint to the practice. P23:527 and P25:571 and P25:575 - Surgeon's letter to GP requested a follow up within a couple of days as platelet levels were high but this never happened and only got picked up 6 weeks later because patient saw his diabetic nurse. Can't get an appointment for a ketone test which CNS had asked him to get done at GPs. Not aware of GSF or its not been put in place.	Just didn't know what to expect after surgery, so wasn't sure if when he felt ill and continued to do so, whether that was normal or not. Who coordinates totality of his care now i.e. his high blood sugars - is it CNS, is it GP? 'Can't get anywhere to get any answer.'	Delays with previous surgical procedure - saw consultant in June 2022 but operation not until 7/9/22 - confusion over date as should have been 5th September, then told end of September, then told they would put him on cancellation list and he was called on the 5th and told he could have the operation on the 7th September in the end.	Wife wanted to accompany husband to appointments, when able, to be able to help take on information FC did everything she could to ensure prescription for penicillin was ready in good time but GP practice let her down. FC feels slightly differently to husband about palliative care support and particularly emotional support - she is she thinks he ought to engage with them. She's trying to be strong for their sons.	Sorting out prescriptions and repeat prescriptions and making sure she is following the right drug regime with patient.
Patient 9 and FC 6 Interview 1	They asked about dietetic support but were 'fobbed off' that it wasn't for them but for people with stomach and oesopahgeal cancer patients. Had some advice on nutrition from community palliative care instead. Also patient had to ask about CREON and was told it wasn't something hospital prescribed automatically.	Only had one phone call with Locum GP since diagnosis. Have been given a code word - Cassandra patient - to use when calling to identify themselves as a priority. However still have to wait to get through usual phone lines - can take FC an hour to an hour and a half sometimes to get through. DNR recorded on GP system.	Doesn't have a clear sense of prognosis - 'does it mean I've got weeks, months, years, which we still haven't got an answer to.' 'It would be nice to know can I start buying Christmas presents for example.' P35:815	Took a month from diagnosis to seeing a gastroenterologist - not oncologist. Community palliative care 'took a long time coming.' Didn't have CREON prescribed automatically - patient had to ask for it and was told he would need to have a blood test first. Results of blood test for fourth round of chemo were lost in system - sat on GP records. Issue re: cross boundary issues and who can access whose systems. At time of interview were trying to sort out bloods again - told community phlebotomist didn't have capacity to do it, so trying to sort something out through GP.	Frustrated by getting blood tests sorted - had to keep ringing to chase - on verge of tears with the frustration of it all. Feels she has a lot of things going on in her mind to deal with - it's stressful.	Ringing and chasing blood tests and calling palliative care hub to get things sorted etc. Chasing people i.e. community phlebotomy service.

A23. Text provided to PCUK for inclusion in the charity's Research Involvement Network Newsletter

Optimising the care and support of people with inoperable pancreatic cancer – A summary of the study findings

A PhD study, undertaken by Hilary Brown, Oxford Institute of Applied Health Research, Faculty of Health and Life Sciences, Oxford Brookes University.

OxInAHR
Oxford Institute of Applied Health Research

This qualitative study explored patient and family carer experiences of diagnosis, treatment, and supportive care services. It also explored health care professionals' (HCPs) views of the challenges in providing care and support to people with inoperable pancreatic cancer and their family carers. The findings consider people's needs and how these change over time, and the gaps that exist in supportive care. The aim of the research is to propose recommendations for how care and support for people with inoperable pancreatic cancer and their family carers can be improved.

The summary presents the findings from 58 interviews undertaken with 13 patients, 12 family carers and 24 HCPs, conducted between May 2022 and November 2023.

Feedback welcome

I would be very happy to receive your feedback on these findings, based on your own experiences of being affected by pancreatic cancer. Do you feel that these findings resonate with your own experience, or if not, how do they differ?

I am now in the process of developing a series of recommendations for practice and I would be keen to hear your thoughts on what could be done to improve people's experiences. I am particularly keen to focus on the areas mentioned above i.e. communication, care co-ordination, and information provision. I am also keen to develop recommendations for the health system as whole, including the acute care sector, community care and primary care.

You can contact me by email at 19154077@brookes.ac.uk

If you provide feedback, it is assumed that you have provided consent for me to incorporate your comments, where appropriate, within the writing up of my thesis, unless you specifically ask me not to. However please note, any identifiable information, such as names of individuals, or organisations will be removed so that any responses are kept anonymous.

Many thanks for reading this summary,

Kind regards

Hilary Brown

Final Sheet – Intentionally left blank