Being one of the cancer statistics: a focus on patients whose cancers recur

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Abstract

Background: The recurrence of cancer will significantly impact an individual's quality of life (QoL) as they adjust to living with an incurable condition. However, several areas related to the well-being of patients after a recurrence remain unexplored. For instance, fear of cancer progression (FOP) at this time is not commonly examined. Importantly, these fears are known to reach levels in which there are consequences to psychosocial QoL.

Methods: This study sought to explore levels of FOP, health-related QoL, anxiety, and depression in patients after a recurrence of their cancer in a longitudinal manner. With the study taking place throughout the COVID-19 pandemic, an assessment of fears related to cancer and the pandemic was included. A sequential mixed method approach was employed for complementarity and expansion purposes. A questionnaire was administered to 24 participants on three different occasions a month apart. A sub-sample of 10 participants then took part in semi-structured interviews.

Findings: FOP was present at moderate levels in patients with a cancer recurrence, with almost half of the sample reaching levels considered dysfunctional. Levels of fear were stable over three months and were not predicted by select demographic or clinical factors. On average, depression was low, but anxiety reached mild levels. Challenges to health-related QoL were evident. Low levels of concern about COVID-19 in relation to cancer were reported. Integrated findings provided more nuanced answers to the research questions, including more specific worries about cancer progression.

Implications: Findings support the development of psychosocial interventions to manage FOP, and future recommendations are provided. Identifying the presence of fears not commonly screened for after cancer recurrence adds to the existing knowledge in this area. Through acknowledging and attending to the psychosocial impact of FOP, healthcare professionals can provide tailored support to enhance the well-being of those with a recurrence of their cancer.

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Dissemination of research

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<h1 style="text-align:center">Chapter One: Introduction</h1>

1.1 Introduction

This chapter provides an introduction to the research project. The broad scope of this project was to focus on patients who have, after treatment with curative intent, had a recurrence of their cancer; with an aim of adding to the existing fear of cancer recurrence (FCR) literature. More specifically, the project sought to explore the concept of fear of progression (FOP) in patients in the time following a recurrence of their cancer. Firstly, the reader will be introduced to the biology of cancer and progression, the phenomenon of cancer recurrence, and the frequent incidence of concomitant psychological problems. Secondly, the specific research objectives that seek to answer the broader research aim will be described. Considerations regarding the development of the project will be outlined, and then a brief summary of all thesis chapters.

1.2 Cancer

Cancer incidence and burden

There are estimated to be over 19 million new cancer cases annually; it is the second most common cause of death worldwide and is responsible for one in six deaths, reaching almost 10 million annually (World Health Organisation 2022). As a result of growing and ageing populations, cancer incidence rates are increasing rapidly in well-resourced countries, as well as more people living with cancer for longer (Miller et al. 2022). This rise in prevalence is partly due to improvements in cancer detection and treatment, as well as improvements in other areas of healthcare such as coronary heart disease; put simply if people live longer and do not die prematurely from other health conditions, they may live to develop a cancer that they would not have otherwise (Siegel et al. 2022). This contrasts with countries with lower levels of social and economic development, wherein cancer is a lesser cause of premature death, though, it is of course still a significant cause of death in such nations (Sung et al. 2021).

Physical manifestation of cancer

Cancer refers to a range of diseases wherein abnormal cells divide without control and can spread to nearby tissues and other parts of the body (Estanqueiro et al. 2015). Once an abnormal cell has begun multiplying this leads to the development of a tumour, and if

this is not treated it leads to consequences such as compression of bodily structures, impacted hormone production, as well as the risk of spreading throughout the body-known as metastasis (Ashelford et al. 2019).

Carcinogenesis is the process in which ordinary cells are changed into cancer cells, and this begins with initiation, where, either spontaneously or due to carcinogenic factors, a cell undergoes genetic mutation and collects the characteristics necessary for uncontrolled growth (Klaunig and Wang 2018). Promotion then occurs, in which the mutated cell is susceptible to promoters (chemicals which accelerate cell division) and accumulates more mutations and leads to cells progressing from pre-neoplastic (susceptible to form a tumour) to forming a malignant tumour. (Lopez et al. 2021). See Figure 1 for an illustration of this process.

How these mutations occur can be seen on the cellular level, where environmental and genetic factors are thought to prompt selective pressures that result in adaptive mutations through a process called clonal evolution (Williams et al. 2019). In a manner similar to Darwinian evolutionary theory, the continued multiplication of these cells and the occurrence of further mutations will result in the progeny of this cell becoming dominant, and further progression of the tumour will occur (Salavaty et al. 2023, Faubert et al. 2020).

Figure 1. Process of carcinogenesis
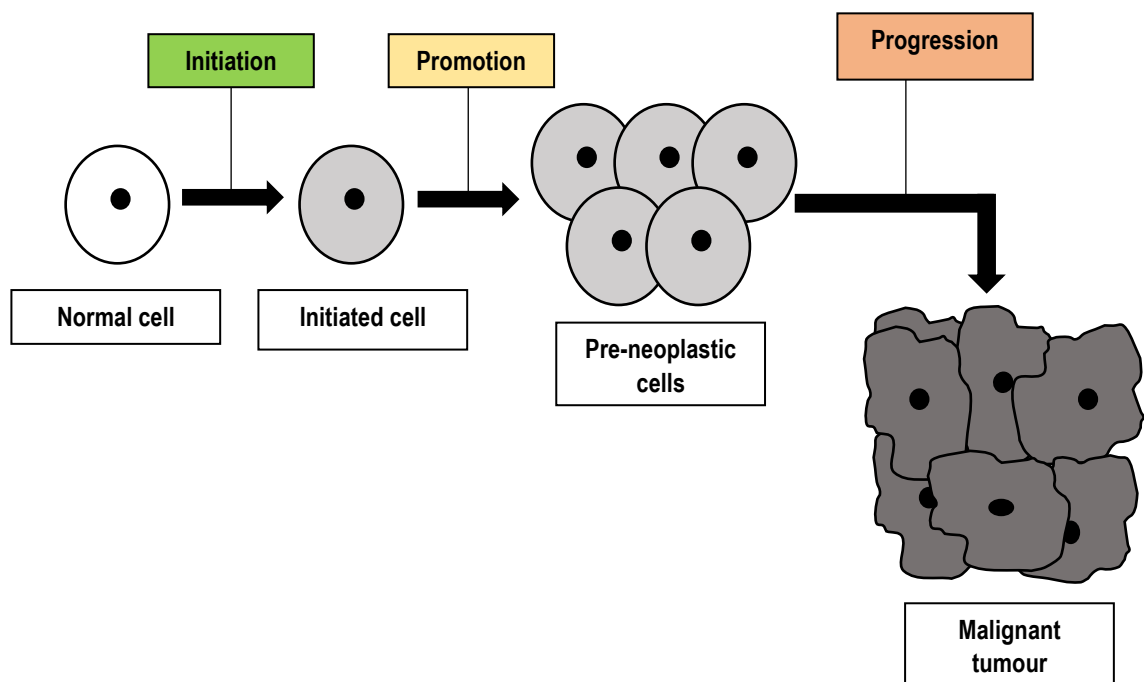
Treatment

When deciding on the treatment profile for a cancer patient two important considerations are the stage of the disease (the extent of its spread) and grading (a subjective score based upon the appearance of the cancer under a microscope) (Telloni 2017). Cancers which have not spread from the primary site may be managed with surgery and radiotherapy. However, if a cancer has metastasised it may require a treatment such as chemotherapy or hormone therapy, as these treatments travel through the blood and are more effective at killing cancer cells that have migrated to other sites of the body (Ashelford et al. 2019). To briefly describe how these treatments work: surgery can be utilised as a method of diagnosis or treatment, and involves the removal of the tumour, possibly alongside lymph nodes. This is most effective in patients where the cancer has not spread from its original site (Ashelford et al. 2019). It is commonly accompanied by radiotherapy, which is the use of radiation to kill cancer cells that remain after surgery, or whose location makes surgery difficult. Chemotherapy attacks cancer cell proteins and interferes with and hinders creation of DNA. Depending on the drug, they either work on cells solely during division, or on cells during both division and rest; and a combination of drugs is commonly used for increased efficacy (Ashelford et al. 2019, Tobias and Hochhauser 2014). There are also hormone therapies, which inhibit or alter the activity of hormones to target types of tumours that require these hormones to grow (Miller et al. 2022). These are just some of the main treatments for cancer and the success of these are subject to a multitude of factors, and include side effects for the patient (Moser and Meunier 2014).

1.3 Cancer care and policy

Having now introduced treatments for cancer, it is crucial for this project to set its objectives within the broader landscape of cancer care and policies in the UK.

Concerning diagnostic pathways, NHS England's policy stipulates that patients should receive a cancer diagnosis within 28 days of an urgent referral from their GP for suspected cancer. This ensures swift clarification for those without cancer, while enabling timely initiation of treatment for those diagnosed with cancer (NHS England 2022b). This element plays a pivotal role in long-term care strategies.

NHS England previously implemented the Achieving World-Class Cancer Outcomes program: a strategy for England 2015-2020 (NHS England 2017), followed by the Long-

Term Plan (NHS England 2019). These initiatives aimed to improve early diagnosis rates and generally improve the experience of cancer survivorship for patients. Similarly, the Cancer Strategy for Scotland 2023-2033 (Scottish Government 2023) outlines the Scottish Government's commitment to improving cancer survival rates and delivering high-quality, accessible care within the NHS in Scotland.

The aforementioned plans underscore the growing significance of cancer survivorship in healthcare policy. They also acknowledge that advancements in cancer survival rates will pose challenges for individuals living with incurable but manageable cancers (White et al. 2021). Various care options exist to support individuals living with and beyond cancer, including regular medical appointments, psychological counselling, and support groups often facilitated by charitable organisations.

A critical focus of cancer care is to minimise the risk of cancer recurrence after curative treatment or the worsening of cancer when managed to a stable level (Aggarwal et al. 2023a). The phenomena of cancer recurrence and progression are pivotal factors affecting both physical and psychosocial well-being.

1.4 Cancer recurrence and progression

Treatment aims to remove the cancer cells from the body, in doing so hope to prevent further progression and recurrence of cancer after treatment (Block et al. 2015). However, cancer progression (the spreading or worsening of the disease) can still occur due to metastasis, again, where cancer cells break off from the tumour and spread to other parts of the body (which is estimated to be the primary cause of death in over 90% of cancer patients). As a result of the Darwinian-like process introduced earlier in this chapter, when cancer cells are killed by treatment such as chemotherapy, resources and space are left for treatment-resistant clone cells (arising from mutations) to remain in the body to multiply and potentially to metastasise (Fares et al. 2020, Shomar et al. 2022). Cancer recurrence is a form of progression but refers to the return of cancer after it is no longer detectable in the body following treatment with curative intent. In other words, cancer progression can take place with a primary or a recurrent disease (Mahvi et al. 2018, Najafi et al. 2019).

Cancer recurrence occurs for a variety of reasons; it is suggested that some cancer cells may remain following treatment for a primary diagnosis and subsequently develop into a new tumour. Much the same as with progression, one explanation for how this occurs is

related to drug resistant cancer cells. Specifically, cancer stem cells are a type of cancer cell that are thought to initiate tumour growth and have a resistance to treatments such as chemotherapy, and consequently, if these cells remain after treatment the disease remains in the body but is asymptomatic (Damen et al. 2021). During this stage, cancer cells stop dividing; and consequently, avoid conventional treatments that target dividing cells. When cells leave this dormant state and start dividing again, a recurrence occurs (Gao et al. 2017). Importantly, cancer recurrence can take place many years after treatment with curative intent. For example, previous research has identified recurrence in breast cancer survivors up to 32 years after primary diagnosis (Pedersen et al. 2022).

Risk factors of cancer recurrence and progression

Rates of recurrence differ, and there are a multitude of factors that can increase the risk of cancer recurrence and progression, often depending on the type of cancer. For example, nearly all patients with Glioblastoma (a very aggressive brain cancer) will experience a recurrence (Birzu et al. 2020). Some other risk factors include modifiable health behaviours and behavioural outcomes such as diet, obesity, and smoking (Friedenreich et al. 2017, Singareeka Raghavendra et al. 2022). Consequently, engaging in positive behaviours such as smoking cessation and physical activity can lead to a reduced risk of recurrence or progression (Peisch et al. 2017). Importantly, previous research has suggested that the physiological consequences of psychological distress may be linked to cancer progression (Surman and Janik 2017). Beyond health and lifestyle factors, the aforementioned cancer treatments can reduce the risk of recurrence and prevent further progression of the disease. Again, the efficacy of these differ according to cancer characteristics and careful consideration is needed to suit the patient's needs due to the serious nature and implications of a recurrence or progression of their cancer (Beckwitt et al. 2018, Mahvi et al. 2018, Wong et al. 2011).

The characteristics of the recurrence will influence prognosis; in some cancers a local recurrence may be treated with curative intent (Artibani et al. 2018, Westberg et al. 2018), but in most cases both local and distant recurrence are not considered curable, though treatment may prolong life (Damen et al. 2021). When it can no longer manage the disease and cancer then progresses and moves into and impairs the functioning of organs, the focus of medication is palliation of the disease for the comfort of the patient (Simon et al. 2020). So, naturally it can be seen how the diagnosis of a recurrence may

elude a new emotional response from patients, not only do they have to adjust to their cancer returning, it also typically represents a more serious diagnosis than the primary diagnosis of cancer (Park and Nam 2020, Wanat et al. 2016). After the recurrence has occurred, patients will now be regularly examined for signs of further cancer progression that may signal the beginning of end-of-life care (Bui et al. 2021).

Cancer recurrence rates vary due to a number of complex factors such as tumour site, grading, treatment received, and the risk factors mentioned above. As such, it is difficult to ascertain overall cancer recurrence prevalence in the UK, and recurrent cancers are not included in published cancer statistics (NHS England 2022a). The process underlying metastasis is the leading cause of cancer deaths (in around 90% of cases) and whilst this can occur at the primary diagnosis, it more commonly accompanies a recurrence, i.e., after treatment for the initial disease (Riggio et al. 2021). Thus, it is reasonable to assume that recurrent cancers make up a sizable proportion of the >160,000 annual cancer deaths throughout the UK (NHS England 2022a).

1.5 Fear of cancer recurrence and progression

When cancer is first diagnosed there is a significant impact on an individual's well-being and this has been extensively examined in the past (Schouten et al. 2019). With the knowledge that recurrent cancer represents such a severe diagnosis, in recent years there has also been a growing volume of research examining the fear that cancer survivors have at the prospect of experiencing a recurrence (Simard et al. 2013, Williams et al. 2021). FCR has been defined as "fear, worry, or concern relating to the possibility that cancer will come back or progress." (Lebel et al. 2016, p. 3266), and has now been distinguished from other psychological disorders and is established as a psychological concern it its own right (Simonelli et al. 2017). It is important to note that FCR at low to moderate levels can be of benefit to patients, as they may become sensitive to signs of recurrence or progression, however if it reaches higher levels it is linked to poorer quality of life (QoL), psychological distress, and functional impairment (Simard et al. 2013).

Key symptoms that are considered to classify dysfunctional levels of FCR (i.e. that are not present at low-moderate levels) have been identified as: high levels of preoccupation and worry (that are persistent), and hypervigilance to physical symptoms (Mutsaers et al. 2020). Further illuminating the burden created by this issue are organisational strains associated with dysfunctional FCR; evidence suggest a link to increased usage of

healthcare system resources (Williams et al. 2021). This is of particular importance as NHS oncology services have struggled to recover from the impact of the recent COVID-19 pandemic (see section 1.7.1 for further discussion of the impact of the pandemic), coupled with ongoing staff shortages (Aggarwal et al. 2023b). As an aside, whilst higher levels of FCR are associated with increased usage of both primary care and oncology services, they are not linked to increased usage of mental health services, possibly indicating that patients do not see it as a mental health issue (Otto et al. 2018).

Similarly, the severity of cancer progression has led to the examination of patients' fears about this occurring. However, in the wider literature, FOP is usually treated as the same phenomenon as FCR (and so the negative consequences of raised levels are the same), as evident from the commonly accepted definition described in the previous paragraph (that FCR is the fear that cancer will progress or come back). Both terms have been used interchangeably in the past to describe the same concept (Lebel et al. 2016). Psychological research related to fears about cancer recurrence or progression is predominately in patients with a primary diagnosis, or after curative treatment, but before recurrence has occurred (Crist and Grunfeld 2013, Coutts-Bain et al. 2022), and there is limited research examining FOP in patients after the cancer has actually recurred. However, findings from Shim et al. (2010) suggest that the fear levels are higher at this stage than before recurrence. The move away from curative treatment may explain the minimal research addressing fears around progression in this population, despite the possibility of living with a recurrence for several years (Shim 2010). Indeed, in the literature, psychosocial interventions to manage FCR/FOP are commonplace with cancer survivors but have not yet been specifically designed to lower fears after a recurrence has actually occurred (Tauber et al. 2019).

1.6 A note on language

It is important to note for clarity in this thesis, FOP will be used to refer to fears after the cancer has recurred (referring to worries about the cancer progressing further from its current state), and FCR will refer to those fears any time before a recurrence takes place (hence worrying about the cancer coming back). When discussing previous research if it is unclear which is being referred to by cited authors, or if they are discussing FCR and FOP outcomes together then FCR/FOP will be used. For example, using the example of a previous systematic review (Simard et al. 2013), the authors sought to provide an

overview of available FCR research at that time. Studies utilising measures of FCR or FOP were both included in their analysis (though it should be noted that only 18 out of 130 examined studies distinctly assessed FOP). This is appropriate given the commonly agreed definition that FCR is the fear that cancer will recur or progress (Lebel et al. 2016) and so differentiating would be unnecessary. However, for the purposes of the current research study described in this thesis, using the FCR terminology may be confusing since recurrence has already occurred. If it is necessary to clarify at any point in this thesis what concept is being described this will be done at relevant points (e.g., when discussing the theoretical development of the concepts in Chapter 2).

1.7 Project development

At the conception of this project, it was planned to examine breast and prostate cancer patients only. This was due to the high prevalence of these cancers across the UK (Hassanin et al. 2022), as well as allowing for comparison between two predominantly gender-based and different physically manifesting cancer types. However, after completing a systematic review examining the impact of cancer type on the impact of recurrence at the start of this project; now published, see Stewart et al. (2021), and appendix 1; as well as from discussion with my supervisory team and advice from members of the London-Stanmore Research Ethics Committee it was evident that it would be prudent not to limit this research project to these groups specifically, and instead include all cancer types.

1.7.1 Impact of COVID-19 pandemic

It is inevitable that the significance of the COVID-19 pandemic, which started during the course of this project, needs to be addressed. Some of these issues have been alluded to already.

Firstly, and most importantly, the pandemic created multifaceted problems for the cancer patients I worked with. They were at higher risk of severe medical consequences and death from contracting COVID-19 than the general population (Han et al. 2022). This required many to socially isolate for longer than others, with potentially severe negative emotional consequences (dos Santos et al. 2020). Further, cancer referrals and screening were impacted. With a decrease in these services a sharp rise in cancer diagnoses is predicted to emerge as the pandemic eases, and many of these may have been detected at an earlier stage otherwise (Wang et al. 2021, Yong et al. 2021). Across the UK the NHS

(including oncology services) has struggled to recover from the effects of the pandemic (Aggarwal et al. 2023b).

Initially, research was planned to take place in person at an NHS hospital site in Ayrshire. After meeting with staff at the site and drafting the necessary documents for ethical approval, the pandemic spread to Scotland and with lockdown measures implemented in March 2020 I was informed that the site would not be continuing research projects for an indeterminate time. This was the case in many hospitals. After adjusting the research to take place remotely, a member of my supervision team started a working position at a specialist cancer treatment hospital in London that was continuing research alongside treatments. The relevant NHS trust agreed to host the study, however, as is described later in the thesis, there were ongoing setbacks with hospital staff absences and patient availability due to positive testing of COVID-19.

Due to the novel impact created by the pandemic, it was decided between my supervisory team and I to factor it into the research with the patients, allowing them to express concerns they may have had about the pandemic and its impact on their lives, and in relation to their cancer treatment.

1.8 Research objectives

The primary aim of this research was to determine the fears of further cancer progression in patients who, on assessment, have shown a clear recurrence of their original disease. This thesis will do this with the following linked objectives; with each informing the next.

- To clarify, employing a systematic literature review, the complex psychosocial impact of cancer recurrence on QoL. Additionally, this review will seek to examine if FOP is routinely measured in patients with a recurrence in the literature.
- To determine, with the use of a mixed methods research study, the levels of FOP present in this population, alongside other psychological and QoL outcomes.
- To provide conclusions and recommendations based upon the research, both for future research and in healthcare settings.

The first of these objectives will be addressed by a systematic literature review (see below for the structure of the thesis), and the second objective will inform the more

specific research questions that the mixed methods study featured in this thesis seeks to address (see section 3.3). The third objective will be addressed via discussion of the findings arising from the research.

1.9 Organisation of thesis

The rest of the thesis is structured into the following chapters:

Chapter 2 (Literature review) will outline the rationale and position the research among the existing literature. This will be done by appraising current knowledge of issues relating to the psychosocial impact of recurrence on individuals and FOP. Psychological theoretical models commonly used to explain FOP will also be described.

Chapter 3 (Methodology and research methods) will describe the approaches taken in the research for this project. In this will be a discussion of why a mixed methods approach was taken alongside other relevant considerations. This will involve a critical discussion of other methods not chosen and an in-depth analysis of the philosophical assumptions underlining these approaches. There will also be a description of the ethical procedures followed, as well as information about the data collection and analysis methods employed in the study.

Chapter 4 (Presentation of quantitative results) will detail the results of the quantitative phase of the research. This includes questionnaire data summarised as mean scores, as well as the application of several different statistical data analyses.

Chapter 5 (Presentation of qualitative results) describes the findings from analysis of semi-structured interviews, conducted after the quantitative phase.

Chapter 6 (Integration of findings) combines the quantitative and qualitative results in order to provide comprehensive answers to the research objectives.

Chapter 7 (Discussion) features interpretation of the results, explains their position in relation to past research, and provides future suggestions that arise. Implications are discussed as well as strengths and limitations of the research. Lastly, this chapter will provide a comprehensive conclusion to the research project.

1.10 Chapter summary

Overall, this introductory chapter presents the biological basis of cancer, relevant risk factors, and the challenges associated with cancer progression and recurrence. The

growing literature around FCR/FOP has been introduced and the areas that require more research have been tentatively noted. The impact of the COVID-19 pandemic on patients with cancer was described, as well as on the management of this PhD project. Lastly, information related to the organisation of the thesis was outlined. In the next chapters the process in which narrower research objectives were established from the broad outline of this project will be detailed to the reader.

Chapter Two: Literature Review

2.1 Introduction

Having presented the intentions of this project in the introductory chapter, this chapter will explore the literature related to FOP and explain how the broad research aim of this project was narrowed to more specific objectives. This will begin with a literature review that appraises current knowledge of issues relating to the psychosocial impact of cancer recurrence on individuals and categorises these into clearer concepts. This will also include an exploration of any potential measurement of FOP in patients with recurrent cancer in this research area. Psychological theoretical models commonly used to explain the mechanisms of FCR/FOP will also be described. Critiques and gaps in the current literature will be outlined to align with the primary aim of the thesis- to determine the fears of cancer progression in patients who, on assessment are found to have shown a clear recurrence of their original disease.

As noted in Chapter 1, this project was initially concerned with only patients with prostate cancer and breast cancer, and as such a systematic review was carried out to explore the psychosocial impact of recurrence- (Stewart et al. 2021), see appendix 1. This research has informed the review in this chapter, which has been altered to fit the updated scope of the project.

2.2 Background and aims

As described in the previous chapter, after the process of carcinogenesis has occurred, (depending on prognosis) treatment is administered with the intention of removing cancer cells from the body and to prevent further progression or recurrence (Block et al. 2015). However, recurrence may take place due to remaining cancer cells which subsequently begin dividing again after an indeterminate time, usually resulting in an incurable diagnosis. Due to the significance of cancer recurrence, previous research has sought to measure the psychosocial consequences of patients at this time. This research has been summarised in part by a meta-ethnography (Wanat et al. 2016), which reviewed qualitative studies featuring patients with recurrent cancer; and by an earlier narrative review (Vivar et al. 2009) that analysed a combination of quantitative and qualitative research with family members as well as the patient. Both reviews highlighted an intricate range of issues patients face when dealing with a recurrence, in relation to their

physical well-being, emotional state, and with personal relationships- both personal and with healthcare professionals.

As an aside, and to explain what is meant by QoL in this context, QoL is a heavily researched concept in the health research literature, and more specifically health-related QoL can be thought of as the impact of one's perceived health status on the capability to lead a satisfying life (Haraldstad et al. 2019). As well as measures of physical functioning, commonly captured in such research is psychological distress (Bakula et al. 2020).

Both reviews indicate that QoL is often rated lowly after a recurrence, and past research has suggested a strong relationship between QoL and FCR/FOP in cancer survivors without a recurrence (Simonelli et al. 2017). As such, if QoL is low, then it is feasible that high levels of FOP could also be present in this population, relating to the research carried out thus far suggesting that patients with a recurrence may have higher levels of fear than those without (Shim 2010). However, it is not readily apparent if FOP is commonly reported in the literature in patients with recurrent cancer. So, this review will also examine if FOP has been measured in studies exploring psychosocial QoL.

As a unique and challenging time for patients with cancer, the primary aim of this review was to explore the existing literature in order to clarify the complex psychosocial impact of cancer recurrence on QoL into separate categories: physical, psychological, and psychosocial indices of QoL. Further, as outlined above, looking for FOP as a measurement alongside QoL will provide a broader focus on the issues faced at the time of a recurrence and lay the groundwork for this project.

2.3 Methods

In the literature, studies relevant to cancer recurrence feature a variety of research designs. Therefore, the current review was conducted in an integrative manner. Briefly, an integrative review allows for the inclusion of a diverse range of research designs rather than focusing on a certain type (e.g. randomised controlled trials) (Hopia et al. 2016). The review was implemented in a systematic manner conforming to a popular methodological approach (Whittemore and Knafl 2005) that reduces the likelihood of biases and errors (Souza et al. 2010).

2.3.1 Search Strategy

Following the rationale of previous reviewers (Wanat et al. 2016) who highlight significant changes in treatments for cancer and within healthcare services, database searching was restricted to studies from January 1994 to April 2019. Four electronic databases were searched: PsycInfo, CINAHL complete, Medline, and Pubmed. The following search terms were used in all databases:

- cancer* or carcinoma* or malignan* or tumour or tumor or neoplasm*
- patient experience or recur* or relapse or time or metastatic* or progress*
- psycholog* or psychosocial or experience* or supportive care or social
- fear or anxiety or worry or shock

2.3.2 Inclusion and exclusion criteria

Papers were included if they: explored the experience of any patients with a recurrence; used either quantitative or qualitative methodology to gather and analyse results; were published between January 1994 and April 2019; were published in English, and with any sample size. Studies were excluded if they did not explicitly state that participants had recurrent cancer.

2.3.3 Screening Procedure

Two researchers (RJS, SC) independently screened studies identified through database searches. First, titles and abstracts were screened, and non-relevant studies were excluded. Second, full papers of remaining studies were obtained and screened against inclusion and exclusion criteria. The procedure for database searching and study screening is outlined in Figure 1.

2.3.4 Data Extraction

Extracted data included sample characteristics, study aim and design, and cancer type and stage. Data were extracted by one researcher (RJS) and checked by a second (SC) for accuracy. Study quality and risk of bias was independently assessed by two researchers (RJS, SC) using the Mixed Methods Appraisal Tool (MMAT) (Hong et al. 2018). The MMAT allows for the quality assessment of all study designs and is therefore suitable for this review. Any discrepancies in data extraction and quality appraisal were resolved through discussion.

2.3.5 Data Abstraction and Synthesis

With consideration to the aim of the review as well as the heterogeneous character of eligible studies, there was limited scope for meta-analysis; instead, formal narrative synthesis was conducted with no minimum number of papers required. Using a convergent synthesis design (Hong et al. 2017), data from quantitative papers were combined with data from qualitative papers and were coded, and findings were categorised into themes based on the breakdown of different experiences. The outcomes synthesised in this review were measured either qualitatively or quantitatively by reliable and valid assessment tools and relate to patient-reported levels of physical, psychological, and psychosocial indices of QoL that have impacted on the patients' experience of cancer recurrence.

2.4 Results

Overall, 1139 studies were identified by the search strategy, of which 33 studies met inclusion criteria (see Figure 2).

2.4.1 Description of Included Studies

Included studies were published between 1997 and 2017. Thirteen were conducted in the USA; six in Sweden; three in the UK; three in Canada; two in Japan; and one each in Australia, Finland, Israel, Italy, the Republic of Ireland, and Spain. This is summarised in Table 1, alongside other study details. Thirteen papers that met inclusion criteria examined the patient experience of breast cancer recurrence; six prostate; five ovarian; one myeloma; one oral; and four examined multiple types within their studies.

Eighteen studies were conducted with quantitative methods, 13 with qualitative methods, and two with mixed methods. More detail on the design, as well as the research aims of included studies are described in Table 1.
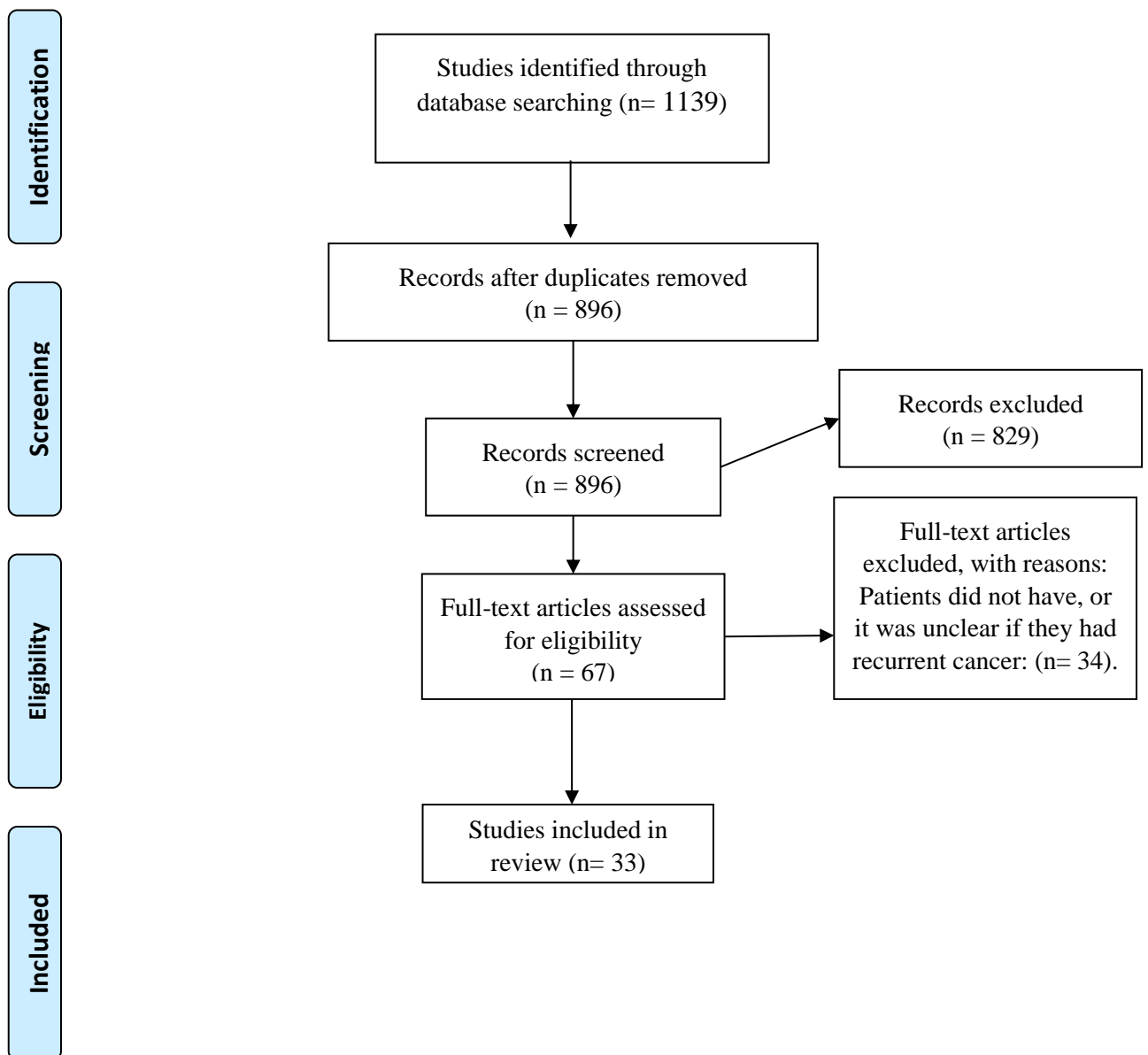
Figure 2. Database searching strategy

Table 1. Characteristics of studies included in review

Study	Cancer Type	Aim	Sample Characteristics	Design	Outcome Measures	Quality Score
Ames et al. 2008	Prostate	To appraise the psychological needs of men with a biochemical recurrence of prostate cancer	28 males, median age=76	Mixed Methods	Semi-structured focus group; FACT-P; SF-36; MAX-PC; POMS-B; LES; PSS	***
Ames et al. 2011	Prostate	To evaluate the acceptability effect size of a quality of life intervention for men with a biochemical recurrence of prostate cancer	57 males, median age=76	Pilot study of randomised controlled trial	FACT-P; SF-36; MAX-PC; PSS-10; POMS-B	***
Andersen et al. 2005	Breast	To analyse patients' reactions to a recurrence of cancer	30 females, mean age=52	Controlled Prospective Study	IES; POMS; CES-D-SF; SF-36; SNI; PSS-Fa; PSS-Fr; DAS; KPS; SWOG rating scale.	****
Brady et al. 2000	Breast	To explore the relationship between social support and adjustment after a recurrence of breast cancer.	41 females, median age=50	Quantitative	Adapted social support questions; BSI; COPE inventory	****
Bull et al. 1999	Breast	Clarify relationship between recurrent breast cancer and quality of life	69 females, mean age=53.3	Longitudinal study	Specifically designed scales.	****
Cleeland et al. 2014	Breast	To characterise symptom burden,	152 females, median age=57	Observational cohort study	MDASI; WPAI; RSCL	***

		activities of daily living, health-related quality of life and work-related ability in order to inform clinical trials and treatments.				
Cohen et al. 2002	Breast	To explore emotional distress and coping strategies in patients with primary breast cancer versus patients with recurrent breast cancer	41 females, mean age=62.3	Observational cohort study	SCL-90; WCQ	*****
Ekwall et al. 2007	Ovarian	To explore the experience of women with recurrent ovarian cancer	12 females, median age=57.5	Qualitative	Semi-structured interview	*****
Ekwall et al. 2011	Ovarian	To examine the relationship between women with recurrent ovarian cancer and their health care professionals	12 females (same sample as Ekwell et al. 2011), median age=57.5	Qualitative	Semi-structured interview	*****
Ekwall et al. 2014	Ovarian	To explore the phenomenon of life with recurrent ovarian cancer	4 females (derived from same sample as Ekwell et al. 2011), age range 46-69	Qualitative	Semi-structured interview	*****
Elit et al. 2010	Ovarian	To explore the experience of women with recurrent ovarian cancer and their treatment decisions	26 females, age range 44-79	Qualitative	Semi-structured interview	*****

Griffiths et al. 2008	Oral	To explore the experience of people diagnosed with recurrent oral cancer	6 females and 3 males, mean age=70	Qualitative	Semi-structured interview	*****
Hall et al. 1996	Breast	To explore psychological morbidity in recurrent breast cancer patients.	61 females, mean age=75 and younger.	Qualitative	Semi-structured interview	*****
Herth 2000	Multiple	To ascertain the efficacy of a nursing intervention to increase levels of hope and quality of life in patients with recurrent cancer	68 females and 47 males, mean age=53.7	Quasi-experimental study	HHI; CARES-SF	*****
Howell et al. 2003	Ovarian	To explore the experience of women with recurrent ovarian cancer	18 females, mean age=53.2	Qualitative	Semi-structured interview	*****
Letho et al. 2014	Prostate	To investigate experiences and psychological well-being in prostate cancer patients who received various types of treatment.	74 males, mean age=67	Cross-sectional study	Specifically designed survey; RSCL; SWLS; IIEF	*****
Maguire et al. 2017	Prostate	To examine the associations between prostate cancer survivors' treatment appraisals and fear of recurrence.	1229 males (222 had recurrence), mean age=68.48	Cross-sectional study	EORTC QLQ-C30; Fear of recurrence scale; DRS	*****

Maher & de Vries 2011	Myeloma	To explore the experience of people with recurrent myeloma and its effect on quality of life.	3 females, 5 males, age range= 48-74	Qualitative	Semi-structured interview	*****
Mahon & Casperon 1997	Multiple	To describe the significance of a cancer recurrence and potential differences between initial diagnosis and recurrence.	13 females, 7 males, mean age=54	Qualitative	Unstructured interview	***
Misra et al. 2013	Thyroid	To examine experiences relating to diagnosis of recurrent thyroid cancer and its surgical treatment	12 females, 3 males, mean age=45.6	Qualitative	Semi-structured interview	*****
Northouse et al. 2002	Breast	To assess the quality of life of patients and their family members after recurrence	189 females, mean age=54	Cross-sectional study	SF-36; FACT	*****
Oh et al. 2004	Breast	To explore the quality of life of breast cancer survivors after a recurrence	54 females, mean age=59.5	Observational cohort study	SF-36; CES-D; PANAS; IES-R; RDAS; MOS-SSS; PTGI; SBI-15R; Specifically developed Meaning and Vulnerability Scale	*****
Okamura et al. 2000	Breast	To study the prevalence of psychological distress	55 females, mean age=52	Cross-sectional study	Structured clinical interview; POMS	*****

		and risk factors of these following recurrence of breast cancer.				
Okamura et al. 2005	Breast	To examine the prevalence of, and factors linked with psychiatric disorders, and the impact on quality of life after recurrence.	50 females, mean age=53	Cross-sectional study	Structured clinical interview; MAC scale; EPQ-R; EORTC QLQ-C30; EORTC QLQ-BR23	****
Pietrow et al. 2001	Prostate	To define the impact of PSA recurrence on health-related quality of life radical retropubic prostatectomy.	88 males, mean age=63.4	Observational cohort study	SF-36; UCLA-PCI	****
Sarenmalm et al. 2007	Breast	To examine predictors of health-related quality of life in postmenopausal women with recurrent breast cancer.	56 females, mean age=65	Cross-sectional study	MSAS; HADS; SOC-13; EORTC QLQ-C30; IBCSG QoL	****
Sarenmalm et al. 2008	Breast	To explore the symptom experience and predictors of distress and quality of life in women with recurrent breast cancer (the same sample as Sarenmaalm et al. 2007 was assessed.	56 females, mean age=65	Longitudinal study	MSAS; HADS; EORTC QLQ-C30	****

Sarenmalm et al. 2009	Breast	To assess the main concerns of women with recurrent breast cancer, and how they were dealing with their situations (this sample was derived from the earlier Sarenmalm et al. studies).	20 females, age range 55-81	Qualitative	Semi-structured interview	*****
Step & Ray 2011	Multiple	To examine the experience of communication between patients and oncologists at the time of both initial diagnosis and recurrence	30 females	Qualitative	Semi-structured interview	*****
Thornton et al. 2005	Breast	To clarify the effects of being diagnosed with cancer for a second time on health-related quality of life.	140 females, mean age=53	Prospective data extracted from larger Randomised Control Trial	SF-36	***
Turner et al. 2004	Breast	To define the key emotional concerns of women newly diagnosed with recurrent or metastatic breast cancer.	68 females, mean age=54.7	Mixed Methods	Semi-structured interview; HADS; IES; CARES-SF	****
Ullrich et al. 2003	Prostate	To compare cancer fear and mood disturbance after biochemical	45 males, mean age=66.1	Observational cohort study	AUA Symptom Index; Previously used	****

		recurrence of prostate cancer with those without recurrence.			Cancer Fear questions; POMS	
Vivar et al. 2010	Multiple	To explore the impact of cancer recurrence on patients and their families	9 females, 6 males, age range 40-80	Qualitative	Semi-structured interview	*****

Notes. AUA: American Urological Association; BSI: Brief Symptom Inventory; CARES-SF: Cancer Rehabilitation Evaluation System-short form; CES-D: Center for Epidemiological Studies-Depression; COPE: Coping Orientation to Problems Experienced; DAS: Dyadic Adjustment Scale; DRC: Decisional Regret Scale; EORTC QLQ-C30 (BR23): European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire (breast cancer specific); FACT (P): Functional Assessment of Cancer Therapy (prostate); HADS: Hospital Anxiety and Depression Scale; IBCSG- QoL: International Breast Cancer Study Group- Quality of Life; HHI: Herth Hope Scale- abbreviated; IES: Impact of Events Scale (R)(Revised); IIEF: International Index of Erectile Function; KPS: Karnofsky Performance Scale; MAC: Mental Adjustment to Cancer; MAX-PC: Memorial Anxiety Scale-Prostate Cancer; MOS-SSS: Medical Outcomes Study-Social Support Scale; MSAS: Memorial Symptom Assessment Scale, LES: Life Experiences Survey; PANAS: Positive and Negative Affect Schedule; POMS (B): Profile of Mood States (brief); PSS-(fa; fr): Perceived Social Support (family; friends); PSS-10 Perceived Stress Scale; PTGI: Posttraumatic Growth Inventory; RDAS: Revised Dyadic Adjustment Scale; RSCL: Rotterdam Symptom Checklist; SBI-15R: System of Belief Inventory; SCL-90: Symptom Checklist; SF-36: Short Form Health Survey; SOC-13: Sense of Coherence Scale; SNI: Social Network Index; SWLS: Satisfaction With Life Scale; SWOG: Southwest Oncology Group; UCLA-PCI: University of California Los Angeles-Prostate Cancer Index; WCQ: Ways of Coping Questionnaire; WPAI: Work Productivity and Activity Impairment.

2.4.2 Quality Appraisal

The MMAT includes five criteria of quality to judge studies (Hong et al. 2018). Included studies' quality scores ranged from meeting three out of the five criteria to meeting all five criteria. These criteria differ based on the design of each study. Most studies were found to be of moderate quality. Of the 18 studies with a quantitative design only six were judged to meet all five criteria (Herth 2000, Letho et al. 2015, Maguire et al. 2017, Northouse et al. 2002, Oh et al. 2004, Okamura et al. 2000). Of 13 studies with a qualitative design, 12 (Ekwall et al. 2007, Ekwall et al. 2011, Ekwall et al. 2014, Elit et al. 2010, Griffiths et al. 2008, Hall et al. 1996, Howell et al. 2003, Maher and de Vries 2011, Misra et al. 2013, Sarenmalm et al. 2009, Step and Ray 2011, Vivar et al. 2010) were judged to meet all five criteria, and one met three of the criteria (Mahon and Casperson 1997). The two studies with mixed methods methodology were judged to meet three criteria. (Ames et al. 2008, Turner et al. 2005). An issue with both of these studies was that the authors did not explicitly describe how each research component integrated with the other. Many studies had small sample sizes as well as being at risk of non-response bias, which lowered the generalisability of the results. Table 2 contains full details of the quality assessment of the included studies, and for ease of comparison quality scores are displayed in Table 1 alongside study details.

Table 2. Quality assessment of studies included in review

Qualitative	Is the qualitative approach appropriate to answer the research question?	Are the qualitative data collection methods adequate to address the research question?	Are the findings adequately derived from the data?	Is the interpretation of results sufficiently substantiated by data?	Is there coherence between qualitative data sources, collection, analysis and interpretation?
Ekwall et al. (2007)	Yes	Yes	Yes	Yes	Yes
Ekwall et al. (2011)	Yes	Yes	Yes	Yes	Yes
Ekwall et al. (2014)	Yes	Yes	Yes	Yes	Yes
Elit et al. (2010)	Yes	Yes	Yes	Yes	Yes
Griffiths et al. (2008)	Yes	Yes	Yes	Yes	Yes
Hall et al. (1996)	Yes	Yes	Yes	Yes	Yes
Howell et al. (2003)	Yes	Yes	Yes	Yes	Yes
Maher & de Vries (2011)	Yes	Yes	Yes	Yes	Yes
Mahon & Casperon (1997)	Can't tell	No	Yes	Yes	Yes
Misra et al. (2013)	Yes	Yes	Yes	Yes	Yes
Sarenmalm et al. (2009)	Yes	Yes	Yes	Yes	Yes
Step & Ray (2011)	Yes	Yes	Yes	Yes	Yes
Vivar et al. (2010)	Yes	Yes	Yes	Yes	Yes
Quantitative randomised controlled trials	**Is randomization appropriately performed?**	**Are the groups comparable at baseline?**	**Are there complete outcome data?**	**Are outcome assessors blinded to the intervention provided?**	**Did the participants adhere to the assigned intervention?**
Ames et al. (2011)	Can't tell	Yes	Yes	No	Yes
Quantitative non-randomized	**Are the participants representative of the target population?**	**Are measurements appropriate regarding both the outcome and**	**Are there complete outcome data?**	**Are the confounders accounted for in the design and analysis?**	**During the study period, is the intervention administered (or**

		intervention (or exposure)?			exposure occurred) as intended?
Andersen et al. (2005)	Can't tell	Yes	Yes	Yes	Yes
Cleeland et al. (2014)	Yes	Yes	No	Yes	No
Cohen et al. (2002)	Yes	Yes	Yes	Yes	Yes
Herth (2000)	Yes	Yes	Yes	Yes	Yes
Northouse et al. (2002)	Yes	Yes	Yes	Yes	Yes
Oh et al. (2004)	Yes	Yes	Yes	Yes	Yes
Pierow et al. (2001)	Yes	No	Yes	Yes	Yes
Ullrich et al. (2003)	Yes	No	Yes	Yes	Yes
Quantitative descriptive	**Is the sampling strategy relevant to address the research question?**	**Is the sample representative of the target population?**	**Are the measurements appropriate?**	**Is the risk of nonresponse bias low?**	**Is the statistical analysis appropriate to answer the research question?**
Brady et al. (1999)	Yes	Yes	No	Yes	Yes
Bull et al. (1999)	Yes	Yes	Yes	No	Yes
Letho et al. (2015)	Yes	Yes	Yes	Yes	Yes
Maguire et al. (2017)	Yes	Yes	Yes	Yes	Yes
Okamura et al. (2000)	Yes	Yes	Yes	Yes	Yes
Okamura et al. (2005)	Yes	Yes	Yes	No	Yes
Sarenmalm et al. (2007; 2008)	Yes	Yes	Yes	No	Yes
Thornton et al. (2005)	Yes	Yes	Yes	No	No
Mixed methods	**Is there an adequate rationale for using a mixed methods design to address the research question?**	**Are the different components of the study effectively integrated to answer the research question?**	**Are the outputs of the integration of qualitative and quantitative components adequately interpreted?**	**Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?**	**Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?**
Ames et al. (2008)	No	No	Yes	Yes	Yes
Turner et al. (2005)	Yes	No	Yes	No	Yes

2.4.3. Patient experiences of recurrent cancer

Physical issues

In a study with a mixed cancer population, most participants reported symptoms of recurrence, such as fatigue, headaches or flu-like symptoms (Mahon and Casperson 1997). Due to the differences in physical manifestation between types of cancer, remaining studies reporting physical issues, will be categorised according to cancer type.

Physical symptoms experienced by patients with recurrent breast cancer included: fatigue; sweats; coughing; a lack of appetite; dry mouth; pain; nausea and vomiting; drowsiness; swelling of limbs; numbness, feeling bloated; dizziness; taste change; problems with sex; constipation; diarrhoea; issues with urination; mouth sores; weight loss; shortness of breath; and difficulty concentrating (Cleeland et al. 2014, Sarenmalm et al. 2007, Sarenmalm et al. 2008, Turner et al. 2005). One study (Northouse et al. 2002) found that those with a recurrence rated their overall physical health lower than those with an initial diagnosis. Further, patients' perceptions of their physical health at recurrence were found to be lower than: pre-recurrence (Bull et al. 1999); primary diagnosis (Andersen et al. 2005, Thornton et al. 2005); cancer patients in general (Northouse et al. 2002); and both population norms and disease-free breast cancer survivors (Oh et al. 2004). One study (Thornton et al. 2005) found that women's perceptions of their physical health were significantly lower when they had a distant recurrence than a local recurrence.

Women with ovarian cancer expressed instinctive awareness that their cancer had recurred due to having experienced similar physical symptoms with the initial diagnosis; and as such felt the need to seek help in a speedy manner (Ekwall et al. 2007, Elit et al. 2010). They attempted to be vigilant for signs of cancer progression; gain good knowledge of the disease and its treatment and how these would affect them (Ekwall et al. 2014). In addition, one study (Howell et al. 2003) noted that the time between the initial diagnosis and the recurrence was brief. Consequently, patients felt little respite from the side effects of treatment. These side effects were so unpleasant that some women described their experience as almost intolerable (Ekwall et al. 2007). Nonetheless, despite the side effects of treatment, patients acknowledged it as necessary if they wanted to live longer (Ekwall et al. 2014).

For patients with recurrent prostate cancer, problems with sexual activity were reported (Ames et al. 2008, Letho et al. 2015, Pietrow et al. 2001), such as sexual dysfunction and low libido. Patients also had issues with experiencing hot flushes from their treatment, frequent urination and incontinence, fatigue, as well as loss of muscle strength (Ames et al. 2008, Maguire et al. 2017). Patients reported pain and low levels of physical well-being (Ames et al. 2011, Ames et al. 2008).

Patients reported adverse side effects from treatment such as pain, fatigue and nausea. These varied in intensity, but fatigue was often described in very high terms (Maher and de Vries 2011).

Psychological Issues

Initial shock at the diagnosis of recurrence was common, accompanied by a range of negative emotions (Misra et al. 2013, Vivar et al. 2010). Uncertainty about the future was frequently reported (Maher and de Vries 2011, Misra et al. 2013).

Psychological problems were common among those with a breast cancer recurrence (Northouse et al. 2002, Turner et al. 2005). In a qualitative study (Hall et al. 1996), half of the study population were found to be clinically depressed or anxious, or both. Okamura and colleagues (Okamura et al. 2000) reported that 42% of their participants met the criteria for major depressive disorder or adjustment disorders; with the prevalence rate of major depressive disorder akin to that found in patients after a primary diagnosis of cancer. However, a later study (Okamura et al. 2005) found the prevalence rate of psychiatric disorders to be lower, at 22% of their sample of recurrent breast cancer patients. There were different negative emotions experienced by those with a recurrence: high cancer-related stress (Andersen et al. 2005); emotional distress (Bull et al. 1999); general stress; worry; sadness; and irritability (Sarenmalm et al. 2007, Sarenmalm et al. 2008, Sarenmalm et al. 2009). However, another study (Oh et al. 2004) found that patients generally had good overall mood, as well as low levels of cancer-specific stress. Findings from one study (Cohen 2002) suggested that, compared to women with primary breast cancer, women with local or metastatic recurrence displayed higher levels of depression, anxiety, and somatisation. A qualitative study (Sarenmalm et al. 2009) reported that participants often viewed recurrence as more distressing than their initial cancer diagnosis; but in contrast, one study (Andersen et al. 2005) reported that patients' stress was equivalent at initial diagnosis as it was at recurrence.

Patients with prostate cancer commonly reported high levels of anxiety (Ames et al. 2008, Lehto et al. 2015) due not only to the recurrence itself, but to PSA testing and subsequent results, as well as related to their physical issues. Some patients reported anger and bitterness regarding their situation, as well as frustration at the lack of a cure (Ames et al. 2008, Lehto et al. 2015). One study (Letho et al. 2015) described patients with recurrent prostate cancer having depressive thoughts and fluctuating moods that were more pronounced than patients with an initial prostate cancer diagnosis. Contrarily, one study (Ames et al. 2011) found participants generally had relatively low levels of anxiety, stress, mental health issues, as well as reasonably raised mood. Moreover, an inconsistent picture emerged in another study (Ames et al. 2008) wherein participants rated their mood as positive when measured qualitatively but contrasted when measured quantitatively. Interestingly, it was found in one study (Ullrich et al. 2003) that recurrence in itself was not associated with greater mood disturbance or cancer-related fear. However, when patients with recurrence also had urinary symptoms, they displayed high psychological distress; suggesting that these symptoms may be a more important factor relating to poorer QoL.

Psychosocial Issues

Patients expressed concern about limitations to their social roles (Northouse et al. 2002, Thornton et al. 2005). One study (Cleeland et al. 2014) reported that several patients faced impairment with daily activities, as well as issues with missing work and impairment when they were actually able to work. Social functioning (the ability to fulfil social roles) was found to be negatively impacted by recurrence in several studies (Andersen et al. 2005, Bull et al. 1999, Northouse et al. 2002, Thornton et al. 2005).

Patients were concerned about their loss of independence and the impact on family members (Turner et al. 2005), though many regarded their condition as having no negative effect on the relationship with their partner (Letho et al. 2015), and some patients described the good quality and importance of their interpersonal relationships (Andersen et al. 2005, Maher and de Vries 2011, Oh et al. 2004). Indeed, some expressed an improvement in family relationships after the diagnosis (Misra et al. 2013, Griffiths et al. 2008). A change in family dynamics was reported, with patients having an increased reliance on family members due to their receiving medical treatments. Furthermore, family were considered an important source of support (Vivar et al. 2010), and for some this led to feelings of guilt and feeling like a burden on family members (Maher and de

Vries 2011). Some reported the maintenance of good social relationships as an important marker of their QoL (Maguire et al. 2017), and social support from friends and family was commonly reported as a valuable method of coping with the cancer (Ames et al. 2008, Lehto et al. 2015). However, some expressed difficulty in reaching out to others, even those close to them (Ekwall et al. 2014). Further, increased psychological distress was associated with decreased emotional support from a partner in one study (Brady and Helgeson 2000).

The relationship between the patient and health professionals was an important issue that arose in multiple studies. Several patients felt unhappy with the information given to them by their direct care team at the time the recurrence was diagnosed; some reported dissatisfaction with the way in which they learned of their condition, in that some felt the delivery too impersonal (Ekwall et al. 2011, Letho et al. 2015). However, the available evidence suggests this was not a universal experience. Indeed, many patients expressed good experiences with their care team (Griffiths et al. 2008, Ames et al. 2008), with some describing oncology nurses as a source of understanding and support (Howell et al. 2003). Maguire et al. (2017) noted that most of their sample were satisfied with the information they received about their condition and largely felt low regret over their choices regarding treatment. Many expressed an importance in being involved in their care and treatment decisions (Ekwall et al. 2011, Ekwall et al. 2014, Howell et al. 2003, Misra et al. 2013), but some felt that they were being ignored or could not influence such judgments in part due to health care policies. A need for clear and accurate information about their condition and treatment options was expressed by patients in order to reduce any uncertainty (Maher and de Vries 2011, Sarenmalm et al. 2009, Elit et al. 2010, Ekwall et al. 2011, Misra et al. 2013). Notably, good communication and easy access to their direct care team were important to reduce this uncertainty (Misra et al. 2013). Further, a familiarity with their care team was considered beneficial, with patients being more comfortable with professionals that they knew from their previous cancer diagnosis and treatments (Ekwall et al. 2011, Ekwall et al. 2014), and having too many professionals involved in their care was not deemed to be desirable (Ekwall et al. 2011).

Recurrence led to a shift in how many patients felt about their treatment; no longer seeing it as a cure and having a subsequent acknowledgement that they would never be clear of cancer again (Elit et al. 2010, Sarenmalm et al. 2009). For some, focusing on QoL rather than the quantity of life, and concentrating on the present rather than the past

or future was important (Sarenmalm et al. 2009). A new appreciation for life was expressed by some patients (Misra et al. 2013). Though, an interesting finding from one study (Cohen 2002) suggested that women with recurrent ovarian cancer were significantly less likely to adopt a positive attitude as a coping mechanism than women with a primary diagnosis. In a qualitative study, physical changes related to the illness and treatment negatively impacted how women with recurrent breast cancer viewed themselves; often feeling less attractive in a feminine sense and feeling alienated from themselves. They additionally describe their reflection when looking in a mirror not matching their self-perceived image. Further, findings from this particular study suggest that this change in appearance led to being treated differently by others, and created a barrier to socialising (Ekwall et al. 2007).

Fear of progression

Fears related to worsening of cancer were measured in one study, however this was FCR before a recurrence took place rather that FOP, revealing a high level of fear in the time at that time (Howell et al. 2003). FOP after recurrence occurred was only explicitly measured in one study using a validated measure (Maguire et al. 2017), and though asking participants about cancer progression the authors refer to it in this case as FCR, and also revealing a high level of fear. Despite the minimal FOP measurement of reviewed studies, several constructs of FOP were captured, e.g., anxiety, distress, and uncertainty; as well as negative factors associated with high FOP (e.g. poor physical and social functioning) (Simonelli et al. 2017). Whilst not FOP in itself in some of the studies in this review (e.g. Elit et al. 2010; Griffiths et al. 2008), participants described being fearful due to recurrence occurring , as well as of the recurrence-specific treatment now required (Mahon and Casperson 1997).

2.5 Discussion

In summary, findings from this review indicate that patients will experience a wide range of adverse effects on their QoL at the time of a recurrence of their cancer, and these can be grouped into categories in order to illustrate the experience of patients. In addition, it has been ascertained that FOP is not a factor typically measured in such a population, despite indications that this fear may be present. Interestingly, in cancer survivors, associations have been found between higher levels of FCR and greater numbers of physical symptoms, emotional distress, and negative health behaviours (e.g., increased

alcohol intake) (Hall et al. 2019). Thus, FCR/FOP is likely to be an issue for the indices of QoL captured in this review.

2.5.1 Comparison to previous research

This review is consistent with findings from a previous meta-ethnography (Wanat et al. 2016) and an earlier narrative review (Vivar et al. 2009), which both describe a wide range of negative issues that accompany cancer recurrence, as well as an indication that the experience of recurrence differs from an initial diagnosis of cancer. The findings summarised from reviewed studies have been arranged into clear categories which shall be discussed in turn below.

A wide range of physical symptoms of cancer and side effects from treatment were identified. This is of course an expected result; and physical symptoms of recurrent cancer are often more severe than in primary cancer, especially if they are due to metastasis (Henson et al. 2020). Previous research suggests that an increased number of physical issues in cancer patients is linked to lower levels of QoL (Salvetti et al. 2020, Triberti et al. 2019). Additionally, physical problems have previously been described as a source of both worry and of FCR/FOP in cancer survivors, as they may be perceived as signs that the cancer is back or worsening (Cho et al. 2018). So, it appears to be useful to capture physical indices of QoL in research with patients with recurrent cancer as findings suggest this is an important factor in determining well-being at this time.

Similar to patients with an initial diagnosis of cancer (Schouten et al. 2019), negative psychological symptoms were commonly reported in patients with recurrent cancer across reviewed studies. Findings suggest that in many cases this is a deeper problem after recurrence than before it takes place. Further, several psychological constructs related to FOP were found to be present. This may indicate that fears related to the worsening of cancer are also prevalent in patients with recurrent cancer, which is worthy of further investigation

It has been established that social support is a meaningful consideration for patients when dealing with cancer (Kleine et al. 2019), and as this review highlights, this is also important at the time of a recurrence. On the concept of social support, it is useful here to distinguish the different classifications this concept can be applied to. These are usually categorised as emotional (e.g., showing sympathy), instrumental (e.g., physical help or

financial aid), and informational (e.g., offering relevant information) (Luszczynska et al. 2013).

Importantly, individuals will have preferences as to which of these different types of social support are desirable given their personal circumstances, and whilst highly-rated social support is positively correlated with higher QoL in cancer patients (Coughlin 2019), social support can also be unhelpful. For instance, emotional support may be judged to be overly emotional and distressing for the patient; instrumental support could be considered unhelpful if items offered were seen as unwanted due to the patient and provider not having a close relationship prior to the diagnosis; and informational support could be deemed unhelpful if it is perceived to be ambiguous or insufficient (Wanzer and Czapla 2022). Importantly, unhelpful support can come from many sources, such as friends and family, acquaintances, and healthcare professionals (Niu et al. 2021).

If viewing the results from the present review, it can be seen in the responses of patients in included studies that both helpful and unhelpful social support are factors experienced by patients after a cancer recurrence and appear to impact on perceived QoL. As such, the role of social support should be included in future psychosocial research. Importantly, an association has been established between greater social support and lower FCR in patients with a primary diagnosis of cancer (Koch-Gallenkamp et al. 2016); and it is plausible that a similar link could be found between FOP and social support after recurrence. As evident from the present review, there is an importance that patients placed on their relationship with healthcare staff. It is known from past research that an association has been found between satisfaction with healthcare staff and lower FCR in primary cancer (Butow et al. 2018). It would be interesting to (after establishing if FOP is present in patients with recurrent cancer) identify if this is also the case for this population.

2.5.2 Limitations

Though the review was exploratory in nature, findings should be read with the caveat that several of the studies were not primarily exploring the experience of patients with recurrent cancer but had some patients who had recurred included in their analysis. Whilst there was a good degree of convergence in findings across reviewed studies, some had contradictory findings. This could be in part related to the wide range of outcome measures employed across studies, the difference in population characteristics, and

differing data collection time points. Mixed study quality ratings should also be taken into account when reading findings from this review.

2.5.3 Recommendations

Due to the lack of studies exploring FOP in patients with recurrent cancer, and the suggested link between cancer progression and the physiological consequences of psychological distress, an exploratory study measuring FOP in this population would greatly add to the findings of this review. Including measures of QoL such as those described in this review would allow for the evaluation of any potential associations between QoL and FOP, which, as mentioned, has been found in non-recurrent patients (Simonelli et al. 2017), as well as the ability to test for convergent validity with any FOP measures. Ensuring high methodological quality of such research would address concerns raised in this review (Masic and Jankovic 2020).

Only two (Ames et al. 2008, Turner et al. 2005) of the studies reviewed included a mixed methods study design. There has been increasing recognition of the benefits of using such an approach in healthcare settings (Halcomb and Hickman 2015, Tariq and Woodman 2013) (see Chapter 3 for more discussion on this issue), and so this appears to be a limitation of the available QoL literature surrounding patients with a cancer recurrence. Additionally, only two of the studies included in this review (Bull et al. 1999, Sarenmalm et al. 2008) were conducted in a longitudinal manner. This type of research has previously been identified as somewhat lacking in psychosocial cancer recurrence research, and there is a need for more in order to assess patients at different phases of recurrence (Vivar et al. 2009). Similarly, an importance has been placed on establishing FCR/FOP trajectories in the relevant literature (Götze et al. 2019, Schapira et al. 2022), and so this should be taken into account when conducting psychosocial research with patients with a recurrence of cancer. Variables that may affect perceived QoL in patients with recurrent cancer (such as age and cancer characteristics) could be explored as moderating variables in this newly suggested research. In doing all of the above it may be possible to establish preliminary understanding of psychosocial interventions that could be implemented in patients after a recurrence of cancer, if judged to be necessary.

2.5.4 Conclusions

This review primarily sought to identify, based on evidence from the published literature, the effect of a cancer recurrence on QoL, as well to ascertain if FOP is typically

measured after a recurrence. The myriad issues arising for patients at the time of a cancer recurrence were categorised into clear groups, thereby building upon findings from previous research (Vivar et al. 2009, Wanat et al. 2016). In addition, FOP is not typically measured in patients with recurrent cancer. It is therefore worthy of investigation to test for FOP in patients who have experienced a recurrence of their cancer. If levels are similar to those found in non-recurrent patients, then it is worth developing psychosocial interventions that can reduce it to manageable levels.

2.6 Theoretical Underpinnings of Fear of Progression

Before going into the next steps of the project following the review, at this stage it is worthwhile to understand the rationale behind fear being examined as a main factor of the experience of patients with a cancer recurrence. This can be understood by describing the theoretical underpinnings of such research.

2.6.1 Common Sense Model of Illness

There are several theoretical models that have been developed in order to understand the reaction of patients to the possibility of recurrence or progression. Of those, the most exhaustive and evidence-based is thought to be Leventhal's self-regulation model of illness (Leventhal et al. 1992), also known as the Common Sense Model of Illness (CSM).

The CSM proposes that, in terms of illnesses, individuals develop personal mental representations of their condition, and these representations subsequently influence their responses. These representations are known as illness beliefs, and according to this theoretical framework are the result of two parallel processes: an objective analysis of a threat to health, alongside a subjective emotional reaction to said health threat. Leventhal and colleagues hypothesised that illness beliefs are made up of five mental representations: identity of the condition; its timeline; its cause; the ability to control or cure the condition; and consequences (what has been experienced, and what will be the result of having the condition). It is thought that these mental representations influence coping behaviours. With this model providing a framework for understanding how cognitions are linked to behaviours during the time of a threat to health, it can be said to have a cognitive-behavioural approach (Brandt et al. 2020).

Figure 3: Leventhal et al. (1992) Common Sense Model of Illness
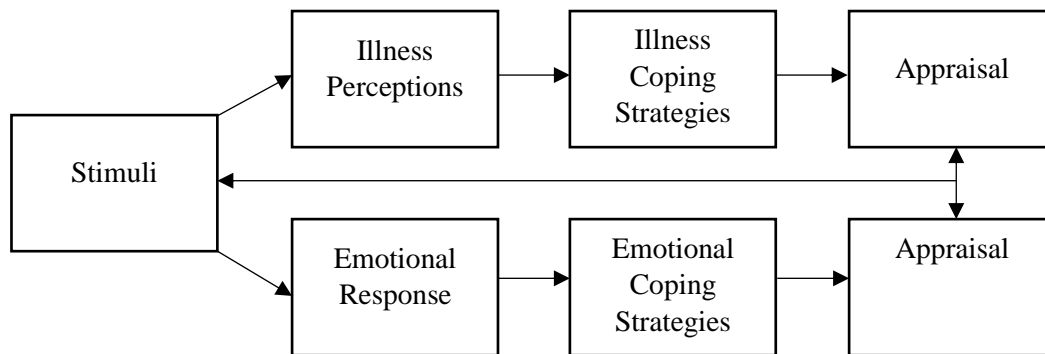
2.6.2 Lee-Jones theoretical model of fear of cancer recurrence

The CSM has been adapted in order to understand FCR (though also applicable to FOP when utilising the commonly held definition provided earlier in this thesis). The most commonly cited of these adapted models is that of Lee-Jones et al. (1997) which posits that the levels of an individual's FCR depend on their cognitive reaction to illness. This model suggests that internal stimuli are interpreted by the individual as a sign that the cancer has possibly recurred or progressed. At the same time external stimuli will raise concerns about recurrence or progression to a greater extent. Subsequently, this subjective perception and accompanying emotions (such as fear) leads to coping strategies and appraisal (see Figure 4).

Figure 4. Model of Fear of Cancer Recurrence from Lee-Jones et al. (1997)

Internal Cues		Cognitions		Behavioural Responses

Internal Cues

Somatic Stimuli → Interpreted as symptoms

Cognitions

Past experience of cancer and its treatment

Knowledge base (e.g., cure and survival rates)

Beliefs about eradication of cancer

Perception of personal risk to a recurrence

Behavioural Responses

Body checking

Seeking advice:
-Friends/relatives
-Professionals

Limited planning for the future

External Cues

Contact with health professionals:

-Follow-up appointments

-Visit to general practitioner

-Visit from community nurse

Media contact (chance exposure):

-Articles presented in magazines, radio, and television programmes

-Local and national advertisements for health screens and checks

Family concerns:

-Direct and indirect probing of health by relatives

-Avoidance by family members to ask about health in situations where once this would have been common

Person's predisposition and past coping style

Emotions

Worry associated with cancer recurring

Anxiety about cancer itself

Remorse over not opting for more aggressive treatments

Psychological Effects

Misinterpretation of symptoms

Increase in somatic activity

Increased propensity to panic attacks

In terms of the model's applicability to FCR/FOP, a previous review identified six different theoretical models that have been formulated to understand the phenomenon, and in doing so identified key processes underlying the issue. These included: the role of cognition and beliefs; triggers (both internal and external); threat appraisal; coping appraisal; vulnerability factors; and behavioural consequence (Fardell et al. 2016). This review established that the CSM covered all of these processes. The authors further describe how illness perceptions are strongly associated with higher levels of FCR/FOP and other worries related to cancer; and that FOP is higher in individuals who consider themselves more at risk of cancer progression and have greater emotional arousal from physical stimuli. In addition, and consistent with the CSM, it was discussed how those with high FCR/FOP display nonadaptive coping measures, such as excessive symptom checking. Further, cautious evidence for the model's application comes from its use in psychosocial interventions designed to lower FCR/FOP to manageable levels (Lebel et al. 2018) (these shall be described next).

2.6.3 Application of theory to FOP interventions

Psychosocial interventions have been successfully developed to lower levels of FCR/FOP. A meta-analysis (Tauber et al. 2019) of past research (with a total of 23 controlled and nine open trials) found a small but significant effect post-intervention, and this was mostly sustained at follow-up (M= 29 weeks). The majority of interventions identified used cognitive behavioural techniques; and this is important as compatibility between the CSM and cognitive behavioural principles has been identified previously (McAndrew et al. 2008). Further, some of these interventions, such as the AFTER intervention (Humphris and Ozakinci 2008) explicitly refer to the CSM in its development; whereas others such as ConquerFear (Butow et al. 2017) make reference to the CSM as a theory among others used in its conceptualisation.

2.6.4 Future intervention development

Understanding underlying individual factors that may be associated with FOP levels are an important consideration in intervention development. There is some suggestion that certain demographic variables such as gender, younger age, and lower education level are associated with higher levels of FCR/FOP, but findings can be inconsistent (Hanprasertpong et al. 2017). Indeed, research has suggested that psychological and emotional variables have a larger impact on FCR/FOP than clinical or demographic

variables (Luo et al. 2020). This follows logically based on past research, as FCR/FOP is considered to have similarities to symptoms of anxiety and depressive disorders (Lee-Jones et al. 1997, Luo et al. 2020). That being said, evidence suggests individuals with pre-existing psychological disorders may be more likely to experience high levels of FOP, but most with high levels of it do not meet the criteria for such psychological disorders. This suggests that FOP is a meaningful mental health concern in itself (Butow et al. 2018).

Factoring in the above, as well as research related to the cancer trajectory (i.e., time since recurrence) may be of use to tailor patient care and inform intervention design (Hanprasertpong et al. 2017, Tauber et al. 2019). Psychosocial interventions thus far tend to focus on those with a primary diagnosis of cancer, so moving forward it would be beneficial to also understand FOP in patients who have specifically experienced a recurrence of their cancer in order to explore any implications this may have on their well-being. This would subsequently allow for understanding of interventions that could be developed for this population if it is considered a significant issue, as noted earlier in this chapter.

In section 1.6 of this thesis, the use of relevant terminology was discussed. Despite common practice a recent study (Coutts-Bain et al. 2022) challenged the conventional treatment of FCR and FOP as the same phenomena. Their analysis reveals that while closely related, these constructs are not identical. Hence, that study advocated for separate treatment in both research and clinical practice. While that research primarily focused on patients with an initial diagnosis of cancer, its implications for the current research are noteworthy. The authors highlight differences in predictors for FCR and FOP, prompting questions about the applicability of existing theoretical models. This necessitates a critical examination of the fit of models such as the CSM and the adapted Model of Fear of Cancer Recurrence in light of the project's findings.

2.7 Conceptual framework of current research

Drawing from the literature review and the discussed theoretical frameworks, a conceptual framework (depicted in Figure 5) was created to steer the research within this thesis. The framework anticipates that internal and external cues will trigger the formation of emotions and cognitions related to Fear of Progression (FOP). The literature

review posits that this relationship will be influenced by specific demographic and clinical variables, along with perceived social support. The ensuing emotions and cognitions will contribute to the intensity of FOP, subsequently influencing behaviours and psychological outcomes that impact overall QoL. Additionally, it is anticipated that levels of FOP will be subject to moderation by demographic and clinical variables, as well as perceived social support.

Figure 5. Conceptual Framework of Current Research
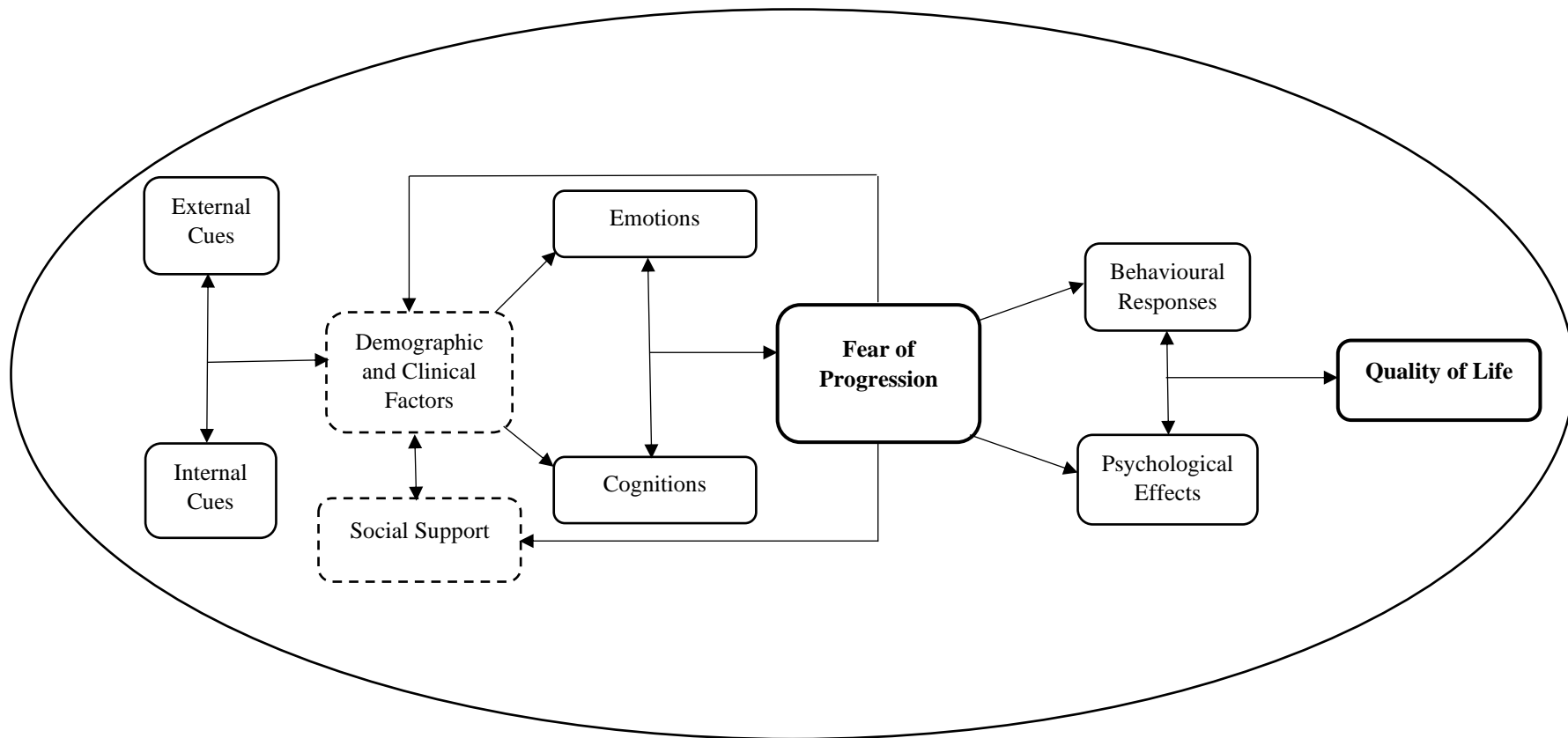
2.8 Chapter Summary

This chapter examined the literature related to the psychosocial impact of recurrence on individuals and the concomitant role of FOP. The literature review established that there are multifarious issues at the time of a cancer recurrence but identified that FOP is not routinely captured in individuals at this time. Psychological theoretical models commonly used to explain fear of cancer progression were described, with good evidence for the use of the CSM to understand FOP, as well as underline relevant psychosocial interventions.

The need for research examining FOP in individuals after a recurrence of their cancer has been identified, as has the notion of including QoL and other psychological measures in such research. The next chapter shall outline the research planned to fill this gap and address the aims of this project.

Chapter Three: Methodology and Research Methods

3.1 Introduction

This chapter presents the methodology and research methods of a longitudinal study that seeks to determine the level of FOP in patients who, on assessment, are found to have shown a clear recurrence of their original disease. As will be described, this study will seek to address the research objectives outlined in the previous chapters. Before this, the rationale for selecting a mixed methods approach in this project will be outlined, beginning with a description of the relevant philosophical underpinnings. Alternative methodologies will be critically assessed to highlight the choices taken in the development of the research. In addition, ethical and organisational considerations associated with the study are considered, as well as proposed data analytic techniques.

3.2 Mixed methods research

3.2.1 Definition

Mixed methods research has been defined as "an intellectual and practical synthesis based on qualitative and quantitative research" (Johnson et al. 2007). It can be considered alongside the traditional quantitative and qualitative, a newer, third methodology (Denscombe 2008).

Regarding the differences between the two traditional approaches, quantitative methods are appropriate to utilise when it is possible to collect quantifiable data relevant to a research question. Hypotheses are tested using formal data collection procedures and measures, thereby generating data that can subsequently be analysed through formal statistical techniques (Queirós et al. 2017). With generally large sample sizes, researchers then generalise these data to a wider population, based on their own sample (Bradley et al. 2007). On the other hand, qualitative research seeks to achieve intimate understanding of a given phenomenon (Aspers and Corte 2019). In contrast to quantitative, qualitative research is generally not numerical and as such is concerned with research problems that may not be quantifiable; this is typically captured through procedures such as interviews and focus groups (Al-Busaidi 2008).

The main principle of mixed methods research, by using both qualitative and quantitative research methods, is to gain a better understanding of a research question than possible by a single method, thereby enhancing findings (Halcomb and Hickman 2015). There has

been debate in the literature about the difficulties in undertaking mixed methods research but the process has been refined over time, and the classification of research designs has allowed for greater clarity in its undertaking (Creswell and Clark 2017).

For the current research, the initial methodology considered was a solely quantitative approach which is the most common in this area of research (Almeida et al. 2019), and making use of questionnaires to assess the relevant outcomes in a cross-sectional design. However, this cross-sectional approach was discounted after examination of the literature illuminated that FCR/FOP levels may fluctuate over time, and distinct trajectories are beginning to be established (Deuning-Smit et al. 2022). In contrast, trajectory analyses have not been conducted when fear has been operationalised as FOP after recurrence takes place. Thus, it was decided that conducting data collection in a longitudinal manner would elicit more informative findings in the research project.

The literature review highlights a scarcity of research on FOP in patients with recurrent cancer, suggesting the need for a comprehensive exploration of the issue. Notably, there is a lack of qualitative investigations into fears related to cancer progression in this population. Opting for a mixed methods design, the decision was made to employ both descriptive and correlational approaches through a survey method and semi-structured interviews. This choice allows for a nuanced understanding of post-cancer recurrence issues and facilitates the examination of relationships among relevant variables.

3.2.2 Philosophical Assumptions

While the theoretical principles of CSM underpinned the FOP aspects of the study, the philosophical position of pragmatism was utilised to inform the mixed methods research design of the study.

The philosophical roots of research differ. Quantitative research has underpinnings in positivism, a philosophical approach that is concerned with knowledge gained through hard scientific evidence (Crossan 2003). Qualitative research is commonly considered to have roots in interpretivism, which posits that knowledge is subjective and based on lived experiences. Mixed methods research seeks to bridge the gap between these two approaches and philosophically is typically considered to be underpinned by pragmatism (Denscombe 2008). In this paradigm it is said there are different realities that can be explored- in other words, knowledge is socially constructed, but the experiences of some individuals fit these social constructions more than others. As such, pragmatism avoids

the debate around reality and posits that the traditional philosophical arguments cannot be resolved (Yvonne Feilzer 2010). In relation to research, if there are multiple layers of reality, mixed methods research has been suggested as a way to capture these (Denscombe 2008). In addition, a pragmatist would suggest that a research study should be conducted with an approach that is best suited for a research problem, with less focus given to the methodology and the main concern being the results (Kaushik and Walsh 2019). This hypothetically allows researchers to have more flexibility in their research methods, though careful consideration of the most appropriate research strategy is still necessary (Brierley 2017). This ties in with the argument that, in research, pragmatism should be thought of as a philosophical set of tools rather than a traditional philosophical paradigm (Biesta 2010). Mixed methods studies in the cancer care literature often explicitly describe pragmatism as underpinning their research, (Dalla Santa et al. 2023, Piil et al. 2022) which suggests that it is indeed a suitable paradigm to help construct the current research study.

3.2.3 Research design considerations

There are various decisions to be made when designing a mixed methods study, and so the general principles behind this will be outlined below with discussion of how they relate to this study. Also to be described is the rationale behind the particular choices made in the development of this study.

Firstly, the purpose of mixed methods research should be established; and there are a number of designs suggested in the literature. Creswell and Plano Clark (2011) propose six, which are outlined below. Of those, two were considered for the design of this project. It is important to note here that a mixed methods study can be either sequential-where the qualitative aspect follows the quantitative component of the study (or vice versa, less commonly), or convergent (also known as concurrent)- wherein both parts are completed at roughly the same time (Fetters et al. 2013).

1. *Convergent parallel approach-* both the quantitative and qualitative components are conducted during the same stage, both are treated equally, and components are mixed only after analysis, during the interpretation and presentation of data.

2. *Explanatory Sequential-* quantitative data is collected and analysed, followed by qualitative data collection and analysis, which is used to supplement and explain the quantitative findings.

3. *Exploratory Sequential-* qualitative data is initially collected and analysed, followed by the collection and analysis of quantitative data, which is to support or test qualitative findings.

4. *Embedded* - both quantitative and qualitative data are collected and analysed within a primarily quantitative or qualitative design to augment the overall design in some way. One of the components must be secondary and the other dominant.

5. *Transformative-* utilising a transformative theoretical framework to address the needs of a specific group and to call for changes or reforms.

6. *Multiphase-* using a combination of both sequential and concurrent phases, making use of different individual studies within a larger project.

After discussion with my supervisory team, it was agreed that the best approach to the current research would be the use of qualitative findings to complement the quantitative, and so firstly considered was the embedded design. However, this was ruled out after further discussion with my supervisory team and based on the advice of Creswell and Clark (2011)- in which it is noted that there is a difficulty in distinguishing embedded designs from others. The advice given to researchers is to think if the secondary data (in this case qualitative) would be meaningful if not embedded in the primary data (the quantitative). In this case I believed the qualitative data would make for useful findings on their own and as such this design was unsuitable. So, next to be considered was the convergent parallel approach, but a decision was taken to use a sampling matrix based on participants in the first phase of the research for the semi-structured interviews to ensure a good mix of demographics at this stage. This meant that the qualitative component was dependent on partial completion of the quantitative, and as such could not be considered a purely convergent approach. This notion of dependence in mixed methods research is important to consider: two study components are considered dependent if the second requires results from the first to commence. Conversely these components would be considered independent if they could be implemented without the results from the other (Schoonenboom and Johnson 2017). This study only required partial completion of data collection and data analysis- some demographics (age, cancer characteristics, and time since recurrence) and FOP questionnaire scores in order to complete the sampling matrix.

This meant that a sequential explanatory study (as illustrated in Figure 6) with a triangulated approach (simply, triangulation refers to the use of different methods to gain

a more complete understanding of a research problem) (Fielding 2012) was the most suitable approach. However, due to the length of time available during the PhD project-hampered by the COVID-19 pandemic, and with the pragmatic approach to this study, it was deemed unsuitable to wait for complete quantitative data collection and analysis before commencing the qualitative data collection. Consequently, after another discussion with my supervisory team it was decided that if the sampling matrix was filled then qualitative data collection could commence whilst quantitative data collection was still underway. Positively, this research approach is common in the wider cancer literature (Cruickshank et al. 2020, Drury et al. 2021, Jaffe et al. 2021), which lends credence to its use in the current research.

Figure 6. Sequential explanatory design
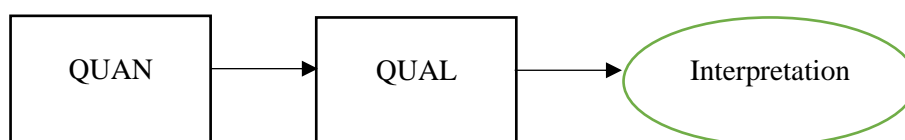
3.2.4 Data Integration

Another important consideration in the development of a mixed methods study is the point of integration- where the quantitative and qualitative aspects are combined. The effective integration of quantitative and qualitative study components is thought to be important in realising the potential of mixed methods research, and so there is a growing recognition of the need for explicit and stringent integration within mixed methods research (Plano Clark 2019). This can take place at one or more points, and within the current research, integration took place firstly at the study design level. Put simply, this was achieved by designing the study as sequential explanatory research (Fetters et al. 2013). Next was integration at the methods level. This took place through the concept of *building*; where results from one data collection procedure informs the next (Creswell and Clark 2017). Lastly, integration took place at the interpretation and reporting level by *integrating through narrative*, in which both components are described, specifically in different sections- known as *the contiguous approach,* as well as through a *joint display*, where data are brought together visually (Fetters et al. 2013).

3.2.5 Mixed Methods Research in Healthcare

Since the study took place within a healthcare setting it is useful to discuss the use of mixed methods research in this environment. Traditionally, quantitative methods have been predominant in healthcare research (Tariq and Woodman 2013), however healthcare systems face increasingly complex challenges, due to a combination of social, environmental, and economic pressures (Halcomb and Hickman 2015). Accordingly, more comprehensive research methods are needed in order to address these multifaceted issues and as such, there has been a significant increase in mixed methods research in healthcare settings (Glogowska 2015). So, it is thought that the use of mixed methods in such settings may give more comprehensive findings than the exclusive use of qualitative or quantitative research methods (Halcomb and Hickman 2015).

Within healthcare systems another important consideration is increasingly important-Patient and Public Involvement (PPI); wherein researchers conducting studies in health and social care settings are advised to include the public and patients in the development of research (Pandya-Wood et al. 2017). As will be elaborated on within this chapter, patients were involved in the development of the qualitative aspect of the current research study.

3.2.6 Maintaining rigour in mixed methods research

Rigour in mixed methods research relates to the confidence that can be taken from findings. In order to maximise this, it is necessary to ensure high methodological quality of such research (Eckhardt and DeVon 2017), and there are a number of frameworks that have been designed to evaluate their quality (Fàbregues et al. 2021). One of these (Harrison et al. 2020) recommends that methodological quality can be established at various points in the research and evidence of high quality involves: including a rationale for the use of mixed methods, reporting a mixed methods research question, and a discussion of the worth of using mixed methods. Researchers should also report the specific data collection procedures, and data analysis for both the quantitative and the qualitative research phases. Importantly, the integration of both components should be explicitly described. The mixed methods design type should be reported, alongside a diagram. Lastly, references should be made to wider mixed methods literature. Efforts have been made throughout this thesis to apply these measures in order to maintain rigour in this research project.

3.3 Research Questions

The broad scope of this project was to focus on patients who have, after treatment with curative intent, had a recurrence of their cancer. More specifically the primary aim was to explore the level of FOP present in this population. To achieve this, the current study sought to address the following research questions (RQs), which were derived from the second of the broader research aims (described in section 1.7) and influenced by the findings of the literature review detailed in Chapter 2.

1. To what extent do patients with recurrent cancer have fear about disease progression, and do these change over time? (RQ1).
2. What level of quality of life and psychological well-being do these patients have? (RQ2).
3. Are certain factors (e.g. cancer type, age) linked to greater fears and poorer quality of life? (RQ3).
4. Can we gain preliminary understanding of any potential interventions that may help this population to reduce levels of fear? (RQ4).
5. Do these patients have fears related to the COVID-19 pandemic in relation to their usual care? (RQ5).

3.4 Research Design

As previously discussed, in this study a sequential explanatory design with a triangulated approach was undertaken (see Figure 7). This is a prospective, longitudinal cohort study featuring a population of patients with a recurrence of cancer. The first (quantitative) phase involved the administration of three questionnaires, spaced out over three months. Data collection via questionnaire fulfils the positivist aspect that the mixed methods approach seeks to bridge with the interpretivist outlook of the second (qualitative) phase, which took the form of semi-structured interviews. Both of these data collection methods have extensive use in past research with a wide range of cancer patient populations (e.g. Davis et al. 2020, Mokhatri-Hesari and Montazeri 2020, Shrestha et al. 2019). As explained previously in this chapter, a longitudinal design was implemented in order to explore if levels of fear (and other factors) change over time or remain stable.

Figure 7. Study design.
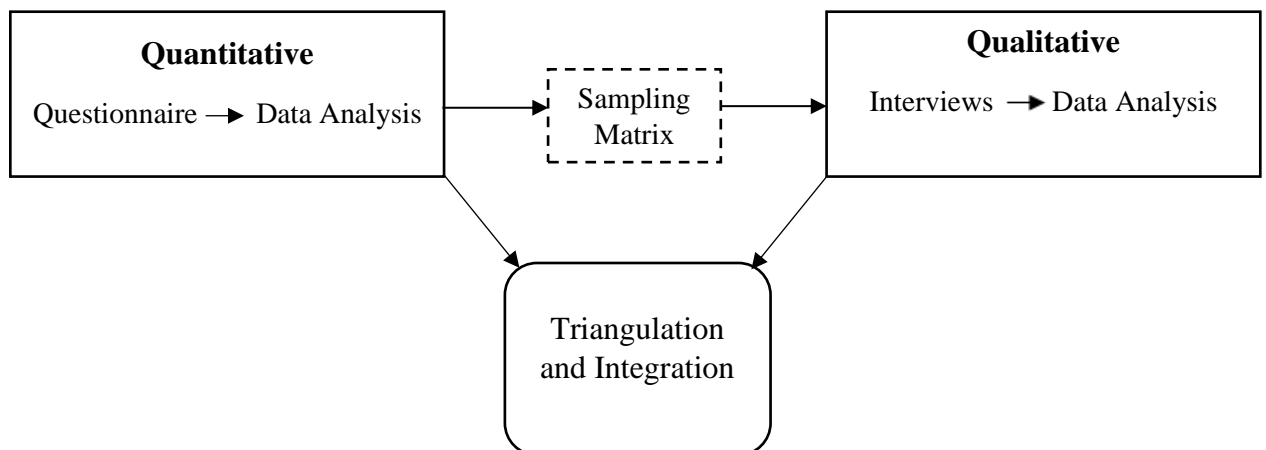
3.4.1 Inclusion criteria

The sample required patients with a recurrence of their cancer. The following inclusion criteria were applied:

- Previous treatment of an initial cancer diagnosis.
- A confirmed diagnosis of cancer recurrence within 3 years.
- Able to understand English.

3.4.2 Sample size

No formal power calculations were conducted to determine an adequate sample size. This was because some of the measurement tools were not developed to the point that the variance of the measure could be reliably stated (see section 3.7). It was initially decided that a convenience sample of 100 would be achievable in the timeframe of the PhD project, the number of available patients likely to take part, as well as fall within the range of sample sizes reported in previous quantitative FCR research (Simard et al. 2013). However, as discussed previously, the COVID-19 pandemic made this unfeasible in the timeframe available, though the number ultimately recruited still falls within the range of sample sizes in similar previous research. A sub-set of the recruited sample took part in the interviews. A further discussion of the final sample size can be found in Chapter 4.

3.4.3 Process of recruitment

The study population was made up of patients from the cancer specialist hospital. The cancer teams identified patients eligible for the study. The patients were approached by a member of their direct care team at hospital sites in Chelsea, London and Sutton, Surrey and informed about the scope of the study, handed the participant information sheet, and asked if their name and telephone details could be passed on to myself or to one of my supervisors (who collectively made up the research team). I then contacted potential participants and offered further information about the study in an informal discussion. If the participant wished to proceed, a verbal consent was documented, and consent forms were then sent- online or by post depending on participant wishes (full consent procedures and ethical considerations are described in detail in the next section of this chapter). It was also noted if participants wished to complete the questionnaires over phone/video call or alternatively be sent a sealed pack of three questionnaires, with an identifying number and dates for when to fill them in. If over the phone, after completion of the first questionnaire the participants were contacted twice more on a monthly basis at a mutually convenient time to repeat the questionnaire responses. Participants selected for interview were contacted after they had completed all three points of quantitative data collection. A poster created for display in the hospital can be found in appendix 2. The participant information sheet and consent form are included in in appendices 3 and 4.

3.5 Ethical Considerations

3.5.1 Sensitive topics

Due to the sensitive nature of the topics being discussed both in the questionnaire and in interview, and an acknowledgement that patients may feel uncomfortable answering some of the questions asked, a number of safeguards were factored into the study. Participants initially discussed the study with a nurse from their usual care team and were given the participant information sheet to read; this explicitly stated that the topics discussed would be of a sensitive nature and may lead to distress. Further, if expressing an interest in taking part, with their consent, their contact information was passed to me, and I arranged to have an informal discussion with them about the study, talk through the participant information sheet and ask if they had any questions. These steps ensured that participants were well informed about the details of the study before agreeing to take part. The consent procedure is outlined in this chapter, but after consent was given and

prior to the commencement of data collection, participants were informed that they would be able to leave the study at any point, without giving a reason and without any penalty, and/or stop the conversation at any point. In addition, if patients wished to speak to a health professional, I could refer them to the appropriate direct care team.

With deeper discussion of sensitive topics, the semi-structured interviews required particular attention. All participants who agreed to be interviewed spoke to the researcher prior to the interview and it was reiterated that the topics were of a sensitive nature and may cause distress. In addition, a distress protocol was developed prior to ethical approval that outlined the procedure to be followed if the participant expressed distress during the interview. It was established that if a participant indicated they were experiencing distress or if they exhibited behaviours suggestive that the discussion was too stressful the first response would be to stop the interview and ask if they wanted to continue. The interview would restart only if the patient felt comfortable to do so. If the participant did not feel able to continue, then the interview would be terminated, and the participant would be advised to contact Macmillan Cancer Support or similar services for additional support. If not interested in one of these options, they would be offered the option of a follow-up call with a member of the research team.

For myself, it is recognised that researchers may find difficulty in discussing sensitive topics related to study subjects- so much so it can be a distressing experience (Dickson-Swift et al. 2006). As such, certain considerations were made regarding my own well-being. An experienced member of the supervisory team was present during the initial interviews, and it was also set out that, if necessary, they could be present for all of them. Following commencement of semi-structured interviews there were weekly scheduled debriefing sessions, and a member of the supervisory team was available for a call at any time. In addition to attending training within the university faculty in qualitative interviewing, I have several years of experience working with different populations of hospital patients with a variety of health conditions and care needs, and so was used to discussing sensitive topics.

3.5.2 Research governance

One of the main ethical concerns in this study related to the protection of participants' personal information. Only the cancer teams at the hospital had access to data about the participants initially. They screened for eligibility and spoke to participants and passed

on the information sheet. A contact name and phone number/email address were the only information passed to the research team until the person entered the study and consent was confirmed. Staff accessed medical records and demographic information only after participants consented to this and were only passed to me once I received a research passport from the hospital.

A unique identifier was given to each participant and their identifiable data was separated before data analysis. All paper questionnaires were scanned and stored on OneDrive alongside digital data and then the paper copy destroyed. In the transcription of audio recording any identifiable details were removed and names were replaced with a pseudonym such as 'participant 1'. Direct quotes were used to support the analysis in publication, and these were anonymised; I was careful not to include other details which may inadvertently identify a participant. Permission was sought from participants to use anonymised direct quotes, with the acknowledgement that they may still be identified from the stories told. The interview data were recorded using an encrypted digital recorder and immediately uploaded to the University of Stirling secure server OneDrive, and the recording deleted. The analysis of all the data were undertaken on a computer that is password protected and data accessed through the University OneDrive.

At the end of the project, files were to be converted to open file formats where possible for long term storage. The University of Stirling requires that research data is stored for a minimum of 10 years from the date of any publication that is based on the data, or the date on which the data was last requested and accessed by a third party. Personal data (e.g. email address, telephone numbers) were kept until the end of the PhD project and then securely destroyed. A summary of the research findings was to be made available to participants by passing this on to the relevant staff at the hospital.

The University of Stirling agreed to undertake the role of sponsor for the study as outlined in the Research Governance Framework for Health and Community Care. Ethical approval was obtained initially from the University of Stirling NHS, Invasive or Clinical Research and then from the NHS London - Stanmore Research Ethics Committee (IRAS 287677); see appendix 5. Separate approval was received from the hospital to host the study.

After the informal discussion with me and after giving 24 hours to think about it, if the participant wished to proceed, verbal consent was documented, and consent forms were

sent (online or by post depending on participant wishes). Once received back these were scanned onto Stirling OneDrive and the paper copy was destroyed.

3.5.3 Amendments to ethical approval

As discussed throughout this thesis, changes had to be made to the study due to a variety of factors. These required amendments to (and subsequent confirmation) of the agreed ethical approvals from the NHS London - Stanmore Research Ethics Committee. These included changes in the recruitment inclusion criteria from solely breast and prostate cancer patients to include all cancer patients, and a change from the most recent cancer recurrence occurring within the past 12 months to 36 months. These were both done to improve recruitment rates, with the change in cancer type criteria also due to the relevant findings in the literature review which indicated that cancer type was not an important factor for QoL research after a recurrence.

3.6 Data Collection

3.6.1 Quantitative data collection

The first phase of data collection was undertaken from June 2021 to August 2022. Participants were approached by clinical staff at the hospital during a regular scheduled appointment and informed about the study and if they were interested in taking part and offered the participant information sheet. If interested, they were asked if their name and telephone details or email address could be passed to the research team. Participants were then contacted and offered further information about the study, and the opportunity to ask any questions. After this discussion and waiting at least 24 hours, if wishing to proceed, verbal consent was taken, and a physical copy sent to them to sign and return to the research team. During this conversation the participant indicated their preference for quantitative data collection- either receiving the questionnaire by post or complete it over the phone at a time convenient for the participant. It was also noted at this stage if the participant wished to be contacted for the qualitative interview component. The questionnaire was administered on two more occasions, one month apart. Participants were thanked for taking the time to be involved in the study. The contact details of the research team were available on the participant information sheet in case of any further queries. The questionnaire used for the research can be found in appendix 6.

3.6.2 Qualitative data collection

After completion of the third questionnaire a subset of participants was invited to take part in a semi-structured interview, which took place over telephone or video call. Utilising individual interviews is the most common method of qualitative data collection in FCR/FOP research (Almeida et al. 2019), therefore this approach is supported. These were conducted within 60 minutes and after completion the participants were once again thanked for their time and reminded of the contact details of the research team. See Figure 8 for an illustration of patients' progression through the study.

Figure 8. Patient progress through study.
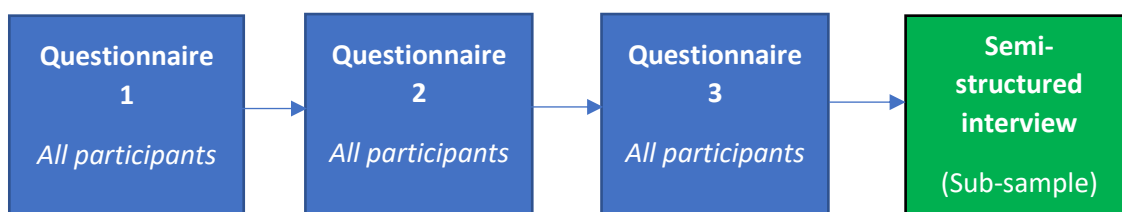
3.7 Questionnaire development

A questionnaire was developed for the purposes of the study comprised of both validated and unvalidated scales, and this was administered at all three data collection time points. The methodological quality of the previously used outcome measures selected were assessed using the consensus-based standards for the selection of health status measurement instruments (COSMIN) checklist, and details about the reliability and validity of included measures are described below. The following components were included:

The *12-item Fear of Progression Questionnaire-Short Form (FOP-Q-SF)* (Mehnert et al. 2006) was developed in Germany from the original 43-item Fear of Progression Questionnaire (FOP-Q), showing reliability ($\alpha = 0.87$) and validity in several cancer populations and across different countries (e.g. (Abd Hamid et al. 2021, Mahendran et al. 2020); and was recommended for use in various cancer populations by a systematic review (Thewes et al. 2012). On a five-point scale, participants are asked how often a particular symptom of FOP is experienced from 1 (never) to 5 (very often). Total scores range from 12 to 60; a score of 34 and over suggests a dysfunctional level of FoP.

The *Fear of Progression 4 item measure (FOP4)* is identical to the Fear of Cancer Recurrence 4 item measure (FCR4) (Humphris et al. 2018), but with references to cancer recurrence (e.g. I am afraid my cancer may recur) changed to cancer progression (e.g. I am afraid my cancer may progress) to be relevant to the study population. The FCR4 is in reasonably early development but has displayed good internal consistency ($\alpha = 0.93$) thus far and requires use in further research. As both the validated 12 item measure (FOP-Q-SF) and the unvalidated 4 item measure were used, associations and internal consistency between the measures was checked. If good associations are found using the shorter version, there could be advantages in subsequent studies by using the FOP4, such as lower patient burden and less time required by clinicians.

The EuroQol 5-dimensional questionnaire five-level version (EQ-5D-5L) (Herdman et al. 2011) was used to measure general health-related quality of life in participants. This scale was developed from the original three-level measure (EQ-5D-3L). Both the original and newer measures have been used extensively in past research, including with patients with cancer (Zeng et al. 2021), and has been shown to be valid and reliable (Janssen et al. 2013, Feng et al. 2021). It is suggested that the five-level version is more reliable, reduces ceiling and floor effects, and allows for more detailed differentiation of levels of health (Van Hout et al. 2012). There are five categories measured: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. One of five ratings is given to each category: no problems, slight problems, moderate problems, severe problems, or extreme problems. A number can be applied to each rating (e.g. a 'one' would indicate no problems and 'five' would indicate extreme problems), and the five are combined (such as 11232) to express the health of the patient.

The Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith 1983) was included in order to measure anxiety and depressive symptoms, as well as test for convergent validity with the FOP measures. This is a 14-item scale with seven items measuring anxiety and seven items measuring depression, which are scored separately. A response that indicates no or very little anxiety/depression is scored as a zero, whereas on the other end of the scale where very high anxiety/depression is indicated, this is scored as a five. As such, a score of zero to seven indicates a 'normal' level; eight to ten indicates a 'borderline' case; and 11-21 would indicate an 'abnormal' case. This measure has been extensively used in patients with cancer in previous research (Vodermaier and Millman 2011).

The *Cancer and COVID-19 Anxiety Scale (CCAS)-* As the research was conducted during the COVID-19 pandemic and treatment regimens were liable to be affected, four items designed to measure patients' fears about COVID-19 and its effect on their cancer and treatment were included. This a study specific scale still in development with a member of my supervisory team Prof. Gerry Humphris, and as such validity is not possible to report at this stage (though the findings of the current research will change this). In this measure patients are asked to indicate how often they worry about certain aspects of the pandemic on their illness and treatment from 'not at all' to 'all the time'. It is important to note that since the completion of this PhD project the name of this outcome measure has been finalised as Clinical Care COVID-19 Anxiety Scale (still CCAS) and has been used in research in a much larger sample (Yuan et al. 2023).

3.8 Qualitative interview schedule

The qualitative element of the research took the form of individual semi-structured interviews. These are flexible by nature, enabling positive interaction between the participant and the interviewer; allowing for deeper responses and enabling follow-up questions based upon the responses given (Kallio et al. 2016). An interview schedule was developed prior to the commencement of the study and submitted for ethical approval. This featured 10 questions and additional prompts developed by the researcher based on the questions in the questionnaire, but with the scope for participants to expand on their answers (this can be seen in the study protocol in appendix 7), as well as describe the role of social support in their experience of cancer. This was discussed with my supervisory team (who have conducted similar research in the past) who approved the schedule before it was subject to ethical approvals. As discussed previously, there is a growing importance on including public and patients in the development of research projects (McMillan et al. 2018). As such, via an online patient platform used by the hospital, patients were invited to discuss the study and help shape the questions asked in interview. Additionally, slight amendments were made after interviews began as new topics emerged. To give an example, patients indicated that they would like to talk about the effect of the pandemic on their social life. As the purpose of the set questions was to prompt relevant discussion there was the flexibly to accommodate this. Also, the order in which the questions were asked could be amended depending on the flow of conversation, and follow-up questions not necessarily on the schedule but based on

patients' responses were asked. This allowed for an exploration of unanticipated themes in addition to those close to the questionnaire data.

At the time of consenting to the study participants were asked if they wished to be contacted for interview. They were reminded of this and asked again at the time their third questionnaire was collected. All interviews were conducted over telephone or video call due to the aforementioned issues arising from the COVID-19 pandemic and issues with in-person data collection. Before commencing the interview, patients were able to ask any questions and once again asked if the wished to take part. Interviews were recorded, and the aim was for each to last around 30 minutes, but with scope for variance. After completion, the patient was thanked for their time and the recording was immediately uploaded to the University of Stirling's secure server. Recordings were then transcribed, and the recording destroyed. Anonymised interview transcripts were uploaded to qualitative data analysis software package NVivo (version 20) to assist with data analysis.

3.9 Data Analysis

Detailed below is the manner in which the data gathered using a mixed methods approach were analysed. As stated earlier, the quantitative and qualitative were analysed independently but findings were integrated at the interpretation stage. These findings are reported in Chapters 4 and 5 and 6, and then discussed in detail in Chapter 7.

3.9.1 Quantitative data analysis

Quantitative data were collected using Microsoft Excel and inputted in Statistical Package of Social Sciences (SPSS) version 28. Any missing values were imputed in psychological constructs according to convention and Missing Completely at Random (MCAR) principles. Each component of the questionnaire used a Likert scale, but these differed. With a four-point Likert scale, the HADS was scored according to convention from 0-3 with a 3 indicating the highest score. Two scores were taken, with distinct subscales for anxiety and for depression. The rest of the components featured a five-point scale and were scored 1-5. In each questionnaire the score from each question was added and a total taken. These totals were reported alongside cut-off points that allow for categorisation where possible. Descriptive statistics of questionnaire data were reported, including frequencies (categorical variables) and means and standard deviations (SD). The EQ-5D-5L does not traditionally give a total score and instead each dimension is

summarised in a five-point 'health score' made up of five scores (e.g. 12345), to provide a longitudinal overview of health-related QoL the mode score was collected from each of the three time points as it is not a continuous scale.

Inferential statistics were reported with multiple regression analysis to predict FOP scores from gender, age, and time since recurrence. As a longitudinal study, an overall mean was taken from mean scores at each data collection time point for this purpose. Logistic regression was run to examine the relationship between age, gender, and time since recurrence on the chance of being categorised as a low-medium or high FOP scorer. For the longitudinal data, a repeated measures ANOVA was conducted to test for an effect of time on each of the questionnaire components. Pearson Correlation Coefficients were calculated to test for convergent validity between the FOP questionnaire components and the HADS subscales. Cronbach's Alpha was measured to test for the internal consistency of the CCAS (as a new scale), and the FOP4 (as it has not been operationalised for FOP as of yet). The results from quantitative data analysis are presented in Chapter 4.

3.9.2 Qualitative data analysis

Qualitative data was analysed using inductive thematic analysis (Braun and Clarke 2006). This process involves six stages: familiarisation, generating initial coding, searching for themes, reviewing themes, defining and naming themes, and reporting of results- as outlined below in Table 3. Briefly, a theme is developed to highlight something meaningful about the qualitative data related to the research question. These themes are developed from codes (coding is the process in which labels are assigned to sections of the raw data- in this case the interview transcripts). The results from qualitative data analysis are presented in Chapter 5.

Table 3. Braun and Clarke's (2006) six phases of thematic analysis

Phase		Description
1	Familiarisation with data	Transcription of data, reading transcripts multiple times, noting initial ideas
2	Generating initial codes	Coding interesting features of the data, group similar data around relevant code
3	Searching for themes	Collating codes into potential themes, gathering all data relevant to each individual theme
4	Reviewing themes	Reviewing themes in relation to the coded extracts, generation of a 'thematic map'
5	Defining and naming themes	Analysis to refine specifics of each theme and the overall story told. Generation of definitions and names for the themes
6	Reporting results	Selection of meaningful excerpts, analysis related to the research question and literature, production of final report

Thematic analysis is considered a flexible approach, meaning it is suitable for a wide range of qualitative research techniques (including semi-structured interviews) and further, thematic analysis is not tied to a particular theoretical position (Joffe 2012), and so is well suited to the pragmatic approach of this research. Further, this approach has been successfully undertaken in FCR/FOP research in the past (Almeida et al. 2019).

Another necessary consideration for thematic analysis is whether to approach the data in an inductive (from the raw data) or deductive manner (from a preconceived theoretical idea). This study primarily makes use of inductive analysis, as the findings were based on the raw data and built up from there. However it is important to note that the approach taken is not entirely without preconception, as a researcher will inevitably have their own beliefs and prior knowledge of a topic (Terry et al. 2017). Relevantly, it should be noted there is a deductive aspect to the analysis as some of the questions asked were based on

the FOP measures, though the quantitative aspect of this study was kept separate at the analysis stage and the thematic analysis was driven by the raw data.

Within thematic analysis there are two types of coding, and this too requires deliberation. Semantic coding refers to the capture of explicit meaning relating to what a participant says. Whereas latent coding refers to capturing implicit meaning; beyond what might be expressed by a participant (Javadi and Zarea 2016). These approaches do not necessarily have to be exclusive, but this study utilised a primarily semantic approach, and as recommended by Braun and Clarke (2006), involves a progression from description (wherein data has been collated in order to highlight patterns and then summarised) to wider interpretation of their meaning and significance.

Importantly, there are three broad types of thematic analysis, each with different approaches that can be taken. These are coding reliability, in which the researcher develops a hypothesis (pre-determined themes), searches for evidence of the themes using a codebook, and seeks to minimise the influence of the research in analysing the data. Also important in this approach is achieving reliability and replicability, and is considered to be partly quantitative rather than purely qualitative. Codebook thematic analysis is similar, also making use of a structured approach to coding, but usually without a view to reliability and replicability, and with a broadly qualitative philosophical approach. Lastly, reflexive thematic analysis includes the approach outlined above (Table 3) and was the chosen manner of analysis for this project. Within this approach, the aim of coding and developing themes is to give an orderly and engaging interpretation, based on the data. It also acknowledges that the result of the analysis is not objective but should be seen through the lens of the researcher, with an awareness of their knowledge and experience, as well as their own biases (Terry et al. 2017).

Crucially, this approach was chosen, not only for its flexibility and suitability for a pragmatic outlook to the current research, but because the exploratory nature of the research meant using pre-existing themes would be unsuitable, and additionally, this approach allows for examination of the factors that influence phenomena (Terry et al. 2017). Thus, it is a suitable approach to get a more detailed understanding of the impact of recurrence and of FOP.

Reflexivity in qualitative research

To give more detail on the reflexive nature of the analysis carried out, it is worth exploring the issue of reflexivity in qualitative research. Qualitative research is inherently conducted in a certain context and there is a circumstantial converging relationship between myself and those I interviewed in this research project (Dodgson 2019). Researchers in these settings will inevitably bring their own beliefs or prior knowledge to studies (Terry et al. 2017). This is where the concept of reflexivity is important to discuss. It is the ongoing process of self-reflection on the role of such biases in the research process (Dodgson 2019). An awareness of such inclinations is thought to improve the trustworthiness and credibility of research projects (Berger 2015). For myself, I recognise that it is important to detach myself from the topics discussed, and create appropriate boundaries (Dickson-Swift et al. 2006).

Coming into the project I considered myself in the position of a relative outsider. Notable differences that were predicted to emerge (and did so) were that I was considerably younger than participants and have not had experience of serious and long-term health conditions as they have. Further, with a sensitive topic matter, my emotional response had to be considered. However, as discussed earlier I have experience that helped negate these factors. Another important issue to take into account is the role of unconscious biases on my part. Something that I felt particularly aware of are power differentials; said to be inherent in researcher-participant relationships (Dodgson 2019). Fostering an atmosphere of participatory research is a technique to address this problem; simply put, this involves collaboration from those who are the subject of the research (Vaughn and Jacquez 2020). I felt this was at least partially addressed in this project from the aforementioned patient involvement, as well as the open and flexible nature of the semi-structured interviews, which always included time for the participants to add in any thoughts they had that they felt were not covered (or not covered in sufficient detail in their opinion) within the research. The process of self-reflection was crucial. Throughout the project I kept a diary noting my thoughts (e.g., decisions made and why, and how I felt about them). At the time of the semi-structured interviews, I made notes regarding how each one went, how did the patient seem, and how I felt, and made a point of re-examining these at least before each subsequent interview. Other than that, evidence of my reflexivity should be evident throughout this thesis, e.g., when I discuss decisions

made during the research process, and full clarity on the techniques used- both of these should increase trustworthiness and credibility of my findings (Dodgson 2019).

Data saturation

An important consideration in qualitative research is the concept of data saturation. This is the point at which further data collection and analysis is unnecessary as no new themes emerge (Saunders et al. 2018). This suggests that no set number is required beforehand, but for the purposes of this study an estimation was required for ethical approval, and approval for up to 20 patients to be interviewed was given, with a view of capturing 10. The reasons for achieving this number were threefold: the number fits within generally accepted criteria for achieving data saturation; (Guest et al. 2006), the aforementioned time constraints on the overall project, and the potentially distressing nature of the interview topics meant it would be pertinent to keep the number from becoming too excessive. Data analysis allowed for continuous checking for data saturation- represented by fewer and fewer themes emerging. This was done by reading each transcript multiple times and then comparing it to the subsequent interview, and so on. In addition, a member of my supervisory team checked my coding and agreement was reached that data saturation was reached. Pertinently this leads onto a discussion of quality in mixed methods research.

3.10 Chapter Summary

This chapter introduced the methodology and more specific research methods that were utilised in order to address the research objectives of this project. Philosophical underpinnings of mixed methods research were described. A selection of different methods that were contemplated were discussed in order to illuminate the choices that were taken. Project management and ethical considerations required of this research were described. Also, a description of the data collection methods and the data analysis techniques that were employed in this project were outlined and the results are set out in Chapters 4 and 5.

Chapter Four: Presentation of results - quantitative analysis

4.1 Introduction

The research objectives of this project were addressed via a mixed methods study with a sequential explanatory approach. The results gathered through data collection will be presented in the following two chapters: firstly, the quantitative and secondly the qualitative findings. Quantitative data analysis was conducted using SSPS version 28 and outlined below is the statistical analysis of the questionnaire data. Firstly, the characteristics of the study population and questionnaire scores are detailed, followed by an examination of the relationship between clinical and demographic variables and FOP as measured in the questionnaire. Next, an analysis of the longitudinal data collected over the three data collection time points is outlined. Lastly, statistical testing of the validity and reliability of the newer scales used in the questionnaire will be described.

4.2 Sample characteristics

The initial target population was 100 patients with cancer who had experienced a recurrence of their cancer. However, as this study was carried out during the COVID-19 pandemic this proved to be a challenging number to recruit in the limited timeframe of a PhD project, as alluded to throughout this thesis. Due to factors such as patient unavailability and staff absences, anticipated participant numbers were revised (with an aim of recruiting as many as possible before a set deadline). Overall, 33 patients were approached, of which 24 (73%) agreed to take part. The remainder did not reply to the approach from the research team and consideration is given to non-responses in section 7.8 of this thesis. Of those patients who took part, 19 completed all three questionnaires, with five (26%) completing either one or two. These participants did not reply to contact for follow-up, and the handling of missing data for analysis purposes is described in section 4.3 of this chapter.

With all types of cancer eligible for inclusion in the study, the final study population featured 13 breast cancer, eight prostate cancer, two bladder cancer, and one melanoma patients. Ages of those ranged between 36 and 83 years old. An initial recurrence of the participants' cancers had occurred between four and 230 months before data collection began, though all had experienced a recent recurrence in the last three years. Descriptive and clinical statistics are displayed in Table 4.

Table 4. Demographic and clinical variables of participants in quantitative phase

Variable	N
Female	14
Male	10
Mean age (SD)	65.83 (13.23)
Cancer type	
Breast	13
Prostate	8
Bladder	2
Melanoma	1
Mean months since recurrence (SD)	46.1 (53)

As can be seen, the dominant cancer types in this study were breast and prostate, and as such were (typically, and in this case) gender based. Preliminary analysis suggested a high level of multicollinearity between cancer type and gender as would be expected, and so cancer type was removed from analysis; as, for the purposes of this study, it would be unnecessary to analyse both cancer type and gender. Suggestions to remedy this for future research can be found in Chapter 7).

4.3 Missing data

There was no missing data from completed questionnaires, however, as noted there were several patients who did not complete all three. Little's MCAR test was run for the dataset and a non-significant result indicated that missing data was considered as missing completely at random. Multiple imputation was subsequently carried out using SPSS 28 in order to account for the missing data. Firstly, the software indicated a monotone pattern of missing values. i.e., if a participant missed a data collection point, they will not be measured again (which was expected in this case and is common in longitudinal research), and the appropriate method of multiple imputation was carried out automatically by the software (Ibrahim and Molenberghs 2009).

4.4 Questionnaire scoring

Average scores from the questionnaire components at each time point are displayed in Table 5. An overall average was taken from the three time points for each measure and this 'average of means' was used for statistical analyses (with the exception of the longitudinal data analysis). As was outlined in the previous chapter, mode scores were calculated for the EQ-5D-5L Health Status scoring.

Table 5. Average questionnaire scores across data collection points

Questionnaire component	FOP-Q-SF	FOP4	HAD-D	HAD-A	CCAS	EQ-5D-5L Health Status Mode
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	
Baseline	31.87 (9.73)	12.67 (3.97)	4.79 (2.64)	6.54 (3.09)	7.54 (3.5)	31332
1 month follow up	33.37 (9.64)	13.25 (4.2)	4.67 (3.25)	6.16 (3.09)	8.42 (4.01)	31222
2 month follow up	33.5 (8.36)	13.25 (3.5)	5.41 (3.4)	7.37 (2.46)	7.16 (2.79)	21322

4.5 Fear of Progression

The primary aim of the research study was to ascertain the level of FOP in patients after a recurrence of their cancer, and multiple analyses were conducted to explore this variable. Firstly, mean scores were calculated for the FOP components of the questionnaire. With a score of 34 in the FOP-Q-SF indicating dysfunctional levels of FOP, the mean score peaked at 33.5 indicating moderate, but just short of dysfunctional levels of fear. However, it should be noted that at this peak 46% of the participants registered a level of FOP that would be considered dysfunctional. For the smaller FOP4 scale, mean scores peaked at 13.25, which also indicated moderate but not quite dysfunctional levels of fear. Consideration is given to the correlation between these measures in section 4.10.

Several demographic and clinical factors were collected, and the relationship between these and FOP was tested through multiple regression analysis. This was run to predict FOP scores from gender, age, and time since recurrence. These variables did not statistically significantly predict FOP, $F(3, 20) = 1.66$, p= .21, $R^2 = .2$. These findings are summarised in Table 6. These results indicate that the demographic factors collected are not associated with a higher or lower level of FOP.

Table 6. Multiple regression analysis of demographic and clinical variables on fear of progression

Predictor variable	B	Std. Error	Beta	t	p	95% CI Lower Bound	Upper Bound
Time since recurrence	0.010	0.022	0.098	0.459	0.651	-0.037	0.057
Age	-0.116	0.099	-0.275	-1.176	0.254	-0.321	0.090
Gender	-3.002	2.599	-0.271	-1.155	0.262	-8.423	2.418
Constant	43.332	5.737	x	7.554	0.000	31.366	55.299

4.5.1 Comparison of patients with different levels of FOP

Creating a cut-off point of the FoP-Q-SF score of 34, participants were divided into two groups to compare those with low-medium FOP and high FOP (thus creating a group with dysfunctional levels and a group with 'normal' levels), based around their clinical and demographic variables (this is displayed in Table 7). Logistic regression was conducted to examine the relationship between age, gender, and time since recurrence on the chance of being categorised as a low-medium or high (dysfunctional level) scorer. The full model was not statistically significant, x^2 (3, N= 24) = 6.54, p= .09, indicating that the independent variables did not distinguish between those with a high and low FOP score (see Table 8). In other words, and in line with the multiple regression carried out beforehand, the demographic factors of participants in this research study did not predict scoring either a normal or a dysfunctional level of FOP.

Table 7. Comparison of characteristics of patients with different levels of fear of progression

Variable	Low-Moderate FOP Group	High FOP Group
N	13	11
%	54	46
Female	6	8
Male	7	3
Mean age (SD)	69.85 (9.74)	61.09 (15.58)
Cancer type		
Breast	6	7
Prostate	7	1
Bladder	x	2
Melanoma	x	1
Mean months since recurrence (SD)	44.77 (42.04)	61.09 (73.61)

Table 8. Logistic regression predicting likelihood of reporting high levels of fear of progression.

Predictor variable	B	S.E.	Wald	Df	p	Odds ratio	95% C.I.for Odds ratio	
							Lower	Upper
Sex	1.984	1.191	2.774	1	0.096	7.273	0.704	75.119
Age	0.036	0.041	0.743	1	0.389	1.036	0.956	1.123
Time since recurrence	-0.010	0.010	1.113	1	0.291	0.990	0.972	1.009
Constant	-2.447	2.571	0.906	1	0.341	0.087	x	x

4.6 Anxiety and depression

On average, participants scored between 4.67-5.41 on the depression subscale of the HAD throughout the study, which falls within the 'normal' score of 0-7. For the anxiety subscale mean scores ranged between 6.16-7.37 throughout the study, indicating at its peak level, the average score exceeded the 'normal' score of 0-7, and indicate the prevalence of 'mild' levels of anxiety.

The relationship between the clinical and demographic factors and anxiety and depression levels was tested through multiple regression analysis. Age was statistically significant in predicting anxiety (p=.006), though the total model was not, $F(3, 20) = 3.66$, p= .03, $R^2 = .354$. None of the variables significantly predicted depression scores, $F(3, 20) = .529$, p= .667, $R^2 = .074$. These findings are summarised in Tables 9 and 10. These results indicate that lower age was associated with greater anxiety but there was no

link between age and depression scores. Time since recurrence and gender did not predict either anxiety or depression scores.

Table 9. Multiple regression analysis of clinical and demographic variables on anxiety scores.

Predictor variable	B	Std. Error	Beta	t	p	95% CI Lower Bound	Upper Bound
Time since recurrence	0.002	0.009	0.042	0.217	0.830	-0.017	0.020
Age	-0.120	0.039	-0.648	-3.086	0.006	-0.202	-0.39
Gender	0.478	1.028	0.098	0.465	0.647	-1.666	2.623
Constant	13.847	2.27	x	6.101	0.000	9.113	18.582

Table 10. Multiple regression analysis of clinical and demographic variables on depression scores.

Predictor variable	B	Std. Error	Beta	t	p	95% CI Lower Bound	Upper Bound
Time since recurrence	-.005	.012	-.090	-.391	.700	-.030	.021
Age	-.024	.054	-.114	-.454	.655	-.137	.088
Gender	-.826	1.420	-.147	-.582	.567	-3.788	2.135
Constant	7.959	3.134	x	2.539	.020	1.421	14.497

4.7 Health-related quality of life

The mode score of the five dimensions of the EQ-5D-5L was collected from the three data collection time points. Accordingly, on average, mobility scores, usual activities, and pain/discomfort ranged between a score of 2-3, indicating slight to moderate problems. Anxiety/depression was rated at 2 throughout, which suggests slight levels of anxiety and depression. Lastly, self-care was rated as 1 throughout, suggesting no problems with washing or dressing, on average.

In order to assess the relationship between health-related QoL and FOP, mode health status scores for each dimension of the EQ-5D-5L were compared to mean FOP-Q-SF

scores using Spearman's rank correlations. No significant correlations were identified between any of dimensions and FOP scores. (see Table 11).

Table 11: Correlational analysis of health-related quality of life and fear of progression

		Mobility	Self-care	EQ-5D-5L Usual activities	Pain	Anxiety and depression
Fear of Progression (FOP-Q-SF)	Correlation Coefficient	-0.349	-0.163	-0.364	-0.029	-0.128
	Sig. (2-tailed)	0.094	0.445	0.080	0.892	0.551
	N	24	24	24	24	24

4.8 COVID-19 concerns

Mean scores on the CCAS ranged from 7.16-8.42 out of a possible 20. Any scores that exceeded two standard deviations above the mean were considered high levels of fear. If taking the average of means as the guideline, this would require participants to score 13 and over, indicating that fears related to cancer and COVID-19 were generally low.

Multiple regression analysis was once again conducted and none of the demographic and clinical variables collected predicted CCAS scores, $F(3, 20) = 1.579$, p= .226, $R^2 = .191$ (see Table 12). This suggests that worries around COVID-19 and cancer were not predicted by age, time since recurrence, or gender.

Table 12. Multiple regression analysis of clinical and demographic variables on COVID-19 fear scores

Predictor variable	B	Std. Error	Beta	t	p	95% CI Lower Bound	Upper Bound
Time since recurrence	.025	.013	.418	1.948	.066	-.002	.052
Age	-.073	.057	-.303	-1.291	.211	-.192	.045
Gender	.228	1.500	.036	.152	.881	-2.901	3.358
Constant	11.054	3.312	x	3.338	.003	4.145	17.962

4.9 Longitudinal data analysis

The longitudinal design of this study has been described, but to briefly reiterate, the questionnaire in the quantitative phase of the research was administered three times, one month apart. The previous analyses outlined above have taken an overall mean score from the mean score at each time point, but for the longitudinal analysis mean scores collected at each data collection time point were examined for changes over time. A repeated measures ANOVA was conducted to test for an effect of time on each of the questionnaire components and no significant effect was found (see Table 13), indicating that FOP, anxiety, depression, and COVID-related fears remained stable throughout the duration of the study.

Table 13. Longitudinal analysis of questionnaire component scales

Measure	Baseline M	SD	Follow-up 1 M	SD	Follow-up 2 M	SD	df	F	p	Partial eta squared
FOP-Q-SF	31.87	9.73	33.37	9.64	33.5	8.36	2, 22	1.16	.33	.09
FOP4	12.67	3.97	13.25	3.5	13.25	3.89	2, 22	.827	.45	.07
HAD-D	4.79	2.64	4.67	3.25	5.41	3.4	2, 22	2.11	.14	.16
HAD-A	6.54	3.09	6.16	3.09	7.37	2.46	2, 22	2.22	.13	.17
CCAS	7.54	3.5	8.42	4.01	7.16	2.79	2, 22	3.01	.07	.22

4.10 Reliability and validity

An advantage of the questionnaire employed in this study was that most of the scales have been shown to be reliable and valid in previous research. However, two of the scales required further attention: as a study-specific scale in development, it was prudent to check the internal consistency of the CCAS, and analysis suggested that this scale showed a high level (Cronbach's Alpha= .84). The other requiring attention was the FOP4; whilst it has been used in previous research it has yet to be operationalised as a measure of progression rather than recurrence (though hypothetically it should perform the same way) (Lebel et al. 2018). Analysis also indicated a high level of internal consistency for this scale (Cronbach's Alpha= .93). These results suggest that both scales surpass the traditionally cited level of reliability necessary for new scales (Taber 2018).

The other aspect of the FOP4 under investigation was its convergent validity to the FOP-Q-SF and the HADS anxiety and depression sub-scales. Based on previous research (Humphris et al. 2018) it was hypothesised that both FOP scales will correlate with these sub-scales. This was indeed the case for both FOP measures. In addition, a significant correlation was found between FOP measures, indicating high convergent validity (see Table 14).

Table 14. Convergent validity of fear of progression measures

| | Pearson Correlation Coefficients | | | |
	FOP4	FOP-Q-SF	HAD-D	HAD-A
FOP4	1	.661**	.594**	.517**
FOP-Q-SF	.661**	1	.450*	.438*
HAD-D	.594**	.450*	1	.465*
HAD-A	.517**	.438*	.465*	1
*p < 0.05 (2-tailed)				
**p < 0.01 (2-tailed)				

4.11 Summary of findings

The statistical analyses outlined in this chapter addressed the research questions of this project. It has been established that on average, patients with recurrent cancer have moderate levels of FOP, with 46% of the study population reaching dysfunctional levels

during the duration of the study. Analysis further indicated that gender, age, and time since recurrence did not significantly affect FOP scores or indeed the likelihood of reporting dysfunctional levels.

Other findings suggest that anxiety and depression were largely in the normal range, but anxiety levels did peak at a mild level, and that younger age was associated with higher levels of anxiety. In terms of health-related QoL, problems were reported in relation to mobility, the ability to perform usual activities, and pain and discomfort. Additionally, another novel finding from the research suggests that patients with a recurrence of cancer generally showed low levels of concern regarding the COVID-19 pandemic in terms of potential adverse effects on their own health and also to their cancer treatment or care. With the exception of the link between younger age and higher anxiety scores, none of the clinical and demographic variables predicted any of the measured outcomes to a significant level. Additionally, all of the outcomes measured were found to be stable over the three-month data collection period on average. This indicates that if a participant scores highly or lowly, they will generally continue to do so.

Lastly, high levels of reliability were found for the two scales in the questionnaire that are in development; and high convergent validity was found between the smaller FOP4 scale and the longer FOP-Q-SF, as well as the anxiety and depression sub-scales of the HADS.

Chapter Five: Presentation of results – qualitative analysis

5.1 Introduction

This chapter will describe the qualitative findings from the semi-structured interviews of this research study. Firstly, detailed below are the characteristics of participants who took part in this phase of the research. Next, the stages of thematic analysis (Braun and Clarke 2006), will be described as they were applied to the current findings. After participants answered a series of open-ended questions five overarching themes were developed in an inductive manner, based on the responses given: **from recurrence to progression, experience across lifespan, managing the impact,** and **cancer and COVID-19.** These all capture important and varied aspects of QoL in patients after a recurrence of their cancer.

5.2 Sample characteristics

Participants were recruited for this phase of the research until a suitable number were adjudged to have been interviewed (when data saturation was deemed to have been reached via evaluation of transcripts and discussion with the supervisory team). Fulfilling the sample matrix, ten participants who had taken part in the first phase of research were invited to take part in a semi-structured interview. The demographic and clinical variables of participants at this phase of the research are outlined in Table 15.

Table 15. Patient demographic and clinical variables of interviewed participants in qualitative phase

Variable	N
Female	6
Male	4
Mean age (SD)	68.2 (13.67)
Cancer type	
Prostate	4
Breast	3
Bladder	2
Melanoma	1
Mean months since recurrence (SD)	55.2 (67.49)
FOP Score	
Low-Moderate	7
High	3

5.3 Stages of thematic analysis

The stages of thematic analysis as set out by Braun and Clarke (2006) have been described in detail in section 3.9.2 of this thesis and so only an account of how these were applied in this research study is set out below.

Stage one- familiarisation with data

All interviews were audio recorded and transcribed verbatim into a Microsoft Word document and subsequently entered into QSR NVivo 20 software. Each transcript was read several times in order to gain a broad overview of the topics discussed.

Stage two- generate initial codes

In an overlap between the first two stages, notes were taken during the reading and re-reading of the transcripts, leading to the creation of initial ideas about what the data was saying. Coding of each transcript then took place. This was undertaken with an open inductive approach, and so conducted with no existing coding framework or with any preconceptions of what the data will express. However, at this point I was acutely aware that I foresaw some aspects of what the participants would say in relation to their experience. This is due in part to the initial quantitative phase of the research, as well as to my previous experience working in a hospital setting, and because of the background reading and research I undertook prior to the study commencing. This is to be expected, as discussed in detail in section 3.9.2 of this thesis (Terry et al. 2017). But by expressing a self-awareness of this, ensuring the transcripts were accurate and comprehensively evaluated, as well as a member of the supervisory team evaluating the coding, it is hoped that accurate representation of what participants said is ensured, and potential biases are sufficiently reduced (Berger 2015).

Coding broke transcripts down into smaller meaningful pieces of data with the use of NVivo software (version 20). To improve trustworthiness, when I had finished coding, discussion of each code took place with a member of my supervisory team and modifications were made where deemed necessary. Initial codes generated were: 'family concerns', 'effect on work', 'worried about future', 'uncertainty', 'treatment concerns', 'feeling alienated', 'the initial diagnosis', 'the recurrent diagnosis', 'non-cancer issues',

'previous cancer experience', 'older patients' sympathy for younger patients', 'acceptance and carrying on', 'acceptance that progression is inevitable', 'quality over quantity of life', 'scanxiety', 'desire for more time', 'COVID worries', 'confidence from vaccinations', 'hobbies', 'distracting oneself', 'social support', 'content with cancer specialist hospital', and 'relationships with staff'.

Stage three- searching for themes

The next step was to collate codes into broader themes that expressed the data collected, and to move away from individual pieces of information. Firstly, codes were reviewed again to ensure that they were relevant to the research aims of the project, and then several overarching themes were established. Firstly, **'age concerns'** was created to illuminate findings that were relevant based upon the age of participants. Within this the coding 'family concerns', 'effect on work', and 'older patients' and 'sympathy for younger patients' featured. **'Further cancer progression'** was the summation of coding relevant to the thoughts of participants in relation to their cancer progressing further from its current state. 'Acceptance that progression is inevitable' was combined with 'acceptance and carrying on' codes into a more general 'acceptance' code. Another new code: 'an uncertain future' was made from combining 'worried about future' and 'uncertainty' into one, and this was added to this theme. The rest of this theme was constituted by 'quality over quantity of life', 'scanxiety', 'desire for more time' and 'treatment concerns'. 'The initial diagnosis' and 'the recurrent diagnosis' codes were applied to a theme entitled **'The time of diagnosis'. 'Cancer and COVID-19'** was simply all of the coding referring to the effect of the pandemic on different parts of the participants' lives. 'COVID worries' was replaced with more specific coding: 'concerns about COVID-19 physical effects' 'disappointment in policy makers', 'easing of lockdown restrictions', 'pandemic effect on cancer treatment', and 'feeling alienated'. Alongside the aforementioned 'confidence from COVID vaccinations' code these constituted the theme. **'Support'** referred to the social support received from healthcare staff, family, friends and facilities that the participants had experienced thus far. This theme was made up of 'social support', and a new theme entitled 'experience of healthcare', which is an amalgamation of 'content with cancer specialist hospital', and 'relationships with staff' coding. Lastly, **'coping methods'** referred to activities that participants took part in in order to help them cope with their diagnosis. This was made

up of three codes that featured throughout interview transcripts: 'personal resilience', 'hobbies' and 'distracting oneself'. Lastly, two codes, 'previous cancer experience' and 'non-cancer issues' was added to a temporary miscellaneous category as per guidance (Braun and Clarke 2006).

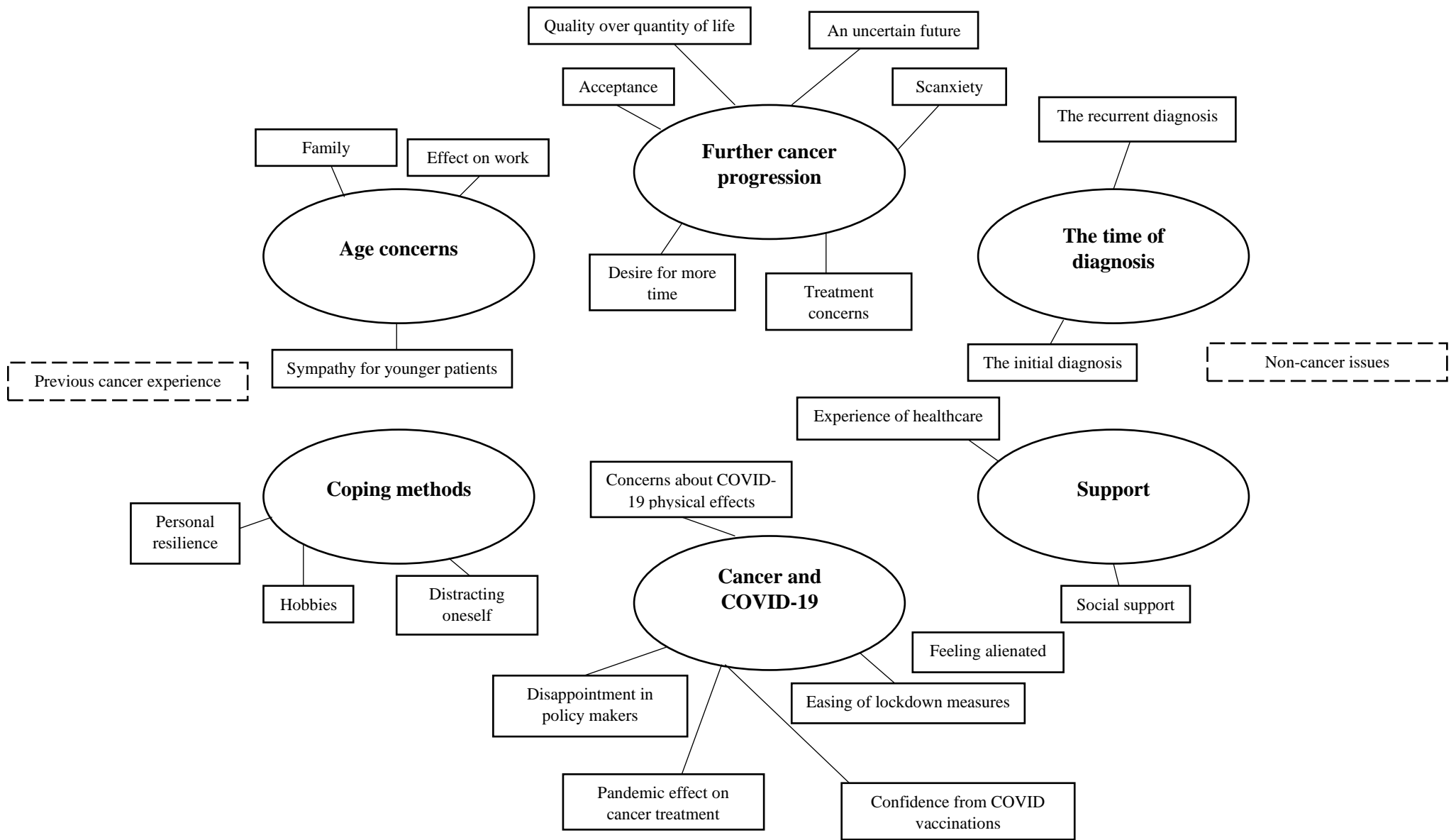For clarity, Figure 9 displays the preliminary themes that were developed at this stage.

Figure 9. Development of preliminary themes

Stage four- reviewing themes

Stage four involved reviewing the preliminary themes. The first step in doing was to have all themes written down in a separate document and a description for each written in order to better define them. A member of my supervisory team and I then looked at the themes and compared them back to the interview transcripts in order to check if the relevant coding supported each theme. Similarities and differences between themes were checked to see if they could be further refined.

'Age concerns' was replaced with a new theme called **'experience across lifespan'**; which was a broader theme that captured patients' insights into differences in the cancer experience due to their experiences in life and various life events. The codes 'non-cancer issues', and 'previous cancer experience' were at this point moved into this theme.

'Managing the impact' was created to combine 'support' and 'coping methods'. This was considered to be an all-encompassing theme that describes different places and people from whom participants drew support and comfort from. A this point it was decided to merge 'hobbies' and 'distracting oneself' into a more succinct code 'distractions', which featured in this theme.

After further review 'the time of diagnosis' and 'further cancer progression' were combined into a new theme **'from recurrence to progression'**, which was judged to describe the experience of patients more succinctly as they described living with a recurrence and facing the threat of further cancer progression.

Stage five- defining and naming themes

This stage of the process is the final refinement of the themes, and is the step in which to define what each theme is about (Braun and Clarke 2006). The definitions of themes can be seen in Table 16, and Figure 10 displays the final themes and displays their component codes.

Stage six- reporting results

This is the final stage of the process in which the writing up of findings occurs. This has been partially conducted above, with details of the generation of codes and themes as well as establishing the basis for interpretation of findings, which shall be discussed next.

Table 16. Summary and definitions of themes

Theme	Definition
From recurrence to progression	Participants described on various feelings they had about the possibility of their cancer progressing further.
Experience across lifespan	The differences in the experience of cancer expressed by participants were often related to their experiences during their life and their current life status.
Managing the impact	Participants expressed a variety of sources that provided them with comfort and support.
Cancer and COVID-19	The COVID-19 pandemic had an impact on the participants, both generally and in relation to their cancer.
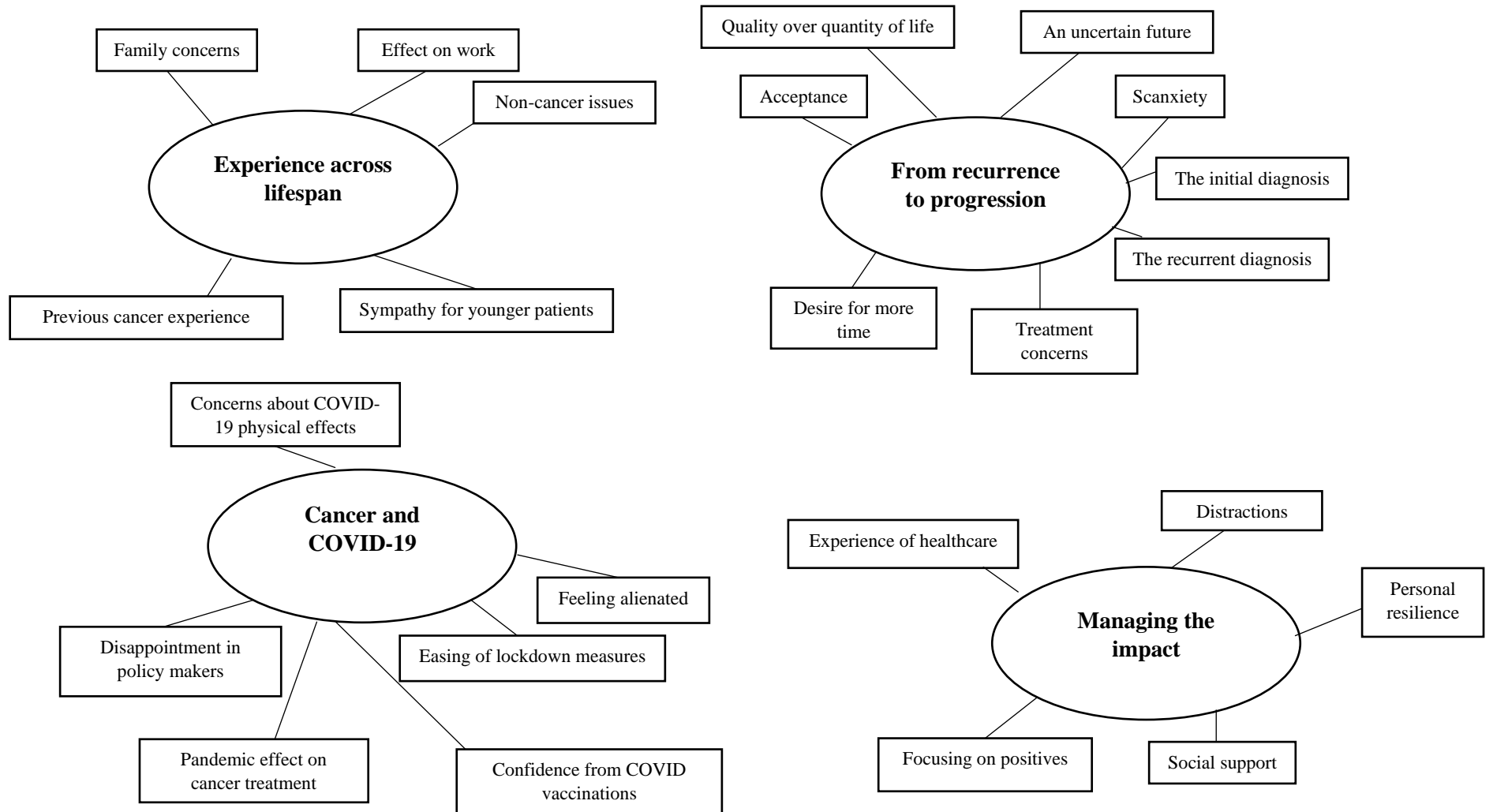
Figure 10. Development of final themes

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5.4 Interpretation of findings

The themes outlined above will now be discussed with interpretation, which will be carefully highlighted by descriptive selections of data from the interview transcripts.

5.4.1 From recurrence to progression

As established, cancer that recurs is typically incurable, and so patients will be aware that they will live with cancer for the rest of their lives and be monitored for signs of further progression. This theme summarised the insights shared by the participants in regard to being diagnosed with cancer, the subsequent recurrence, and facing further progression.

Participants were asked to describe their thoughts about receiving their initial diagnosis of cancer. Several described this as a period of shock and the diagnosis was often unexpected.

> *"You don't expect the really bad news, so basically then things go really fast. You know when the process goes fast that there's something wrong, and I'm whipped into a rapid diagnostic clinic. And for me it was a nightmare … that's how it was diagnosed. So, it was a shock, a terrible shock".* — B3 (55 years old, breast cancer patient).

> *"They told me they found a tumour on my spine and the consultant told me, and I'll never forget this, 'it's hard to predict with any real accuracy but based on the thousands of cases we've dealt with, based on men approximately your age, and your approximate state of advancement of this cancer, you've probably got around six months to live so you'd better make your arrangements', an awful surprise".* — M1 (76 years old, melanoma patient).

When discussing their subsequent recurrent diagnosis some described being surprised once more after being successfully treated.

> *"And then came the shock in February. When suddenly, they said to me, your PSA's gone back up from practically zero the month before".* — P2 (64 years old, prostate cancer patient).

Others described feeling frustrated at receiving the news that their cancer had recurred.

> *"After a year or so, tests showed it had come back and metastasized, which was a terrible shock; actually, rather frustrating, I wasn't upset as such".* —Bl1 *(83 years old, bladder cancer patient).*

> *"It wasn't so much a shock as a frustration, I had been through all of this before and quite frankly couldn't bothered dealing with it again!".* — P3 *(76 years old, prostate cancer patient).*

Conversely, others described their feelings at this time as less of a shock but acknowledged that the diagnosis was now incurable.

> *"But with the recurrence it was definitely less of a shock but more of an acceptance. A sad one, but an acceptance. The staff were again quite kind, but this time felt more realistic I suppose, less hopeful. There were treatment options, so it wasn't total doom and gloom, but I had to accept it was never going to be gone like before".* — B2 *(72 years old, breast cancer patient).*

This acceptance was echoed by several participants who expressed being at peace with their current condition and that further progression will occur.

> *"I know I'm near the end so I suppose I want to maintain a certain quality of life at this point, if it was to go downhill soon then I would rather it didn't take too long. And that's not me being morbid or anything I'm quite relaxed really".* — Bl1 *(83 years old, bladder cancer patient).*

> *"At my latest stage. I've now got to get used to the fact that my PSA is never likely to go down again. Which I'm fine with now to be honest".* — P2 *(64 years old, prostate cancer patient).*

Indeed, some further described focusing on the QoL in the time that they had rather than extending the years they had to live.

"Besides it's the quality I'm more interested in now. As long as I'm enjoying my time, I'm happy". — Bl1 (83 years old, bladder cancer patient)

"I maintain a certain quality of life at this point, and you know I would go a bit mad I think if things got worse from here". — P1 (58 years old, prostate cancer patient).

"So, for me, what's the point of being kept alive if you're going to spend it in an armchair, suffering extreme anxiety? And winding yourself up with trying endless different treatment approaches and spending all your savings". — B3 (55 years old, breast cancer patient).

Though it should be noted that some participants felt that they were living with a great deal of uncertainty in regard to further progression, so found planning ahead difficult.

"I suppose it's more that it's nice to think if things stabilise then maybe it would be possible (travelling to visit family*). It's hard to plan too far ahead, something can always come up". — B1 (40 years old, breast cancer patient).*

"But the other way I find it exceedingly challenging is decision making. I find it very, very difficult to know, like when I was initially diagnosed, they thought I'd be dead very quickly and so I gave up work in order to spend time with my kids and changed my life." — B3 (55 years old, breast cancer patient).

Despite living in a state of relative acceptance, several participants reported feeling anxious in the period before a scan appointment or before receiving subsequent results.

"Yes of course, it is something I think about, particularly nearing scan appointments and whatnot, I've just got to hope that it's kept at bay for a while, but it does enter my mind and I might be a bit tetchy close to the time". — B2 (57 years old, breast cancer patient).

"The only time I worry is probably a couple of days leading up to the scans because the scans will show whether the cancer is expanding, or whether it's contracting, or whether it's stabilised. Because, dependent on the result of that,

you know, I may or may not stay on this trial. So that's really a very critical point every nine weeks". — P4 (80 years old, prostate cancer patient).

The latter participant above described being involved in an ongoing treatment trial, and another finding from the research suggests that participants worried about progression of their cancer affecting their options for treatment.

"I'm quite happy to keep trying new treatments. I hope it doesn't progress so much that I have no other option". — P4 (80 years old, prostate cancer patient).

"As I say I'm more scared of running out of treatment options". — P1 (58 years old, prostate cancer patient).

"I try not to think about it. I know by now I won't be cured but as long as I can keep going with treatments, and you know it doesn't progress so much that it's not possible, I'll just about manage". — B1 (40 years old, bladder cancer patient).

Whilst a degree of acceptance is evident in the interview transcripts in relation to cancer progression, a desire for more time was expressed in some of the younger participants.

"And quite frankly I still feel like I have, or should have at least, plenty of years left". — P1 (58 years old, prostate cancer patient).

"Sometimes I think, you know, that, with the treatment I'm on, I might get a bit better and have a bit more time, that's the best I can hope for really. It's nice to think I can have more time". — B1 (40 years old, breast cancer patient).

5.4.2 Experience across lifespan

This theme highlighted how the participants' experiences with cancer often differed based on their life events and their current status in life, be that due to age, having children, or previous experience of cancer.

A large number of participants were of retirement age, but a younger breast cancer patient noted that she had difficulty with not only being physically able to work, but also with planning ahead and taking on large volumes of work.

"... do I go back to work, do I not go back to work, and if I go back to work do I live the same lifestyle I had before? You know, I used to be manic and do loads of things simultaneously and so, do I want to take that on if I'm going to be dead? What's the point? — B3 (55 years old, breast cancer patient).

The same participant expressed worries about her ability to perform her usual activities for her family, as well as the implications of the diagnosis on her husband and children.

"Yeah, I mean you need support for different needs, like I need a lot of practical support for two young children that needed picking up from school and I was in hospital for hours"… but also it's very difficult for him (her husband) to come to terms with what's happened to me and I think possibly my children, so I think support is needed sometimes more for the rest of your family. Because they're just, you know, helpless observers". — B3 (55 years old, breast cancer patient).

It was common with older participants to express fairly low concerns about their children as they were adults themselves at that stage in their life.

*"The thought (*of the effect on family if they were to pass away) *makes me saddened more than anything, but they are grown up now". — P4 (80 years old, prostate cancer patient).*

"Of course, you would worry about your family but I'm not a young man anymore. You know if you'd asked me that 20-30 years ago my answer would have been different". –M1 (76 years old, melanoma patient).

Relatedly, an interesting finding that emerged was that several of the older participants expressed sympathy for younger patients with cancer in spite of their own condition.

"I suppose it's just; you know I'm in my 70s, I've had a great life- not that I want it to end anytime soon, but someone younger, especially with the recurrence, that must be hard. Again, I'm by no means saying it's easy for me, but I bet 20 years ago I would be much worse, much more distressing". — P3 (76 years old, prostate cancer patient).

"...it's one thing getting this diagnosis after 80, I've been through a lot so maybe it wasn't so bad. You meet younger people sometimes who have it rough with their cancer. I bet if I was younger I'd be more worried". –Bl1 (83 years old, bladder cancer patient).

Participants also described non-cancer physical issues that that have occurred in their life and an uncertainty of attributing symptoms to the cancer recurrence.

"I say to my sister, oh, I do feel tired today and my sister is 66. She said, well, are you surprised I get tired as well?". — P2 (64 years old, prostate cancer patient).

"I suppose I don't really think about how long I have left. I know it's not going to be a long, long time; but would it be anyway? You know, with the age I am anyway. I often wonder if, when I'm feeling a bit run down or what have you, that's probably normal". — Bl1 (83 years old, bladder cancer patient).

Some participants expressed that their previous experience of cancer had alleviated some of their concerns about their current condition.

"I've had a lot of different symptoms and side effects now, so worried probably isn't the word to use anymore, I've had most of them probably". — B2 (57 years old, breast cancer patient).

"Cancer has been around me for a long time and with this more recent recurrence it's not a joyous position to be in, but I'm somewhat used to it and in all honesty. I just put it behind me". — Bl2 (78 years old, bladder cancer patient).

"I was very glad to have avoided chemo for such a long time, and that was something I didn't want to go through at this stage of my life. With how long I've been living with cancer there's no way I would choose to go through anything so severe. I've made peace with that". — M1 (76 years old, melanoma patient).

5.4.3 Managing the impact

This theme was created to capture the sources of comfort and support that participants expressed helped them to cope with their condition. This could be people, places, activities they might do, or indeed their own thought patterns.

Linking somewhat to the acceptance that some displayed about their condition and the threat of future progression of their cancer, some of the participants suggested that they generally knew how to handle adverse life events- displaying a self-perceived resilience.

> *"A few weeks ago, I started on a new treatment and that's basically the current state of play. In terms of how I've dealt with that, as well as the rest of it, you know, pretty well. But I think I've always been quite good at that, at that sort of time when things get rough". — M1 (76 years old, melanoma patient).*

> *"I don't especially get down about things. I'm certainly not sitting around worried sick about things going downhill. That's always been my nature really." — B3 (55 years old, breast cancer patient).*

A degree of sympathy for other patients was described previously, and this was evident again as some participants described feeling fortunate not being on treatments that they perceived as more severe.

> *"And the other thing is I'm not on chemo, but I did really feel sorry for the people on chemo, they must have been absolutely terrified" — B3 (55 years old, breast cancer patient).*

> *"I've been quite lucky I think in terms of treatments, some people I've met along the way have had it much worse than me, you can't help but feel sympathetic, oddly it makes you feel lucky in a way". — M1 (76 years old, melanoma patient).*

Indeed, some described feeling grateful they would probably not be affected by other diseases that they deemed worse than their recurrent cancer.

"However, what I will say on the on the flip side, my father took 15 years to die with dementia. Now I know that that is not likely to happen to me. I have to say, that is a blessing". — P2 (64 years old, prostate cancer patient).

Some participants stated that taking part in activities took their mind of their cancer and helped them to cope with the condition.

"I also volunteer at a museum; I try to make sure that I've got other things, other aspects of my life to think of besides the cancer, and that really, really helps". — P2 (64 years old, prostate cancer patient).

"Well, while you're exercising, you do take your mind off things, but there are proven benefits of exercise in terms of, you know, dealing with the cancer, dealing with the side effects of chemotherapy and there's so much evidence coming out about exercise being part of a potential treatment for not just cancer, but for other diseases as well. So, you know I when I was diagnosed, I said okay, well, how can I help myself? You know, when you look into it as well as the medical treatment, there's three other key areas which are exercise, nutrition, and mental health, which I could control myself. — P1 (58 years old, prostate cancer patient).

Participants often emphasised the importance of social support from their friends and family in helping them cope with their condition.

"I had support from my friends and family. My family isn't here in this country though, they are abroad, but I have a good group of friends here who have been so helpful and supportive." — B1 (40 years old, breast cancer patient).

"In this country I have a wide range of friends no family of course and thanks to the miracle of video calls I speak to my wife and granddaughter who are abroad every night without fail". — M1 (76 years old, melanoma patient).

"You mean in terms of family and friends? Absolutely. Yeah, absolutely, you know without them you just, there's no point in keeping things bottled up because that just makes things worse". — P1 (58 years old, prostate cancer patient).

Further, some felt that relations were enhanced with relatives after their diagnosis.

> *"Well, if you'd spoken to me about 15 years ago, my sister would have been very low on the agenda because we didn't always get along… she does care about me a great deal now.". — P2 (64 years old, prostate cancer patient).*

> *"I've got a great family who are always there for me. Since the diagnosis, they've really rallied around me, and I know if I need anything they will be there". — P1 (58 years old, prostate cancer patient).*

Though some participants stated that they did not want to feel like they were burdening their loved ones.

> *"I certainly don't discuss it very often with my wife and she knows as much as I do, and I don't want to make her unhappy by talking about my health". — Bl2 (78 years old, bladder cancer patient).*

> *"I know my husband used to hate coming with me to appointments, particularly when you sit in a in a side room waiting for the doctor to come in with your results. You know, that's very frightening. And he didn't want to do that. You know, he got traumatised by it after a while". — B3 (55 years old, breast cancer patient).*

Some participants described feeling comforted by coming across other people that were also experiencing cancer.

> *"Generally, I'm very good, but I do go to a hospice, which is now called the well-being centre, two days a week. That always encourages you to feel better because you see how the other people are dealing with it as well". — P2 (64 years old, prostate cancer patient).*

> *"I can recall chatting to others whilst waiting for appointments and whatnot. It can be a bit of a reminder that others are going through it. A bit of camaraderie I suppose". — Bl2 (78 years old, bladder cancer patient).*

However, it should be noted that some did not find spending time with others with similar conditions particularly helpful.

> *"It's not hugely helpful… some people, cancer becomes their entire universe. That's all they'll talk about. And then they'll talk endlessly about, what do you call it, alternative treatments and all these other things and literally they just talk about nothing else. I find that a bit depressing and so I guess it would depend very much on your coping style. I guess my coping style is much more around getting on with life…". — B3 (55 years old, breast cancer patient).*

The dealings had with healthcare staff across the cancer experience was a common talking point. Some described the importance of a positive relationship.

> *"But I know I can talk to the staff at the hospital if I'm a little overwhelmed, if I phone them, they call me back pretty quickly if I need anything. I talked to a counsellor there a while back and thought that was helpful". — B2 (57 years old, breast cancer patient).*

> *"The staff have been great; they really care about me. They call in case I have any side effects or if I'm not feeling well. If I call them and leave a message, they'll call me back within an hour. They've been very, very, very cooperative here". — B1 (40 years old, breast cancer patient).*

Others felt that they had had negative experiences with staff due to poorly perceived communication.

> *"But basically, he stood there looking traumatized himself clutching an MRI scan and then had to say to my husband, 'I'm really sorry, I know we've been sort of telling you all along that it hasn't spread, but actually we now know it has'… and the doctor said it means your wife's going to die, which was very, very blunt. Not a very good way to give people bad news, it's like delivering news with a mallet, isn't it? — B3 (55 years old, breast cancer patient).*

"It was probably the worst experience of my life. The way it was delivered was atrocious. The oncologist basically said to me it was terminal; the way he put it across was really, really dreadful. So obviously we weren't expecting it, and to go from, we were thinking things were relatively okay, to a terminal prognosis is an absolute shock". — P1 (58 years old, prostate cancer patient).

As well as talking about poor communication, participants expressed a desire to be involved in their treatment and have good understanding of the state of their condition.

"I'm never shown anything that I can understand. I'd love it if they could put up a slide and say look this is your cancer this is where it was this is where it is now. We never get that far as they just talk in very general terms about lymph nodes and other technical medical terms… I've said to them 'look exactly what is it and can you show me?'. For example, on the results of a scan, point out exactly what's going on. but that's never actioned. Maybe they don't want to alarm me, maybe they don't have time to bring scans down to consultations. I'm never truly in the picture, let's put it like that." — Bl2 (78 years old, bladder cancer patient).

"The staff were in a huddle which I was excluded from, and at one point I said to them 'I really can't understand what you're saying' and they didn't acknowledge me, that was quite frustrating". — M1 (76 years old, melanoma patient).

Also evident from the interviews was the positive effect of being treated at a cancer specialist hospital.

"We went to see her, and it was an altogether different experience. I said to her, 'is it the right thing we're doing coming to see you?'. And she said, well… 'you know you're at the centre of excellence in cancer research'. So anyway, after nine years, the cancer was still slowly growing. But she had managed to relatively stabilise things and I've had high quality life from that time, it's been great being here really". — P4 (80 years old, prostate cancer patient).

"You know, she was brilliant, and she was glass half full and she's been a lot more optimistic and a lot more proactive in my treatment. So, generally I'm very lucky to be treated where I am". — P1 (58 years old, prostate cancer patient).

"99.9% of my experience with staff has been very, very positive especially at the current hospital I have to say". — M1 (76 years old, melanoma patient).

5.4.4 Cancer and COVID-19

The last theme for this research was developed to highlight how participants had discussed various aspects of the COVID-19 pandemic in relation to their cancer treatment and to their lives more broadly.

A very commonly expressed concern participants had in this regard was to do with the pandemic potentially affecting their ongoing cancer treatment.

"I don't want to risk catching it and missing an appointment". — B1 (40 years old, breast cancer patient).

"I suppose it did worry me at the start. I'm more concerned now about missing my appointments if I were to catch it again, that would be a real pain. But in terms of the illness, no not so much anymore". — P3 (76 years old, prostate cancer patient).

"And there was that initial worry but the staff at the hospital reassured me that treatments would be ongoing, even now the worry is more of inconvenience, if I was to miss an appointment because I had covid, rather than, you know, worrying about physical issues from catching it". — B2 (57 years old, breast cancer patient).

Participants yet again expressed feeling grateful for being treated at a cancer specialist NHS hospital site which had no treatment interruptions due to COVID-19 and was not used for the treatment of COVID-19 infections.

"I think the difference is it's a specialist hospital, isn't it? So, nurses are specialists. They are not overrun with lots of other things. They are skilled in looking after people with cancers. And there's a whole different dynamic about the hospital. So, during COVID, you know, you felt quite privileged to be going to there…". — P4 (80 years old, prostate cancer patient).

Though less common, some participants did express concern about the effect of the virus on their health.

> *"I have been told by my nurse, he said to me one day, 'you do not want to catch COVID'. I do my best not to not to catch it and I'm on the highly vulnerable list. I do PCR tests at home, and should I become ill I would get the antiviral drugs". — P3 (76 years old, prostate cancer patient).*

> *"It is a concern. That's also partly to do with how severe my disease is, and I'm also at very severe risk. So, they are trying to keep a very close eye on me". — B3 (55 years old, breast cancer patient).*

But several participants stated that the greatest fear in this regard was at the beginning of the pandemic, and by the time that they were interviewed they expressed feeling safer due to vaccinations against COVID-19.

> *"But you know we've had all of our vaccines so it's easier now, but not to say I'm throwing caution to the wind, but they give you that confidence you know? So, no I'm not worried anymore". — B2 (57 years old, breast cancer patient).*

> *"My wife and I have both of our vaccinations and boosters which gives us a little bit more confidence to return to a pretty normal life". — Bl2 (78 years old, bladder cancer patient).*

> *"If I catch it, that's not great. But I'm not like so worried about catching it because I haven't caught it in the two years, and I've gotten my shot, and my booster. So no, I'm not really worried". — B1 (40 years old, breast cancer patient).*

Participants also described their feelings related to the easing of lockdown restrictions in the UK. Participants broadly expressed feeling positive about returning to a life that they considered more normal.

"It's been a relief in many ways and a worry in others, very funny, isn't it? That being said I am not in the position I was before covid with the restrictions on my mobility. Best to make the most of it though, I'm blessed that I can see my family again. That was hard at the start of the lockdown, but not an issue now of course" — Bl1 (80 years old, bladder cancer patient).

But several felt that they still had to take extra precautions.

"I know you don't have to, but I just don't want to throw caution to the wind. I'm concerned about it when, like right now the weather is warm, it won't spread as much, but once it gets colder, the colder months, then it spreads. So, I try to minimise my outings to a very basic level, these days it's minimal, really just the hospital". — B1 (40 years old, breast cancer patient).

"I don't take stupid risks and of course I don't go on the trains now where there is a good chance you're going to catch something. But I mean, I went to a conference for two days in Birmingham last week and I came out of it with a cold, but I didn't consciously think oh this is dangerous, I might catch COVID here". — P4 (80 years old, prostate cancer patient).

Some participants felt that, because they were taking extra precautions compared to people not at high risk of health complications, they were looked at negatively by others.

"When it when we first put into lockdown, everyone was in it together. But for people who are now vulnerable, you feel a bit forgotten. Everyone else thinks it's not that big a deal to catch covid now. I feel further away from society than I did when the government was taking it seriously. If you go in a crowded space. You have to make a choice. Do I risk catching it? Do I enjoy what I'm doing or do I not?... I love going to the theatre but now I feel resentful of people who go into theatres. This is probably wrong of me, but I feel resentful of people going to theatres who don't have any issues, who show no consideration for people who may have to be more careful. They don't think about it". — P2 (64 years old, prostate cancer patient).

"When I was stable enough, I would go out to events, even feeling a little silly to be honest sometimes, I still put my mask on and everything". — B1 (40 years old, breast cancer patient).

Some participants expressed disappointment and frustration with policy makers at government level in relation to the easing of pandemic restrictions.

"One thing that bugged me, I must just say quickly, is that at times during the pandemic I've felt a bit kind of left out and when I say that I mean that some people, even our leaders didn't seem to care that some of us remained vulnerable and maybe, I don't know, I just felt a little forgotten". — P3 (76 years old, prostate cancer patient).

"Not to get political but stopping the free tests is the biggest mistake they have ever made. And I don't blame anyone for this. If it's their choice of feeding and clothing or kids, or paying out for tests what would any sensible person do?... one of the most frustrating things in my in my life in general is that the government seems to have little direction. Well, our current one does anyway. I find for long term planning you never know what they're going to think of next". — P2 (64 years old, prostate cancer patient).

5.5 Quality in qualitative research

Some processes in which the credibility and reliability of qualitative research can be improved were discussed briefly in Chapter 3, but it is useful at this point to have a discussion on how this can be done in relation to the above interpretation of the findings. There is considerable debate in the literature regarding how this is best done.

Reflexivity has of course been outlined already and is an ongoing process throughout this research project. It is thought to be helpful in improving methodological rigour, and therefore produce more trustworthy results (Rettke et al. 2018). Triangulation of qualitative methods (i.e., using two different qualitative methods) has been suggested (Mays and Pope 2000). Whilst this did not take place in this research, triangulation of quantitative and qualitative methods took place, and is thought to improve validity of the overall combined findings that emerge (Moon 2019). It is also recommended to include

detailed verbatim quotes and to seek out similarities and differences between participants' transcripts accounts to represent the variety of discussion points (Noble and Smith 2015), both of which have been detailed in this chapter.

There are some techniques that could have been used. Working with other researchers to reduce bias is recommended in qualitative research (Noble and Smith 2015), and the manner in which a member of my supervisory team checked the thematic analysis carried out is described. However, it would have been preferential to have had another researcher code the data separately and have inter-rater reliability calculated (Roberts et al. 2019). But the time constraints of the PhD project meant this was not feasible. Another method is respondent validation, in which research participants are asked to look at data (such as an interview transcript) to assess their accuracy and test credibility (Torrance 2012). This was deemed unsuitable for this research due to the demands required of the participant, and instead great care was taken to accurately capture participants' interview data.

5.6 Chapter Summary

Analysis of the transcripts of participants' interviews afforded interesting insights into their feelings after a recurrence of their cancer; and four themes were identified to summarise these. The first of these, and addressing the primary research objective of this project, *from recurrence to progression* described the feelings that participants had in relation to living with a recurrence through to the possibility of their cancer progressing further. Participants talked of their initial diagnosis, which was often described as unexpected and a shock to them. They also discussed their recurrent diagnosis, in which some again felt shocked or frustrated at this news after successful treatment of their cancer. Several participants did express an acceptance of their current health status, and that progression would occur. Some described focusing on their QoL rather than thinking of how long they may have left, but on the other hand there were some who did express a desire for more time. A particularly common finding was an increase in fears in the time preceding a scan, or when awaiting scan or test results. Further, several expressed concern in running out of treatments due to progression of their cancer, meaning that their current health status would not continue to be prolonged. Some participants described difficulty with planning ahead due the uncertainty associated with a condition that could worsen at any time.

The second theme *experience across lifespan* illuminated the ways in which participants' experiences differ with cancer based on their life events. Many participants were of retirement age, but a younger breast cancer patient described difficulties around work because of the diagnosis. Having a young family meant that the same participant was concerned their condition would make it hard to perform typical family activities. Several older participants were less concerned about family as they had grown up, rather than young children. Further, some of the older participants expressed sympathy for younger people living with a cancer recurrence. Some participants described an uncertainty of whether the cancer and treatment were responsible for some of their symptoms, or if they were simply related to normal ageing. Another interesting finding was that some participants felt that their previous experiences with cancer alleviated some of the concern they might have had otherwise, perhaps suggesting a certain benefit in the removal of some unknowns in cancer treatment.

The third theme *managing the impact* highlighted the sources of comfort and support that participants described during their interviews, that helped them to cope with their diagnosis. Some participants described focusing on what they considered the positives, such as not being on treatments that they perceived as more severe, or indeed not having another disease that they considered to be worse than their cancer. Some participants described having hobbies that helped them to cope with the condition. Social support was a regular talking point, and its importance was often highlighted. Some even thought their family relationships improved after their diagnosis, but others described not wanting to burden their loved ones because of their condition. Some found support from peers, but this was not always helpful for others. Relationships with healthcare staff was another important issue, and a positive relationship was considered to be beneficial to participants, whilst they remembered negative experiences, particularly in relation to poor communication. This was further emphasised with participants expressing a desire to be involved in the decision making about their treatment. Participants were particularly pleased to be treated at a specialist cancer treatment hospital, expressing positive emotions towards the staff and treatment options available to them.

The final theme was *cancer and COVID-19,* in which participants described a variety of issues related to the COVID-19 pandemic. Some participants expressed concern at the potentially severe effects of the disease, but a prevalent finding was that participants were worried about catching it and then having to miss their ongoing cancer treatment as

a result. Subsequently, participants again felt positive at being treated at a cancer specialist hospital site which continued treatment throughout the pandemic and was not used for the treatment of COVID-19 patients. Several participants felt confidence from being vaccinated against the disease and were no longer unduly concerned about catching it, though acknowledging that they still took extra precautions; and taking extra precautions did lead some participants to feel stigmatised by others in society who were not at high risk of severe consequences. Several expressed feeling broadly positive about lockdown restrictions ending, but some disagreed with UK Government policies related to the easing of restrictions, and expressed their frustration.

Chapter Six: Integration of quantitative and qualitative results

6.1 Introduction

The manner in which findings have been handled in this project has been outlined previously, but to briefly reiterate, quantitative and qualitative data were analysed independently before they were brought together, which this chapter will lay out. This will allow for the overall interpretation of project findings and then a discussion of wider implications of the research will follow (Fetters et al. 2013).

6.2 Integration of findings

As described in section 3.2.4 of this thesis, integration was conducted at the interpretation and reporting level through *integrating through narrative*, and a *joint display* (Fetters et al. 2013). In short, the former refers to a description of the manner in which results integrate, and the latter describes a table or figure (in this case a table) that displays the links between the quantitative and qualitative components of the study in order for associations to be compared (Skamagki et al. 2022). These can be done in different manners, but for this project an integrated visual display was used, which displays quantitative and qualitative findings next to each other (McCrudden et al. 2021).

Firstly, associations were looked for in relation to the two components. Consideration was given to the key themes that emerged from the qualitative data analysis, *from recurrence to progression, experience across lifespan, managing the impact,* and *cancer and COVID-19,* as well as the quantitative measures employed in the first phase of the study. With the use of the integrated visual display, the quantitative findings were compared to these themes.

When evaluating the integration of both components there are terms which are useful: *convergence* refers to agreement between the quantitative and qualitative findings; *expansion* is when findings have similarities but scope for deeper understanding emerge, *complementarity* is when differing but compatible findings are found; and *divergence* refers to the two components contradicting each other (Skamagki et al. 2022). As can be seen in Table 17, the integration of results was judged to provide expansion to each of the main topics.

Table 17. Integration of quantitative and qualitative findings

Subject	Quantitative results	Qualitative results	Integration
Fear of cancer progression	Moderate FOP was present in the sample, and almost half of participants reached dysfunctional levels. Top three highest scoring questions on the FOP-Q-SF were 'worrying what will become of family if something happens to me, 'being afraid of disease progression; and 'being nervous prior to doctor's appointments or periodic examinations'. Three lowest scoring questions were 'being afraid of not being able to work anymore, 'being afraid of pain' and 'being afraid of relying on strangers for activities of daily living'.	*"I know by now I won't be cured but as long as I can keep going with treatments, and you know it doesn't progress so much that it's not possible I'll just about manage". — B1 (breast cancer patient).* *"Yes of course, it is something I think about, particularly nearing scan appointments and whatnot, I've just got to hope that it's kept at bay for a while, but it does enter my mind and I might be a bit tetchy close to the time". — B2 (breast cancer patient).* *"I certainly don't discuss it very often with my wife and she knows as much as I do, and I don't want to make her unhappy by talking about my health". — Bl2 (bladder cancer patient).*	**Expansion** Qualitative and quantitative findings converge on a general level with FOP expressed throughout both phases. A degree of convergence was also found when comparing individual questions from the questionnaire to the interview transcripts. Expansion resulted from further discussion that was possible from the interviews. For example, more nuanced answers were given in regard to the timing of fear levels.
Psychological concerns	On average, participants scored between 4.67-5.41 on the depression subscale of the HAD throughout the study, which falls within the 'normal' score of 0-7. For the anxiety subscale mean scores ranged between 6.16-7.37 throughout the study, indicating at its peak level, the average score exceeded the 'normal' score of 0-7, and be classed as having 'mild' levels of anxiety. EQ-5D-5L indicated mild levels of anxiety and depression.	*"The only time I worry is probably a couple of days leading up to the scans". — P4 (prostate cancer patient).* *"No in all honesty I keep things to the back of my mind and don't worry about it I can still do most things I like and if I can't then there's no point worrying about it so equally there is*	**Expansion** Both components of the study complement each other in the sense that when talking about day-to-day life many participants were not very anxious or depressed. Again, qualitative findings allowed for more discussion on how these levels may

		no point in anticipating it". — *M1 (melanoma patient).* *"And so, when something happens to you and you think to yourself, this isn't good. You then have to reset your focus and saying, well, I'm here now. So what do I do about it? To get through it?".* — *P2 (prostate cancer patient).*	vary, e.g., giving more insight into coping methods.
Health-related quality of life	On average, mobility scores, usual activities, and pain/discomfort ranged between a score of 2-3, indicating slight to moderate problems. Self-care was rated as 1 throughout, suggesting no problems, on average.	*"I did like to go walking with my friends and just kind of socialise, but truth be told I don't have the energy these days with the treatment, that's a little frustrating, I did like that".* — *Bl1 (bladder cancer patient).* *"The previous time I was on chemotherapy I was able to run and cycle and I was really, really quite active. But this time because I've got tumours around the base of my skull, they recommended that I didn't do anything too active."* — *P1 (prostate cancer patient).* *"At the moment it's been, a little down because of a new growth that's affected my stability and making me quite dizzy".* — *B1(breast cancer patient).*	**Expansion** Both sets of findings support each other; not every participant expressed issues in their health-related QoL, but others did, and primarily in relation to their comfort and ability to perform usual activities. Interviews allowed participants to go into more detail than was possible with just the questionnaire, providing more comprehensive answers and greater insight.

| COVID-19 pandemic | Mean scores on the CCAS ranged from 7.16-8.42 out of a possible 20, indicating that fears related to cancer and COVID-19 were generally low. | *"I suppose it did worry me at the start. I'm more concerned now about missing my appointments if I were to catch it again, that would be a real pain. But in terms of the illness, no not so much anymore". — P3 (prostate cancer patient).*

"But you know we've had all of our vaccines so it's easier now, but not to say I'm throwing caution to the wind, but they give you that confidence you know? So, no I'm not worried anymore". — B2 (breast cancer patient).

"You know, I was. I'm just now, if I catch it, that's not great. But I'm not like so worried about catching it because I haven't caught it in the two years, and I've gotten my shot, and my booster. So no, I'm not really worried". — B1 (breast cancer patient). | **Expansion**

Quantitative findings suggest a generally low level of fear. This is supported by the qualitative data, which indicates participants were not unduly worried about the pandemic at the time of interviewing. However once again, qualitative data illuminated responses in a more detailed manner (e.g., much of the concern about having COVID-19 was in relation to missing a subsequent hospital appointment). |

6.3 Interpretation of integrated results

The integration conducted suggests that generally, the qualitative findings expand on those derived from the questionnaire used during the quantitative phase. The quantitative evidence that participants had, on average, moderate fears about their recurrent cancer progressing from its current state is supported by qualitative data, which indicates a varying level across participants, but with more nuanced answers regarding particular aspects of concern. This was also the case for other psychological concerns in which, anxiety and depression levels were generally low when measured quantitatively, and interviews again allowed for more discussion on how these levels may vary than is captured by solely quantitative measures. Quantitative measures of health-related QoL suggested problems with pain and discomfort and the ability to perform usual activities. This was a common finding in interviews, and once again this qualitative phase allowed for more detail on these problems. Lastly, issues around the COVID-19 pandemic were consistent across the study components but, as before, interview data allowed for more in-depth understanding of these issues than would have been possible solely with the questionnaire. Quantitative and qualitative findings both suggest a generally low level of pandemic-related fears and the interviews illuminated answers in a more detailed manner and allowed for discussion of participants' concerns.

Whilst aspects of the quantitative data were expanded upon with the qualitative findings, it should be noted that some insights were captured by the interviews that did not feature in the questionnaire responses. These were not necessarily part of the original research objectives of the study, but topics that were judged to have meaning for the participants and constituted some of the major themes developed during thematic analysis. Some of the qualitative data that led to the development of the *managing the impact* theme does not tie in explicitly to the quantitative findings. Rather, these findings arose organically from further discussion of topics related to the questionnaire components. To give an example, the FOP-Q-SF has an item regarding relying on strangers for daily activities, as well as a question about worrying about family members. This evolved into a broad interview discussion point about social support. This discussion was subsequently coded into the aforementioned theme, which also included viewpoints about the role of healthcare staff (which was not asked about in detail via the questionnaire).

Another important finding that arose from the interview data was the notion that life experience appeared to affect the thought patterns of participants in relation to their

recurrent cancer. As described earlier, the questionnaire measured FOP but did not capture the nuanced answers given in interview. To use the example given above of the question in the FOP-Q-SF that asks participants about family concerns; some participants had young families, which is a different concern to having grown up children. Whilst both are a point of concern, without interview this subtlety would not have been captured.

These are an example of *complementarity,* as the quantitative measures did not explicitly capture these aspects of the patient experience but did not contradict the qualitative findings, but rather elaborated on related issues. Thus, both the *expansion* and *complementarity* identified between the two components of the research suggest that the mixed methods approach taken in this project is supported.

7.1 Introduction

The purpose of this chapter is to summarise the findings of the PhD project in relation to the research questions and wider FCR/FOP literature. In addition, the implications of these findings will be discussed in connection to future research and clinical suggestions. The strengths and limitations of the project will be described before conclusions are drawn. The broad scope of this project was to focus on patients who have, after treatment with curative intent, had a recurrence of their cancer, aiming to explore levels of FOP present in this population. The study that was conducted sought to address the following research questions:

1. To what extent do patients with recurrent cancer have fear about disease progression?
2. What level of quality of life and psychological well-being do these patients have?
3. Are certain factors (e.g. cancer type, age) linked to greater fears and poorer quality of life?
4. Can we gain preliminary understanding of any potential interventions that may help this population to reduce levels of fear?
5. Do these patients have fears related to the COVID-19 pandemic in relation to their usual care?

7.2 Summary of thesis

After introducing the broad topic of cancer recurrence in Chapter 1, a systematic literature review was conducted in order to explore the relevant literature and identify research gaps (see Chapter 2). Findings from this review suggested that patients with a recurrence of their cancer face a plethora of issues that affect their QoL. This review sought to clarify an often complex time by grouping these issues into clear categories. Importantly, it was identified that worries related to the progression of cancer are not routinely captured in QoL research after a recurrence has occurred. The theoretical underpinnings of FCR/FCP research were then outlined in order to provide potential explanations of how the phenomenon occurs and to further establish the setting for the current research project.

Next, in Chapter 3 this thesis described the development and relevant considerations of the research study before Chapter 4 outlined the quantitative findings and Chapter 5 the qualitative. Chapter 6 described the integration of these two components. Below, findings are described and interpretation provided, alongside contextualisation within past research. The primary findings related to FOP, but the secondary results are described first in order to set the context in which results should be read, and allow for deeper discussion of the main results.

7.3 Psychological concerns

FOP is known to be a distinct psychological concern in itself (Yang et al. 2022) and the examination of anxiety and depression in this study revealed that on average, participants displayed low levels of depression, and anxiety levels peaked at a higher but mild level. Corroborating this, when measured again with the EQ-5D-5L, anxiety and depression levels were classified as 'slight' in the study population, on average. To link to the wider literature, previous research is conflicted; anxiety and depression have been found to be fairly prevalent in patients with cancer in general (Khalil et al. 2016, Nikbakhsh et al. 2014), though in the recurrent cancer literature mixed findings have been reported, at times these factors are scored highly, but sometimes research has found fairly low levels in this population (Stewart et al. 2021); and so the findings from the current research in this regard are not contradictory to the wider literature.

In the current study, statistical analysis suggested that anxiety, but not depression was predicted by age, meaning that younger age in participants was correlated with higher levels of anxiety. This is a common finding in the literature with patients with cancer (Inhestern et al. 2017) in spite of often poorer prognosis and comorbidities in older adults with cancer (Hinz et al. 2019, Weiss Wiesel et al. 2015). This is supported within the qualitative data from the current study which suggested greater work and family demands in some younger participants, which may plausibly manifest as higher levels of anxiety for some. In addition, a meta-analysis (Zhang et al. 2022) examining research with older patients with cancer revealed a bidirectional relationship between anxiety and depression, which is common in a wide range of populations, not just patients with cancer (Jacobson and Newman 2017). In other words, the presence of anxiety may indicate future problems with depression and vice versa. So, while depression was not a common issue in the current research, in practice this should be carefully monitored for because of its links to anxiety, which was found to be a present in the study population.

7.4 Health-related quality of life

In regard to health-related QoL, the most commonly reported problems were associated with mobility, the ability to perform usual activities, and pain and discomfort, which were rated at the slight to moderate problem level, on average. The ages, cancer characteristics, and treatments differed between participants and thus, physical symptoms and side effects are likely to have varied between those in the study, which are likely to reflect on the self-reported scores given for the EQ-5D-5L. There are caveats with self-reported measures that will be discussed later in this chapter, but another potential issue is with the nature of the question asked in regard to the lowest scoring of the EQ-5D-5L dimensions, namely self-care. It may genuinely be the case that participants did not have any problems with washing or dressing themselves, but previous research with patients with cancer using the EQ-5D-5L suggests that the number of patients who report problems with self-care varies (two examples are provided, one of 20% and one of 49% of their respective samples) (Borchert et al. 2020, Huang et al. 2018). It is worthy of consideration that this may have been perceived to be a more sensitive topic than the other questions, and thus less likely to be scored negatively (Gnambs and Kaspar 2015).

Nonetheless, cancer recurrence has previously been identified as having a negative impact on health-related QoL and as is well established, FCR/FOP is associated with poorer QoL (Simard et al. 2013). Despite this the current research found no significant correlation between any of the health-related QoL dimensions and FOP scores. Though this may be an interesting finding for the post-recurrence population, this may also be due to the smaller than desired sample size (see section 7.8 for further discussion of the limitations of this research), which can result in some difficulty in inferring results from correlational statistical analysis (May and Looney 2020).

7.5 Cancer and COVID-19 concerns

The implications of the COVID-19 pandemic are a particularly important consideration for patients with cancer as their immune systems are often suppressed because of their disease or treatment, and are therefore more at risk of infection and adverse complications than the general population (Al-Quteimat and Amer 2020). Indeed, at the beginning of the pandemic, those who were more at risk were identified and targeted for early isolation- otherwise known as shielding (Vaid et al. 2021). However, findings that emerge from this study suggest that in general, patients with recurrent cancer did not

worry about COVID-19 and its impact on their cancer and care to a significant level. Whilst this is, of course, a fairly recent phenomenon, research supports this finding in the UK (Hulbert-Williams et al. 2021), which suggests that the onset of the pandemic did not significantly impact on QoL and psychological distress in patients with cancer. There are some important points to consider when examining these findings. It is necessary to remember this is within a UK context, wherein healthcare is at a more developed standard than some places in the world, and vaccination against COVID-19 has been prevalent, being particularly targeted at those most vulnerable to negative health consequences of contracting the disease (Mathieu et al. 2021). Another point to consider is that the nature of the pandemic changed drastically over the period in which this research took place. Indeed, other research suggests that fears related to catching the virus were reasonably high at the beginning of the pandemic when routine vaccination was not available (Leach et al. 2021).

When interviewed a common finding was that participants were not terribly worried about the pandemic as they were being treated at a cancer specialist hospital which had kept treatments running throughout the pandemic and did not treat COVID-19 in their wards. Additionally, participants often expressed that if they were to worry about the disease it would be in the event that they had to miss their regular oncology appointment due to having caught the virus. This relates to the available literature, where patients with cancer have communicated a negative effect on the availability of their treatment due to the pandemic more often than concerns about the potential negative medical consequences (Dhada et al. 2021, Hulbert-Williams et al. 2021).

The probability of catching the virus can be avoided to a certain degree by taking precautions such as diligent hand washing, the wearing of face masks, or by avoiding social interactions (Clark et al. 2020). However, as national virus suppression measures eased over time, some participants described continuing to follow more diligent precautions, which led to feeling 'different' from the general public whom they perceived to have stopped employing the same level of caution more freely. Further, some described feeling frustrated at national policy makers for their decision making in terms of easing lockdown restrictions. Additional research could explore the feelings of immunosuppressed patients in regard to the easing of lockdown measures, and indeed into the factors specific to them during the course of the pandemic (such as the requirement for shielding).

These findings suggest that great care and sensitivity should be taken regarding precautionary advice to patients with cancer undergoing treatment, and this could be tailored to the individual, who should be given space to express any relevant feelings. As alluded to previously, this study took place over several months in the pandemic, which was a fluid situation with restrictions and guidance changing over time in relation to waves of the virus. This was particularly pertinent during the first phase of the research as restrictions were in place to varying degrees, and so results should be read with that caveat. By the time of the semi-structured interviews (April-October 2022) virus control measures were minimal (Smith et al. 2022), and participants had also been eligible to be fully vaccinated against the illness (though vaccination status was not captured, all who were interviewed freely described being fully vaccinated); indeed, several participants expressed confidence in resuming life as it was pre-pandemic due to this.

7.6 Fear of progression in patients with recurrent cancer

As detailed throughout this thesis, the primary aim of the research study in this project was to examine the levels of FOP that are present in patients after a recurrence of their cancer. Below, the relevant findings are summarised and related to previous research. Thought is also given to the trajectory of fear levels over the course of the longitudinal study and potential determinants of fear before discussion of this project's contribution to the wider theoretical assumptions of FCR/FOP research.

The findings in this project indicate that patients with recurrent cancer have moderate FOP, with almost half of the study sample (46%) reaching dysfunctional levels when these fear levels peaked. Integrated findings from the mixed methods approach undertaken in this research suggest that some consequences of cancer progression concern participants more than others, and it is possible to identify these, based partially on the quantitative findings and in more depth in the qualitative phase.

Comparing levels of FOP in cancer groups in previous research is challenging as different definitions of what constitutes dysfunctional FOP have been applied in the past (Dinkel and Herschbach 2017). Linking with the current research, studies which also used the FOP-Q-SF have found a range of results. The 46% which reached dysfunctional levels in the current research compared to 68% in a breast cancer study (Niu et al. 2019), 17% in a mixed cancer sample (Hinz et al. 2015), 33% in patients with melanoma (Wagner et al. 2018), and 47% in a population with gynaecological cancers (Myers et al.

2013). To compare to recurrent cancer populations, it has been discussed throughout this thesis that FOP is not usually explicitly measured in recurrent cancer groups, though the minimal research conducted thus far suggests that levels of FOP are higher after a recurrence than in non-recurrent patients, and similar to levels of FOP present in those with a metastasis (Shim 2010). It should be noted that the authors use a different outcome measure than in the current research and there is no mention of how many of their participants would be classed as having dysfunctional levels in their published work. As such it is difficult to place the current findings among the existing literature, other than to say they fall within the range of previously reported levels of FOP in a variety of cancer patient populations. Caveats to this interpretation are given later in this chapter.

7.6.1 Trajectory of fear of progression

The next consideration is the longitudinal aspect of the research. An important and novel finding from this research is that the statistical analysis conducted indicates that levels of FOP remained stable over the course of three months. The research emanating from this project is a first but important step in establishing the understanding of the trajectory of FOP after recurrence has occurred and suggests that if a patient scores highly for FOP at one data point, then they are likely to continue to score highly- though it would be useful to examine longer periods of time. In the wider literature, evidence suggests that patients with a primary diagnosis of cancer also have fairly stable levels of FCR/FOP up to two years after baseline assessment (Crist and Grunfeld 2013). More recent research confirms this is still the case, even for more advanced cancers (Butow et al. 2021).

Previous research has suggested that where FCR/FOP may fluctuate is in relation to positive treatment outcomes (Simard et al. 2013). Accordingly, an examination of FCR in breast cancer survivors measured the fear levels of participants in the time around mammogram appointments. This revealed that FCR levels were raised before and after mammograms but lowered after favourable test results (McGinty et al. 2016). This is an interesting finding in relation to the current research project, as participants expressed FOP in the time prior to a doctor's appointment or examination. Adverse psychological reactions at this time have been studied extensively in recent years, and is a concept colloquially referred to as 'scanxiety'; the worry emerging in the time before, during and after cancer-related scans (Derry-Vick et al. 2023). To the researcher's knowledge, this phenomenon has not been specifically examined in patients with cancer recurrence, but has been found to be a prevalent issue in those with advanced cancers generally (Bui et

al. 2022), and so current results are in alignment with the available literature whilst also contributing novel findings.

Interestingly, despite the level of FOP present in the sample, several participants expressed a certain degree of acceptance at their prognosis of an incurable diagnosis, but with a desire to continue treatments that would increase their lifespan and allow them to maintain a certain QoL. Taken together this suggests that despite accepting the reality of having an incurable diagnosis, many of the participants still wished to avoid further progression which a medical appointment may reveal. As can be seen even from the current participants, recurrence can last for very different periods of time depending on the nature of the cancer, and the findings from this research suggest that patients with recurrent cancer are likely to be interested in maintaining their ongoing well-being.

7.7 Determinants of measured outcomes

Clinical Variables

The statistical analyses indicated that the measured demographic and clinical variables of participants in this study did not predict FOP levels, though fear levels were significantly associated with both anxiety and depression. To compare to the wider literature, in two systematic reviews of FCR/FOP quantitative research, Simard et al. (2013) and Crist and Grunfeld (2013) also found that anxiety and depression were associated with higher levels of FCR/FOP. Time since recurrence has of course not been examined in patients pre-recurrence, but there is mixed evidence and often contradictory findings from past literature about the role of clinical variables including time since diagnosis, cancer type, and stage of the disease in relation to levels of FCR/FOP (Bergerot et al. 2022), though symptom severity and treatment factors are typically linked to higher fear levels (Simard et al. 2013). Therefore, it is somewhat challenging to compare the current study to previous research as several clinical variables were not measured; however, findings do not diverge drastically from the literature in this regard, and these additional factors could be considered in future research in patients after a recurrence.

Demographic variables

Of the variables captured in the current research, the aforementioned systematic reviews had evidence to suggest that higher FCR/FOP levels were strongly correlated with those of a lower age, and also for those who have young children (Crist and Grunfeld 2013;

Simard et al. 2013). Despite the findings from the statistical analysis in the current research this is an interesting consideration. Whilst this was not measured in detail quantitatively, it should be noted that 'worrying what will become of family if something happens to me' was the highest scoring response on the FOP-Q-SF on average). In the qualitative phase of the research, those with young children expressed concerns including their caregiving commitments and the emotional toll placed on a young family. Perhaps with a larger sample size (in line with much of the previous research) (Simard et al. 2013), age differences in FOP levels may have been evident in the quantitative phase of the current research.

Much like the clinical variables there are several demographic factors which were not examined in the current research that may predict levels of FCR/FOP, though again findings are somewhat contradictory in previous research (Crist and Grunfeld 2013; Simard et al. 2013). Despite this, there is moderate evidence that educational attainment is linked to higher FCR/FOP, but associations to other demographic factors remain inconsistent but have not been studied extensively in the past and so require further research (Bergerot et al. 2022).

Supportive factors

In this research project one of the qualitative themes that emerged encompassed some of the ways in which participants drew on support and comfort from in order to cope with their condition and the threat of further progression. Social support was highlighted by several as an important factor in their ongoing well-being and this is a common finding in the wider literature. Previous research suggests that social support is significantly associated with greater well-being and positive mood in patients with cancer (Usta 2012). There is also a growing suggestion that lower levels of FCR/FOP are linked to greater perceived social support (Koch-Gallenkamp et al. 2016, Lu et al. 2023, Mehnert et al. 2013), though this remains inconsistent (Crist and Grunfeld 2013). A more thorough examination of the role of social support on FOP levels in the time after a cancer recurrence would be useful in future research.

In the wider cancer literature, it is suggested that a good professional relationship and communication levels between patients and healthcare staff has positive consequences on the mental well-being and even some clinical outcomes of the patients (Rodin et al. 2009). In the current study, during interview several participants expressed an

importance on the relationships they had with healthcare staff; some described feeling let down at various times in their cancer journey, and others described positive experiences throughout, and this mixed result is with precedent in the literature (Stewart et al. 2021). Interestingly, there is evidence to suggest that patients with advanced cancers are often less satisfied with healthcare professionals (Alessy et al. 2022), and dissatisfaction with healthcare staff has been linked to higher levels of FCR/FOP before recurrence occurs (Anderson et al. 2021). So, in-depth measurement of satisfaction levels in patients after a recurrence would be of benefit to complement current findings.

Participants valued clear communication, and some also expressed a desire to be involved in their treatment decisions. As stated earlier in this thesis, patient involvement in their care is increasingly recommended in practice, and achieving a balance between the patient's input into decision making and the expert opinion of the medical staff is important (Løwe et al. 2021). A method of ensuring this is to provide clear communication by tailoring the information used to the patient, using understandable language, and the appropriate use of statistics that will aid in decision making (Freeman 2019). An interesting finding was the satisfaction participants reported with the cancer specialist hospital site which hosted the study, which at times contrasted with the disappointment some felt with other NHS facilities they used previously. This is perhaps to be expected; cancer patient satisfaction has been recorded as higher in hospitals with more cancer specialist staff and for those diagnosed through screening programmes rather than through primary care appointments (Alessy et al. 2022).

Coping strategies and resilience

Another consideration that arises from the current findings is that of individual coping strategies and resilience in relation to dealing with both the recurrence and the threat of further progression of cancer. Several participants described different ways in which they coped with their condition, and this ties in to previous research; a systematic review (Seiler and Jenewein 2019) summarised that patients with cancer who used adaptive coping strategies (those thought to be positive, such as counselling or good health behaviours) expressed greater QoL and lower levels of distress than those who used maladaptive coping strategies (methods that may provide short-term relief but longer term issues, such as alcohol abuse), or those who utilised avoidant coping methods (avoiding dealing with adverse events). Coping responses have also been identified as an important predictor of FCR (Crist and Grunfeld 2013), and so capturing the coping

methods used by participants in this study in a more systematic manner would have allowed for comparison to FOP scores after recurrence.

In patients with cancer, coping is considered to be an important aspect of resilience, which refers to the capacity of an individual to sustain or recover their psychological state to a stable level after troublesome life events (Seiler and Jenewein 2019). Resilience in the face of such stressors is thought to be determined by several factors including an individual's optimism, self-esteem, and the ability to adapt one's thoughts and behaviours; it is thought to be innate but can be strengthened through appropriate psychosocial intervention (Grafton et al. 2010, Ludolph et al. 2019). This was not measured explicitly in the quantitative phase of this research, but during interview several participants described generally dealing with the cancer recurrence fairly well, with some expressing a long-held ability to cope with adverse events in life. Personality factors are important in determining resilience, but research suggests that the perceived support levels experienced are also a significant consideration, relating back to the earlier findings of this research (Seiler and Jenewein 2019).

To summarise all of the points made above, it may be the case that FOP after a recurrence of cancer is similar to FCR/FOP before a recurrence takes place, with potential determinants all playing a role in the levels experienced by an individual. Despite statistical analysis within the current study suggesting that age, gender, and time since recurrence did not predict fear levels, it is worth remembering the lower than desired sample size in this interpretation, alongside the more nuanced discussion points from the semi-structured interviews that constituted the second phase of the current research.

7.8 Limitations

At this point it is necessary to describe the limitations of the current research, some of which has been alluded to already. Firstly, the quantitative phase of the research was intended to recruit more participants; the reasons behind this have been outlined previously in this thesis, but there were time constraints on the recruitment period that are standard to many PhD projects, exacerbated by continuing issues arising from the COVID-19 pandemic.

The retention rate of participants in the quantitative phase of the research was generally good, with 88% of participants completing all three data collection points. This is above

average for longitudinal research, though naturally a smaller sample size should be taken into account as this number is easier to skew than with larger studies (Teague et al. 2018). Of the patients approached to take part in this study 72.7% agreed to partake. See section 3.4.3 for more details on patient recruitment, but all of those approached expressed interest to a member of staff at their hospital site. A number of patients subsequently not replying to further approach from the research team leads to an increased risk of non-response bias, which means that results are less generalisable; it is possible that there is a key factor that is common in non-responders that is not captured by the research (Meterko et al. 2015). However the response rate of the current research exceeds generally acceptable rates (Fincham 2008), and assuming the reasoning for non-response would be subject to speculation. However, the possibility that the sensitive nature of the topic discouraged some patients from taking part cannot be entirely discounted (Scott et al. 2011).

A smaller sample size in this case does not mean that the current results are redundant, indeed the recruited participant numbers are within the range of quantitative research featuring patients with recurrent cancer (Stewart et al. 2021), and the sample size for the qualitative phase is also within range of previous similar research (Almeida et al. 2019). However, a smaller sample size does mean that some caution should be taken when interpretating results as it may be more difficult to extrapolate results to the wider population of patients with recurrent cancer (Faber and Fonseca 2014). Additionally, though the results have much convergence with previous research, this limitation may also be partially liable for where the current results diverge from what is available in the literature. This could be simply addressed by repeating the study with larger numbers. Also worth considering is the predominance of breast and prostate cancer patients, which made up most of the study population. This means that there may be limitations in generalising findings to wider cancer populations, though other aspects of the cancer recurrence experience are not thought to differ greatly between cancer types (Stewart et al. 2021).

On the topic of generalisability, it is crucial to repeat at this point that the current research took place within a cancer specialist hospital site, which was reflected in positive experiences described by participants. However, this creates some issues for the wider implications of the study. It is entirely plausible that the standard of care and the time that is able to be devoted to patients at such a site may not be possible in other NHS

hospitals; consequently, the experiences of patients with recurrent cancer may differ elsewhere. This is worthy of further investigation in future research, and as described, a finding in the qualitative phase of the current research suggests that patients were pleased to be treated at a specialist site. Indeed, previous research indicates there may be greater patient satisfaction and improved cancer treatment outcomes in healthcare sites with more specialist staff (e.g. Ganti et al. 2017, Griffiths et al. 2013, Vernooij et al. 2009). Further, the negative impact on cancer treatment due to the COVID-19 pandemic suppression measures is now established (Teglia et al. 2022), and so the current research taking place with patients at a site where cancer treatment was relatively unaffected may affect the generalisability of the findings.

The questionnaire used in the first phase of the study was made up entirely of self-report measures, and whilst these have been shown to be reliable and valid, the usual caveats of such measures apply, in that responses may be subject to bias (Althubaiti 2016). Similarly, as discussed in section 7.4, one last consideration needed is that the study questionnaire and the interview schedule contained sensitive questions, and thus there is a possibility that some participants did not respond accurately due to not wishing to disclose such information (Tourangeau et al. 2010).

7.9 Contributions towards fear of progression theory

 Chapter 2 described the theoretical underpinning of FCR/FOP research, and the use of such models helps to explain how the fear manifests in the individual. In particular, the CSM (Leventhal et al. 1992) and the subsequent Model of Fear of Cancer Recurrence from Lee-Jones et al. (1997) adapted from this were detailed. An important finding of the current research suggested that individual factors may be more important in predicting FOP than clinical and demographic variables. This supports a key assertion of the models, that illness representations (a patient's beliefs and expectations about their disease) are personalised based on their own experiences and knowledge.

The constructs of the model were also somewhat supported by the thematic analysis of the qualitative phase of the research. External cues (particularly contact with healthcare staff and an individual's predisposition and past coping style) appear to have led to participants considering their risk of cancer progression (cognitions) and produce a relevant emotional response (fear, worry), and certain behavioural responses (such as

limited planning for the future), and psychological responses were evident. It should be noted, from interview data with participants, that internal cues (such as pain and tiredness) were present, but these did not appear to be acting as a cue to begin worrying about the possibility of cancer progression (implications of this are discussed further in section 7.11). Overall, these findings suggest that constructs from the CSM may account for variation in FOP levels in patients with cancer recurrence, though more direct assessment of these would be beneficial in future, and ultimately could be factored into intervention development. The components of the FCR model proposed by Lee-Jones et al. (1997) that are evident in the findings of the current research are displayed in Table 18.

Table 18. Components of FCR model (Lee-Jones et al. 1997) evident in the study.

Theoretical component (Lee-Jones et al. 1997)					
Internal cues	External cues	Cognitions	Emotions	Behavioural responses	Psychological effects
Physical symptoms*	Contact with health professionals	Past experience of cancer and its treatment	Worry associated with cancer progressing	Limited planning for future	Misinterpretation of symptoms
	Coping styles	Beliefs about eradication of cancer	Anxiety about cancer itself	Seeking advice from friends and professionals	Increase in somatic activity
	Family concerns	Knowledge base			

*Present but not expressed as interpretation of progression

For the current research, a conceptual framework was developed based on the established theoretical models for FCR/FOP. It was expected that internal and external cues led to the development of emotions and cognitions related to FOP. The findings from the literature review (chapter 2) suggested that this association would be moderated by demographic and clinical variables, as well as perceived social support. This is partially supported by the association found between anxiety and age, and the qualitative findings, wherein participants expressed the importance of social support in coping with negative

emotions due to their cancer. However, it was expected that levels of FOP would also be moderated by the demographic and clinical variables and perceived social support. No correlation was found between FOP levels and the measured clinical and demographic factors in this study and so this notion is unsupported, though as discussed earlier in this chapter, the limitations of the current research may explain this. See sections 7.11 and 7.11.1 for discussion of the implications arising from the current research for the theoretical models used to explain FOP.

7.10 Contribution to mixed methods research

The reasoning and advantages of utilising a mixed methods approach have been described in places in this thesis. To reiterate, employing quantitative data collection allowed for the generation of numerical data and subsequent analysis using formal statistical procedures, and the use of qualitative methods in this study allowed for more detailed insights to be created. In simple terms, quantitative research can be thought of as asking 'how often' or 'how many', as opposed to qualitative research, which usually asks 'how' or 'why' (Malina et al. 2011). Consequently, the advantage of utilising both components is clear: results from the first phase are further explained by the second, which also illuminated insights that were not captured by the first. These are examples of *complementarity* and *expansion* as described in section 6.2 (Skamagki et al. 2022).

Attempts have been made to explicitly discuss how the quantitative and qualitative phases were integrated with each other, as successful integration is considered one of the key challenges of conducting mixed methods research (Fetters et al. 2013). It is argued that this was done sufficiently in the current research. Another important aspect is the increasing prevalence and importance of mixed methods approaches in healthcare research (Tariq and Woodman 2013); this is thought to allow for deeper understanding of often complex issues and provide insight into accounts given by patients (Guetterman et al. 2015). Thus, it is hoped that the current research has useful contributions for health research and practice, which shall be discussed below.

7.11 Implications for future research

To the best knowledge of the researcher this is the first longitudinal study examining FOP in patients who have experienced a recurrence of their cancer. Similar designs in future research would greatly enhance findings from this study (particularly with larger sample sizes, as described previously), and without the time constraints of a PhD project

it would be possible to test the trajectory of FOP over a longer period of time; which has been possible for previous research in patients with cancer without a recurrence (Dinkel and Herschbach 2017).

This is also thought to be the first study featuring a qualitative aspect in relation to FOP in this population, and this is an important first step for future research. In a systematic review and meta-synthesis of FCR/FOP qualitative research (Almeida et al. 2019) the authors stress the importance of qualitative research in regard to FCR/FOP, noting that it is a research area in which quantitative measures are predominately used, but qualitative methods allow for participants to express their feelings about recurrence or further progression, which can vary drastically between individuals. So, the continued use of mixed methods in research with patients with recurrent cancer is recommended from the current findings.

Given the limited diversity in cancer types within the study population, future investigations should explore FOP levels after recurrence in other cancers. This approach would provide valuable evidence for tailoring care to specific populations, especially those with haematological malignancies (e.g., leukaemia, myeloma), characterised by more unpredictable disease trajectories compared to solid tumours (Verhoef et al. 2020), and likely to possess unique care needs.

Moreover, the current research was conducted with patients based in a specialised NHS cancer site. While the implications of this finding have been discussed, it is imperative to conduct studies assessing FOP after recurrence in various hospital settings (e.g., non-specialist sites, community care settings) to ascertain if similar results emerge across diverse patient populations. This is crucial, given the recognition emphasised throughout this thesis that individuals may live with cancer recurrence for many years, and there is an established recognition that the care needs of patients are often best managed outside of hospital settings (Lisy et al. 2021). For a more in-depth discussion on implications for practice, refer to section 7.12.

To mention the newer scales used in this study, the findings of the current research indicate the 4-item FOP4 questionnaire used in this study had a high level of internal consistency, as well as being significantly correlated to the longer 12-item FOP-Q-SF, and both the HADS anxiety and depression sub-scales, suggesting high convergent validity with these measures. This indicates that the FOP4 is a useful measure in itself

and may be suitable for exclusive use in future research with similar patients. Being of a smaller size means that the time required of participants, who may be experiencing treatment side effects and other physical issues cause by their cancer, is lessened. With the COVID-19 pandemic, newer scales are in development in order to assess the level of fear people may have in regard to it (Ahorsu et al. 2020). Results in the current study suggest that the CCAS has high internal consistency and as such may be a useful tool for capturing concerns related to COVID-19 and cancer treatment in future research, but this requires more use in order to test this further.

An issue that emerges from this project is the terminology used when describing FCR and FOP. In this thesis FCR was generally used to describe the time after successful treatment and before a recurrence occurs, FOP for when recurrence has occurred, and FCR/FOP when this was unclear in previous research, which was often the case. Indeed, it can be seen throughout this thesis that FCR/FOP was most commonly used, and that is because much past research does not distinguish between the two concepts. This may be considered confusing, but if it is treated as the same concept, as per the commonly used definition (Lebel et al. 2016), then this is perhaps unimportant and such distinctions are unnecessary. However, this notion has recently been challenged, and some findings from this review lend credence to this.

As introduced in Chapter 2, a recent study (Coutts-Bain et al. 2022) questioned whether the two concepts should continue to be treated as the same phenomenon. In research with cancer patients, the authors conducted exploratory factor analysis on a FOP outcome measure and a FCR outcome measure. Additionally, structural equation modelling was conducted to test if a theoretical model fit both concepts equally (specifically the cognitive processing model) (Fardell et al. 2016). Findings indicate that FCR and FOP are closely related but not identical constructs and as such should be treated separately in research and clinical practice. Even though this was primarily based on research with patients with an initial diagnosis, there are ramifications based on the current findings. The need to clarify whether one is referring to FCR or FOP seems particular unnecessary in patients after a recurrence has actually occurred, and this could be avoided in future research. Also, if these concepts are indeed distinct, then that may imply that more research is needed solely focusing on FOP, as there is a disparity between the two in the evidence base (Coutts-Bain et al. 2022). There are also implications in regard to how

these fears can be managed through psychosocial interventions (see section 7.11.1 for further discussion of future intervention development).

There was discussion (in section 7.9) about the fit of the CSM to the current research findings. It is suggested that one component of the model that was not apparent was internal cues (such as pain) acting as a trigger for the patient to be concerned about cancer progression. Of course, it must be acknowledged that the fit of theoretical constructs was somewhat informally looked at, and more direct testing would be beneficial in future. But it is plausible that the model should be adjusted to explain the mechanisms of FOP, though to stress again, more research is required before such a claim can be substantiated. However, as stated in Chapter 2, in the previously mentioned research from Coutts-Bain et al. (2022) the authors note that their findings suggest that there are some differing predictors of FCR to FOP, and this then raises questions about the fit of current theoretical models that are used to explain the function of both. Furthermore, as detailed, the conceptual framework formulated for this study received partial support. However, to draw more definitive conclusions about this framework, further research is needed to address the limitations identified in the study.

7.11.1 Fear of progression intervention development

The evidence emerging from this project indicates that FOP is present in patients with a recurrence of their cancer at moderate levels, with almost half of the sample reaching levels that are classified as dysfunctional (Mehnert et al. 2006). As described earlier in this thesis, psychosocial interventions have been successfully implemented in other cancer populations, thereby lowering high FCR/FOP to manageable levels (Bergerot et al. 2022). Thus, from the current findings it is recommended that such interventions should be designed for patients with recurrent cancer. Despite receiving an incurable diagnosis, many patients will live with cancer recurrence for several years, so it is important to ensure QoL is as high as possible at this time; addressing FOP where necessary will help to do that.

Several considerations are necessary when developing psychosocial interventions. The use of a theoretical model has been identified as a factor that can beneficially guide intervention development but has been inconsistently applied in past research with patients with cancer (Fardell et al. 2016, Tauber et al. 2019). Evidence from the literature supports the use of the Fear of Cancer Recurrence Model adapted from the CSM (Lee-

Jones et al. 1997, Leventhal et al. 1992) in such a way, alongside tentative support in the current research, especially if consideration is given to adapting the model in order to address FOP after a recurrence had occurred. This is pertinent, as most psychosocial interventions have targeted FCR rather than FOP, and it is possible that there may be a lesser effect size for intervention efficacy when only applied to FOP, possibly due to different underlying mechanisms that determine fear (Coutts-Bain et al. 2022).

Within the literature it is recommended that psychosocial interventions be tailored to the needs of the individual patient (Tauber et al. 2019). Whilst none of the clinical and demographic factors captured in the current research predicated FOP levels to a statistically significant level, it is entirely possible that other factors may play a role, and this should be tested further. It is hoped that identifying such predictors and subsequently shaping an intervention to suit the needs of an individual will increase their efficacy (Antoni 2013, Shay et al. 2016).

The timing of intervention application is important to consider. Evidence from the current project suggests that FOP is reasonably stable over time, in line with previous research into FCR/FOP in patients without a recurrence (Simonelli et al. 2017). However, as previously discussed, during the semi-structured interview phase of the research participants suggested that their fear levels in relation to further cancer progression rise around the time of medical scans or appointments; in accordance with previous findings (McGinty et al. 2016). This is a factor that should be considered in future intervention development, in regard to screening for fear levels as well as subsequent intervention implementation. There is a suggestion that intervening early may be important, as patterns of FCR after a primary diagnosis might be well established by the time interventions have been utilised previously (Butow et al. 2019). Thus, intervening early may also be beneficial for FOP after a recurrence, and this should be investigated further.

Another important consideration needed in psychosocial intervention development (with implications for practice as well as research) is the mode of delivery. Previous FCR/FOP interventions in cancer populations are commonly delivered by healthcare staff, and research has indicated that these can be successfully implemented as part of a routine oncology appointment (Liu et al. 2021). This is a useful notion as an additional appointment to conduct the intervention would be unneeded, and such interventions can be designed to be brief and so requiring less of the staff and patients' time (Liu et al.

2019). On that note, there is evidence to suggest that group-based FCR/FOP interventions are more effective than individual treatment (Tauber et al. 2019), possibly due to the social aspects involved. This may create feelings of connectedness with other group members and the opportunity to socially reinforce positive thoughts and actions (Kealy and Kongerslev 2022). Considering that such treatments are less demanding of the time of healthcare professionals than equivalent individual sessions this is a useful consideration for future. As stated previously, the time following a cancer recurrence is a complex time and may vary drastically between patients. Interestingly, it is suggested that the feeling of connectedness in psychosocial therapy groups may be partially sustained by differences in the way problems arise for members as these are addressed by the group (Kealy and Kongerslev 2022), and so the use of these groups for patients after a recurrence may be useful.

In addition, the use of remote interventions (typically phone or web-based) is increasingly common in various areas of psychological therapy, but there is a dearth of evidence in relation to the use of remote interventions for FCR/FOP (Cincidda et al. 2022), and so this should be examined in future research as results in other areas of psychotherapy are promising (Olthuis et al. 2016). This would be beneficial for patients whose psychological issues or limited physical functioning which may impede them from attending in-person therapy (Bee et al. 2008), or simply for the convenience of not travelling from home if not necessary. Interestingly, with the (at the time of writing) recent COVD-19 pandemic, this could be an important consideration in relation to COVID-19 and any ongoing restrictions, as well as any future virus control measures that may emerge in the future.

Ultimately, based upon the evidence presented in the above section it is clear that much thought must be given into any future psychosocial interventions that may be developed to treat FOP after a recurrence of cancer has occurred. There is ample evidence for the use of similar interventions in the past in non-recurrent patients and careful consideration should be given into how these can be best tailored to meet the needs of patients at this time (Tauber et al. 2019). Relatedly, research has suggested that patients wish to be involved in decision making related to interventions, which is very much in line with other findings that suggest patients with a recurrence wish to be involved in their care and treatment decisions (Stewart et al. 2021). This notion holds implications for practice,

which shall be discussed below alongside other connotations arising from the current research findings.

7.12 Implications for practice

An important finding from the current research that links to the discussion on intervention development above is that participants indicated no problems with completing the questionnaires and answering the questions about FOP. As such, there is promise in integrating the data collection tools used in this study into practice. From the PPI online platform used in the development of this study, and particularly from the semi-structured interviews, it appears that discussing cancer progression was not stressful for participants and so health care professionals should not be deterred from asking about this factor, particularly as there is now evidence that FOP is present and can reach high levels in this population.

A particularly common finding in the qualitative phase of the study was a desire for clear communication from healthcare staff and to feel included in treatment and care decision making. This is a common finding in patients with cancer after a recurrence (Stewart et al. 2021), and further highlights the importance of this as one of many factors that have an impact on the well-being of the patient. Positively, health care organisations around the world are recognising the importance of person-centred care. To reiterate, simply, person-centred care is recognising the individual needs of patients and ensuring that they are treated as partners that help to make up a multidisciplinary approach to their care alongside their healthcare professionals (Coulter and Oldham 2016). This approach complements the aforementioned concept of public and patient involvement in health research, which is an increasingly important issue for policy makers in the UK, and is designed to ensure research is relevant and understandable for participants (Evans 2014).

Unfortunately, with a multitude of competing priorities for healthcare staff the principles of person-centred care may not always be actioned to as great a degree as desired (Ocloo et al. 2021). Moreover, research indicates that oncology specialists often perceive their primary role in patient care as focused on monitoring for recurrence and managing symptoms, while psychosocial well-being falls within the purview of primary care providers (Lisy et al., 2021). This may link to the current finding wherein some participants conveyed negative healthcare experiences, and even those with generally positive experiences still felt excluded from decision-making. Despite this, previous

studies reveal a generally positive reception to the person-centred approach by policymakers, staff, and patients, emphasising the need for ongoing efforts to enhance standards (Coulter and Oldham 2016, Ross et al. 2015).

With the incidence of cancer in the UK expected to rise and NHS cancer services facing challenges in recovering from the impact of the COVID-19 pandemic, along with continuing issues with staff shortages (Aggarwal et al., 2023a), the complexities of cancer care are exacerbated. Notably, more adults are living with treatable but incurable cancers (White et al., 2021) and psychosocial concerns persist throughout the cancer experience. Therefore, it is crucial to ensure that the organisational concerns do not hinder the ability to intervene appropriately and proactively.

To address structural challenges, policymakers should focus on diligent implementation of strategic plans, such as the NHS Long Term Plan (NHS England 2019), which advocates for personalised care, including needs assessment, a care plan, and health and wellbeing information and support for every person diagnosed with cancer. The findings of the current research suggest that this personalised care package should specifically consider the potential emergence of FOP to both recurrent and non-recurrent cancer patients.

7.13 Author's reflections

I have made a conscious effort to provide reflexivity of my experience over the course of this PhD project throughout this thesis. Not only is it considered an important part of health research (Doyle 2013), it was useful to guide my decision making and help to retrospectively contemplate each phase of the process. For clarity, the examples of this evident throughout shall be summarised in this section of the thesis alongside other information that may be useful for the reader.

In order to not repeat myself this will be brief, but it is inescapable that I must mention the COVID-19 pandemic again. To summarise here, whilst engaging in a PhD is a challenging project in itself this was made particularly challenging at times due to the COVID-19 pandemic which emerged early in my 2nd year, shortly before data collection was intended to begin. This led to many changes in the design and implementation of the mixed methods study which featured as the main body of work of the project, and as described in this chapter a smaller sample size than desired was recruited in order to

complete the project in time, despite this, the conclusions that emanate from this project add to the existing knowledge base and provide novel and useful findings.

A concern that was raised several times in the process of receiving ethical approval for the research study was that of the sensitive nature of the topic area and potential distress to both the participants and I. However, with my own experiences prior to commencing the PhD project and the support I received from my supervisory team I at no point had concerns in this regard. As described earlier, a distress protocol was created for use in the case of participants getting upset during the course of the data collection, but this was unused throughout the research. Indeed, I was given the impression that participants were happy to be involved in the research and share their experiences.

As discussed previously, as an inexperienced qualitative researcher, being aware of my own biases was particularly important for this phase of the research, and though measures to address this were followed, it is impossible to rule out the presence of bias, however it is important to note that separation of the researcher from the research is not considered to be possible or even desirable (Galdas 2017).

7.14 Conclusion

This final section of this chapter will conclude this thesis, and this project. The topic area was firstly introduced, and the relevant literature was systematically reviewed- leading to a publication (Stewart et al. 2021), see appendix 1. This thesis then described a mixed methods research study examining FOP and other related factors after a recurrence of cancer, with a broad aim of providing a focus on patients whose cancers recur. The rationale behind the study, as well as the methods used were outlined, followed by a description of the findings. Containing the first mixed methods and longitudinal study examining FOP in the time after a cancer recurrence, a number of novel findings have emerged from this project.

Statistical analysis of the questionnaire responses from the quantitative phase of the research indicated that FOP is present at moderate levels, with almost half of the sample with fear that reached levels that are classified as dysfunctional- which is in turn linked to poorer QoL and other negative psychosocial outcomes in the literature (Simard et al. 2013). Indeed, further analysis in the current research indicated that participants had problems with some areas of health-related QoL, as well as mild issues with anxiety.

Semi-structured interviews in the qualitative phase of this research created illuminating insights that further explained quantitative results, but also provided interesting findings in their own right. With the benefits of a mixed methods approach, integrated findings from this project produce comprehensive information about the needs of patients with recurrent cancer and have wide implications for future research and practice. With the recommendations that arise, it is hoped that this research project is a useful contribution to the evidence base and can help guide support to patients with cancer.

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Appendices

Appendix 1: Published Manuscript of Systematic Review

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in Psychology

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Does Cancer Type Influence the Impact of Recurrence? A Review of the Experience of Patients With Breast or Prostate Cancer Recurrence

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Objective: Patients will experience a plethora of issues when faced with a recurrence of their cancer. It is unclear if cancer type is a significant factor in how recurrence is experienced by an individual. The aim of the current review is to explore the evidence base and summarise the experiences of patients specifically with a recurrence of breast or prostate cancer (the most common for women and men, respectively) and then provide a comparison of these experiences. These experiences include the physical, psychological and psychosocial issues that arise at this time.

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Methods: A systematic search was conducted of studies published between January 1994 and April 2019. Due to the mix of research designs used previously in the literature, this review was conducted in an integrative manner; allowing for inclusion of diverse research designs. Results were synthesised narratively, with data categorised according to physical, psychological, and psychosocial indices of quality of life. The review protocol was registered in the international database of prospective systematic reviews in health and social care- (CRD42019137381).

Results: Fifteen breast cancer and six prostate cancer articles were identified, each reporting one relevant study. Patients reported several negative issues at the time of a breast or prostate cancer recurrence. Similarities were found between cancer types, with physical problems such as fatigue, psychological issues including anxiety and depressive symptoms, and psychosocial concerns such as issues with healthcare professionals common in both cancers. Certain findings were inconsistent across studies, with some experiences differing between studies rather than due to cancer type.

Conclusions: Differences in the experience of recurrent cancer appear to be more heavily influenced by individual factors, rather than cancer type. Findings are confounded by gender; and should be considered preliminary. Effects of recurrence should be studied in samples where cancer type and gender are not confounded. Concerns are raised about available study quality and differing outcome measures in this interpretation. Care and support of the individual at the time of a cancer recurrence is a key focus. Future research suggestions with implications for clinical practise are included.

Systematic Review Registration: PROSPERO 2019 CRD42019137381.

INTRODUCTION

Individuals will experience a range of negative consequences when faced with a cancer diagnosis, and the significance of an initial diagnosis is well-established in the literature (Schouten et al., 2019). However, it has been suggested that cancer recurrence may have a more significant impact on the individual than the initial disease as it often represents a more serious diagnosis (Step and Ray, 2011), particularly if the recurrence is not local. Consequently, the fear that cancer will recur is a common issue (Lebel et al., 2016); and has been addressed through psychological interventions (Chen et al., 2018).

In accordance with the negative consequences of a recurrence of cancer, some previous research has sought to capture the experience of patients at this time. A meta-ethnography (Wanat et al., 2016) reviewed qualitative studies involving recurrent cancer patients. This added to an earlier narrative review (Vivar et al., 2009) that summarised findings from varying study designs describing the impact on family members as well as the patient. Both reviews highlighted a complex range of issues patients face when dealing with a recurrence in relation to their physical wellbeing, emotional state, relationships- both personal and with healthcare professionals, as well as adjusting to new uncertainty and coming to terms with their own mortality.

In the UK, breast cancer is the most common malignancy in females, and prostate cancer the most common in males (Cancer Research, U. K., 2017b,c), and naturally the manner in which recurrence manifests will differ. In prostate cancer a patient may be diagnosed with biochemical recurrence. This refers to rising levels of prostate specific antigen (PSA) in the blood, but patients may not experience local or distant recurrence for some years after this (Artibani et al.,

2018). In comparison, breast cancer recurrence may be identified in a manner similar to initial diagnosis, that is physical symptoms (Cancer Research, U. K., 2017a). With cancer in general it is known that several factors (including cancer characteristics) are important in understanding the well-being of patients (Schouten et al., 2019), but it is suggested that recurrence is a unique experience (Wanat et al., 2016) and yet there is little understanding of the effect of cancer type on how a recurrence affects the well-being of patients. Whilst being very common, these cancers manifest very differently, and as such may be a more useful point of comparison when establishing differences in reactions to recurrence than cancers with a more similar physical manifestation and treatment profile.

The aim of this review is to explore the existing literature in order to clarify if cancer type will influence the perceived impact of recurrence. By specifically examining prostate and breast cancer this review will explore highly prevalent, physically contrasting, and predominately gender based cancers; leading to a pertinent and multifaceted comparison. This will be conducted by summarising studies that evaluated the experiences of patients specifically with a recurrence of breast or prostate cancer; and then comparing these. For the purposes of this review, the patient experience refers to physical, psychological, and psychosocial issues that arise after a recurrence of cancer that may impact quality of life. For clarity, these experiences will relate to outcomes from studies assessing patient-reported levels of physical, psychological, and psychosocial indices of quality of life (QoL).

By addressing the question of cancer type potentially influencing the impact of recurrence it is suggested that findings from this review will help to develop a wider understanding of recurrence, highlighting differences (or the lack thereof) in personal reactions to a recurrence of these cancers. It is hoped that this will contribute knowledge to clinical care settings with implications for healthcare professionals treating patients with these cancer types. This includes professionals involved in regular personal care with these patients, such as cancer nurses. This is particularly important as, for some time, the NHS has outlined the need for a comprehensive approach to healthcare, in particular "person-centred" care- identifying the individual's wider well-being as crucial to their overall recovery, thereby providing a more personalised experience than in the past (Howe, 2020).

METHODS

In the literature, studies relevant to cancer recurrence feature a variety of research designs. Therefore, the current review was conducted in an integrative manner. This was considered a suitable method as it allows for inclusion, and deep understanding of diverse research designs (Hopia et al., 2016). The review was implemented in a systematic manner conforming to the methodological approach by Whittemore and Knafl (2005) that reduces the likelihood of biases and errors (Souza et al., 2010). The review protocol was registered in the international database of prospective systematic reviews in health and social care- PROSPERO 2019 CRD42019137381.

Search Strategy

Following the rationale of previous reviewers (Wanat et al., 2016) who highlight that there have been significant changes in treatments for cancer and within healthcare services, it was decided to restrict the search from January 1994 to April 2019. Four electronic databases were searched: PsycInfo, CINAHL complete, Medline, and Pubmed. The following search terms were used:

- cancer* or carcinoma* or malignan* or tumour or tumour or neoplasm*

- patient experience or recur* or relapse or time or metastatic* or progress*
- psycholog* or psychosocial or experience* or supportive care or social
- breast cancer or prostate cancer • fear or anxiety or worry or shock.

Inclusion Criteria

Articles were included if they: reported a study which explored the experience of any patients with a prostate or breast cancer recurrence (both local or distant recurrence were applicable, and data could have been collected at any time from directly after recurrence to end of life); used either quantitative or qualitative methodology to gather and analyse results; were published between January 1994 and April 2019; and were published in English.

Exclusion Criteria

Articles were excluded if they: did not explicitly state that in their studies, participants had recurrent cancer and were subsequently included in data analysis. That is, studies may include participants with metastatic cancer which is not necessarily recurrent, hence these would be excluded. In addition, if no distinction is made between cancer types in analysis (i.e., breast or prostate cancer patients may be included in a study but analysed together with other cancers with no distinction) they were excluded.

Screening Procedure

Two researchers (RJS, SC) independently screened articles that were identified through the database searches. First, titles and abstracts were screened, and non-relevant articles were excluded. Second, full articles of remaining studies were obtained and screened against this inclusion and exclusion criteria. Lastly, as a supplemental approach, reference lists of articles deemed to match the inclusion criteria were scanned. The procedure for database searching and study screening is outlined in **Figure 1**.

Data Extraction

Extracted data included: sample characteristics; study aim and design; and cancer type and stage. Data were extracted by one researcher (RJS) and checked by a second (SC) for accuracy. Study quality and risk of bias were both independently assessed by two researchers (RJS, SC) using the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018). The MMAT allows for the quality assessment of all study designs and is therefore suitable for this review. Any discrepancies in data extraction and quality appraisal were resolved through discussion.

Data Abstraction and Synthesis

With consideration to the aim of the review as well as the heterogeneous character of eligible studies, there was limited scope for meta-analysis; instead, formal narrative synthesis was conducted with no minimum number of articles required. Using a convergent synthesis design (Hong et al., 2017), data from quantitative studies were combined with data from qualitative studies and were coded, and findings were categorised into themes based on the breakdown of different experiences. The outcomes synthesised in this review were measured either qualitatively or quantitatively by reliable and valid assessment tools and related to patient-reported levels of physical, psychological, and psychosocial indices of quality of life (QoL) that have impacted on the patients' experience of cancer recurrence. Themes related to the experience of prostate cancer patients with a cancer recurrence were compared to those of breast cancer patients with a cancer recurrence.

The precise timing of a recurrence will have a specific impact on the individual's health-related quality of life. This impact will differ between studies. If there is a comparison group alongside a recurrence group the difference between these will be used to judge the impact of recurrence. If there is no comparison group the impact of recurrence will be based upon scores from quantitative measures (if used by the authors). These measures will have scoring guidelines to judge what would be considered a normative or "standard" score. If there are qualitative findings with no comparison group these will be used to supplement results to build a wider comprehensive "picture" of the experience of patients at the time of recurrence. A withinsubjects comparison can also be made where reference is made to previous assessments from patients at their primary diagnosis.

After the results have been presented from both cancer types, a comparison will take place. Any main similarities and differences will be outlined at this point and evaluating these will allow for judgement of if the subjective experience of recurrent breast cancer is broadly similar or different to that of prostate cancer, i.e., if several findings emerge in breast as well as prostate studies this would perhaps suggest a similar experience, whereas differing results would possibly suggest a different experience. Due to the outlined physical manifestations of breast and prostate cancer more credence will be given to the psychological and psychosocial concerns at this time when considering this comparison.

RESULTS

Overall, 392 articles were identified by the search strategy, of which 21 met inclusion criteria (**Figure 1**). Each article reported one relevant unique study.

Description of Studies

Included articles were published between 1996 and 2017. Ten were conducted in the USA; three in Sweden; two in Japan; and one each in Australia, Finland, Israel, Italy, the Republic of Ireland, and the UK. **Table 1** summarises details of the breast cancer studies and **Table 2** the prostate cancer studies. Fifteen articles that met inclusion criteria examined the patient experience of breast cancer recurrence, whereas six articles examined the patient experience of prostate cancer recurrence. Reporting of age differed throughout studies. For the studies examining the experience of breast cancer recurrence 11 reported mean ages, and these had an aggregate mean of 56.7 years old. Two studies reported a median age- one of 50 (Brady and Helgeson,

FIGURE Flow diagram of database searching and study
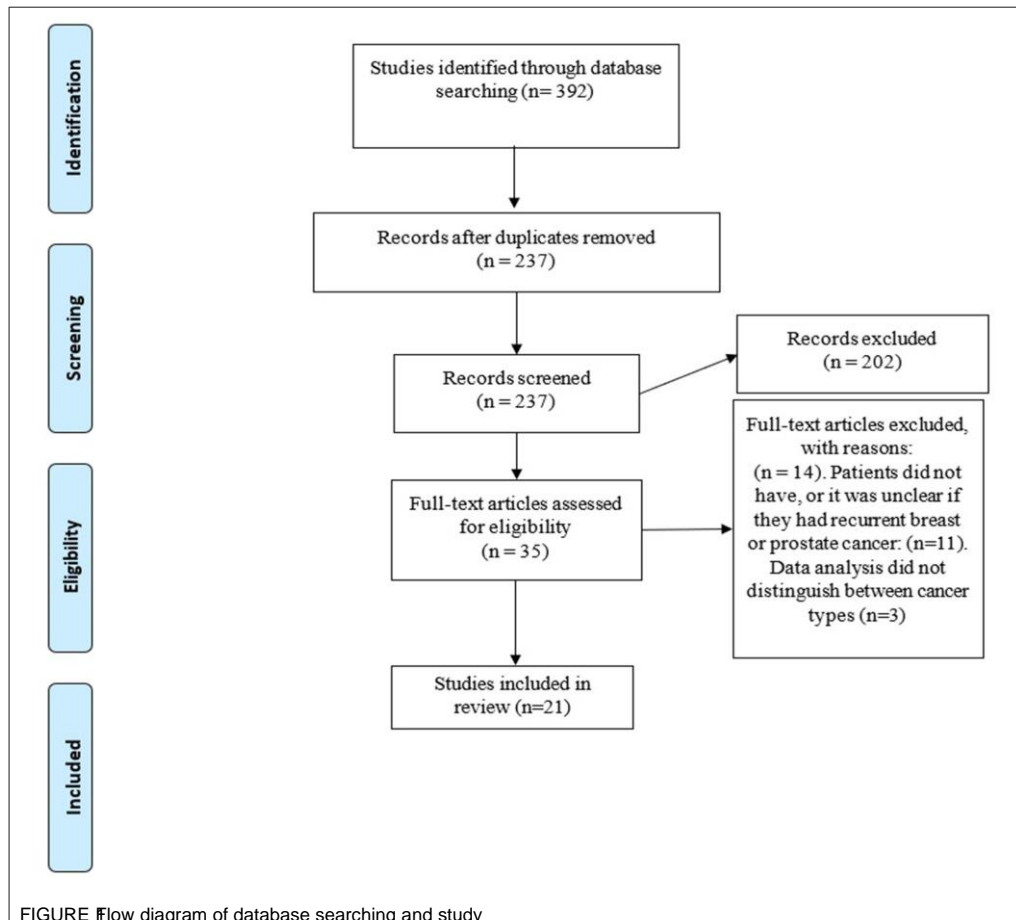
2000) and the other of 57 (Cleeland et al., 2014). The last two studies reported age ranges: one simply 75 years and younger (Hall et al., 1996) and the other an age range of 55– 81 years old (Sarenmalm et al., 2009). It is important to note that three of these articles used the same sample of participants, but for slightly different research aims- as such any findings highlighted in this review will be referenced to which particular article they came from (Sarenmalm et al., 2007, 2008, 2009). Of those studies examining the experience of prostate cancer recurrence, four (Pietrow et al., 2001; Ullrich et al., 2003; Lehto et al., 2015; Maguire et al., 2017) reported mean ages, with an aggregate mean of 66.2; and the other two (Ames et al., 2008, 2011) each reported a median age of 76, respectively.

Study Methods

Of those studies examining the experience of breast cancer all but three were conducted with quantitative methods; with two using qualitative methods (Hall et al., 1996; Sarenmalm et al., 2009) and the other utilising mixed methods (Turner et al., 2005). One study (Ames et al., 2008) utilised mixed methods to examine the experience of prostate cancer, the remainder were conducted quantitatively. The research aims of included studies are described in **Tables 1**, **2**.

TABLE 1 | Breast cancer studies included in review.

References	Aim	Sample characteristics	Design	Outcome measures	Quality score
1. Andersen et al. (2005)	To analyse patients' reactions to a recurrence of cancer	30 females, mean age = 52 (SD = 11.6)	Controlled Prospective Study	IES; POMS; CES-D-SF; SF-36; SNI; PSS-Fa; PSS-Fr; DAS; KPS; SWOG rating scale.	****
2. Brady and Helgeson (2000)	To explore the relationship between social support and adjustment after a recurrence of breast cancer.	41 females, median age = 50	Quantitative	Adapted social support questions; BSI; COPE inventory	****
3. Bull et al. (1999)	Clarify relationship between recurrent breast cancer and quality of life	69 females, mean age = 53.3 (SD = 8.89)	Longitudinal study	Specifically designed scales.	****
4. Cleeland et al. (2014)	To characterise symptom burden, activities of daily living, health-related quality of life and work-related ability in order to inform clinical trials and treatments.	152 females, median age = 57	Observational cohort study	MDASI; WPAI; RSCL	***
5. Cohen (2002)	To explore emotional distress and coping strategies in patients with primary breast cancer vs. patients with recurrent breast cancer	41 females, mean age = 62.3 (SD = 7.7)	Observational cohort study	SCL-90; WCQ	*****
6. Hall et al. (1996)	To explore psychological morbidity in recurrent breast cancer patients.	61 females, age = 75 and younger.	Qualitative	Semi-structured interview	*****
7. Northouse et al. (2002)	To assess the quality of life of patients and their family members after recurrence	189 females, mean age = 54 (SD = 11.2)	Cross-sectional study	SF-36; FACT	*****
8. Oh et al. (2004)	To explore the quality of life of breast cancer survivors after a recurrence	54 females, mean age = 59.5	Observational cohort study	SF-36; CES-D; PANAS; IES-R; RDAS; MOS-SSS; PTGI; SBI-15R; Specifically developed Meaning and Vulnerability Scale	*****
9. Okamura et al. (2000)	To study the prevalence of psychological distress and risk factors of these following recurrence of breast cancer.	55 females, mean age = 52 (SD = 9)	Cross-sectional study	Structured clinical interview; POMS	*****
10. Okamura et al. (2005)	To examine the prevalence of, and factors linked with psychiatric disorders, and the impact on quality of life after recurrence.	50 females, mean age = 53 (SD = 10)	Cross-sectional study	Structured clinical interview; MAC scale; EPQ-R; EORTC QLQ-C30; EORTC QLQ-BR23	****
11. Sarenmalm et al. (2007)	To examine predictors of health-related quality of life in postmenopausal women with recurrent breast cancer.	56 females, mean age = 65	Cross-sectional study	MSAS; HADS; SOC-13; EORTC QLQ-C30; IBCSG QoL	****

References	Aim	Sample characteristics	Design	Outcome measures	Quality score
12. Sarenmalm et al. (2008)	To explore the symptom experience and predictors of distress and quality of life in women with recurrent breast cancer [the same sample as Sarenmalm et al., 2007 was assessed].	56 females, mean age = 65	Longitudinal study	MSAS; HADS; EORTC QLQ-C30	****

(Continued)

TABLE 1 | Continued

References	Aim	Sample characteristics	Design	Outcome measures	Quality score
13. Sarenmalm et al. (2009)	To assess the main concerns of women with recurrent breast cancer, and how they were dealing with their situations (this sample was derived from the earlier Sarenmalm et al. studies).	20 females, age range 55–81	Qualitative	Semi-structured interview	*****
14. Thornton et al. (2005)	To clarify the effects of being diagnosed with cancer for a second time on health-related quality of life.	140 females, mean age = 53 (SD = 9.7)	Prospective data extracted from larger Randomised Control Trial	SF-36	***
15. Turner et al. (2005)	To define the key emotional concerns of women newly diagnosed with recurrent or metastatic breast cancer.	68 females, mean age = 54.7 (SD = 13.5)	Mixed Methods	Semi-structured interview; HADS; IES; CARES-SF	****

BSI, Brief Symptom Inventory; CARES-SF, Cancer Rehabilitation Evaluation System-short form; CES-D, Center for Epidemiological Studies-Depression; COPE, Coping Orientation to Problems Experienced; DAS, Dyadic Adjustment Scale; EORTC QLQ-C30 (BR23), European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire (breast cancer specific); FACT, Functional Assessment of Cancer Therapy; HADS, Hospital Anxiety and Depression Scale; IBCSG- QoL, International Breast Cancer Study Group- Quality of Life; IES, Impact of Events Scale (R)(Revised); KPS, Karnofsky Performance Scale; MAC, Mental Adjustment to Cancer; MOS-SSS, Medical Outcomes Study-Social Support Scale; MSAS, Memorial Symptom Assessment Scale; PANAS, Positive and Negative Affect Schedule; POMS, Profile of Mood States; PSS-(fa; fr), Perceived Social Support (family; friends); PTGI, Posttraumatic Growth Inventory; RDAS, Revised Dyadic Adjustment Scale; RSCL, Rotterdam Symptom Checklist; SBI-15R, System of Belief Inventory; SCL-90, Symptom Checklist; SF-36, Short Form Health Survey; SOC-13, Sense of Coherence Scale; SNI, Social Network Index; SWOG, Southwest Oncology Group; WCQ, Ways of Coping Questionnaire; WPAI, Work Productivity and Activity Impairment. *** refers to meeting 3 out of 5 quality criteria, **** is 4 out of 5, and ***** is 5 out of 5.

Themes

Themes that emerged during data analysis were assigned to three broad categories: physical, psychological, and psychosocial issues. For ease of comparison between cancer types the main findings that emerged in included studies are outlined in **Table 3**, but more detail is described below.

Breast Cancer

Physical Issues

Physical symptoms experienced by breast cancer patients with a recurrence included: fatigue; sweats; coughing; a lack of appetite; dry mouth; pain; nausea and vomiting; drowsiness; swelling of limbs; numbness, feeling bloated; dizziness; taste change; problems with sex; constipation; diarrhoea; issues with urination; mouth sores; weight loss; shortness of breath; and difficulty concentrating (Turner et al., 2005; Sarenmalm et al., 2007, 2008; Cleeland et al., 2014). Furthermore, one study (Northouse et al., 2002) found that, in comparison to cancer patients in general, those with a recurrence rated their overall physical health lower. Further, patients' perceptions of their physical health at recurrence were found to be lower compared to: pre-recurrence (Bull et al., 1999); primary diagnosis (Andersen et al., 2005; Thornton et al., 2005); cancer patients in general (Northouse et al., 2002); and both population norms and disease-free breast cancer survivors (Oh et al., 2004). One study

(Thornton et al., 2005) found that perceptions of physical health of women with distant recurrence were rated significantly lower than women with local recurrence.

Psychological Issues

Psychological problems were common among those with a breast cancer recurrence (Northouse et al., 2002; Turner et al., 2005).

In a qualitative study (Hall et al., 1996), half of the sample (of a total of 38) were found to be clinically depressed or anxious (or both). Okamura and colleagues (Okamura et al., 2000) reported that 42% of their participants met criteria for major depressive disorder or adjustment disorders; with the prevalence rate of major depressive disorder akin to that found in patients after a primary diagnosis of cancer. However, a later study (Okamura et al., 2005) found the prevalence rate of psychiatric disorders to be lower, at 22% of their sample of recurrent breast cancer patients. Further, one study (Oh et al., 2004) found that in their sample, women with recurrent breast cancer did not suffer from clinical depression, prior to or following recurrence. There were different negative emotions experienced by those with a recurrence: high cancer-related stress (Andersen et al., 2005); emotional distress (Bull et al., 1999); general stress; worry; sadness; and irritability (Sarenmalm et al., 2007, 2008, 2009). Though another study (Oh et al., 2004) found that patients generally had good overall mood, as well as low levels of cancer-specific stress. A qualitative study (Sarenmalm et al., 2009) reported that participants often viewed recurrence as more distressing that their initial cancer diagnosis; but one study (Andersen et al., 2005) reported that patients' stress was equivalent at initial diagnosis as it was at recurrence, and another (Oh et al., 2004) reported some patients felt it was more stressful but others did not. Findings from one study (Cohen, 2002) suggested that, in comparison to women with primary breast cancer, women with local or metastatic recurrence displayed higher levels of depression, anxiety, and somatisation.

Psychosocial Issues

Self-reported overall QoL was negatively impacted by the diagnosis of a recurrence: in comparison to pre-recurrence (Bull

TABLE 2 | Prostate cancer studies included in review.

References	Aim	Sample	Design	Outcome measures	Quality rating
1. Ames et al. (2008)	To appraise the psychological needs of men with a biochemical recurrence of prostate cancer	28 males, median age=76	Mixed Methods	Semi-structured focus group; FACT-P; SF-36; MAX-PC; POMS-B; LES; PSS	***
2. Ames et al. (2011)	To evaluate the acceptability effect size of a quality of life intervention for men with a biochemical recurrence of prostate cancer	57 males, median age = 76	Pilot study of randomised controlled trial	FACT-P; SF-36; MAX-PC; PSS-10; POMS-B	***
3. Lehto et al. (2015)	To investigate experiences and psychological well-being in prostate cancer patients who received various types of treatment.	74 males, mean age = 67	Cross-sectional study	Specifically designed survey; RSCL; SWLS; IIEF	*****
4. Maguire et al. (2017)	To examine the associations between prostate cancer survivors' treatment appraisals and fear of recurrence.	1,229 males (222 had recurrence), mean age = 68.48 (SD = 7.87)	Cross-sectional study	EORTC QLQ-C30; Fear of recurrence scale; DRS	*****
5. Pietrow et al. (2001)	To define the impact of PSA recurrence on health-related quality of life radical retropubic prostatectomy.	88 males, mean age = 63.4	Observational cohort study	SF-36; UCLA-PCI	****
6. Ullrich et al. (2003)	To compare cancer fear and mood disturbance after biochemical recurrence of prostate cancer with those without recurrence.	45 males, mean age = 66.1 (SD = 6.4)	Observational cohort study	AUA Symptom Index; Previously used Cancer Fear questions; POMS	****

AUA, American Urological Association; DRC, Decisional Regret Scale; EORTC QLQ-C30, European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire;
FACT-P, Functional Assessment of Cancer Therapy- Prostate; IIEF, International Index of Erectile Function; MAX-PC, Memorial Anxiety Scale-Prostate Cancer; LES, Life Experiences Survey; POMS (B) Profile of Mood States (Brief); PSS-10 Perceived Stress Scale; RSCL, Rotterdam Symptom Checklist; SF-36, Short Form Health Survey; SWLS, Satisfaction With Life Scale; UCLA-PCI, University of California Los Angeles-Prostate Cancer Index. *** refers to meeting 3 out of 5 quality criteria, **** is 4 out of 5, and ***** is 5 out of 5.

et al., 1999; Andersen et al., 2005; Thornton et al., 2005); and compared to those with an early-stage primary diagnosis of cancer (Northouse et al., 2002). Issues with medical staff were reported; satisfaction with medical professionals was found to be fairly low (Bull et al., 1999; Turner et al., 2005). Furthermore, several patients in the study by Turner et al. (2005) expressed frustration at the method in which the diagnosis was given, and over 40% of their sample felt that there had been too long a delay between their reporting of concerning symptoms and the subsequent action by medical professionals leading to diagnosis of recurrence. Thirty out of 38 patients in one study (Hall et al., 1996) claimed to have received no support whatsoever from their hospital following recurrence.

Patients were concerned about their loss of independence and the impact on family members (Turner et al., 2005), and limitations to their social roles (Northouse et al., 2002; Thornton et al., 2005). Cleeland et al. (2014) reported several patients faced impairment with daily activities as well as issues with missing work and impairment when they were able to work. Social functioning (the ability to fulfil social roles) was found to be negatively impacted by recurrence (Bull et al., 1999; Northouse et al., 2002; Andersen et al., 2005; Thornton et al., 2005). Some patients described the good quality of their interpersonal relationships (Oh et al., 2004; Andersen et al., 2005). Brady and Helgeson (2000) examined the correlations between social support and adjusting to

TABLE 3 | Common patient-reported issues after cancer recurrence.

Breast cancer			Prostate cancer		
Physical	Psychological	Psychosocial	Physical	Psychological	Psychosocial
Fatigue	Anxiety	Low QoL	Fatigue	Anxiety	Low QoL
Urination problems	Depression	Issues with medical staff	Urination problems	Depression	Issues with medical staff
Sexual problems	Stress	Importance of social support	Sexual problems	Frustration	Importance of social support
Shortness of breath	Emotional distress	Poor social functioning	Loss of muscle strength	Fluctuating mood	–
Poor appetite	Worrying	Unable to fulfil daily activities	Hot flushes	Anger	–
Taste change	Sadness	–	Incontinence		–
Weight loss	Irritability	–	–	–	–
Mouth sores	–	–	–	–	–
Dry mouth	–	–	–	–	–
Pain	–	–	–	–	–
Nausea and vomiting	–	–	–	–	–
Drowsiness	–	–	–	–	–
Limb Swelling	–	–	–	–	–
Numbness	–	–	–	–	–
Dizziness	–	–	–	–	–
Difficulty concentrating	–	–	–	–	–
Feeling bloated	–	–	–	–	–
Constipation	–	–	–	–	–
Diarrhoea	–	–	–	–	–
Coughing	–	–	–	–	–
Sweating	–	–	–	–	–

breast cancer recurrence. They found that emotional support from a partner and communicative support from an oncologist were correlated with fewer physical issues, but not to psychological distress. Further, psychological distress was related to decreased emotional support from a partner. Findings from the qualitative study by Sarenmalm et al. (2009) suggest that re-examining and altering social relationships was found to be a method of adjusting to cancer recurrence, and distress was lessened by receiving reassurance in regards to fears and uncertainty. Patients from this study found importance in changing their expectations from being cured, focussing on the quality of life rather than quantity and concentrating on the present rather than the past or future. An interesting finding from one study (Cohen, 2002) suggested that women with recurrent breast cancer were significantly less likely to use the adoption of a positive attitude as a coping mechanism than women with a primary diagnosis.

Prostate Cancer

Physical Issues

For recurrent prostate cancer patients, problems with sexual activity were reported (Pietrow et al., 2001; Ames et al., 2008; Lehto et al., 2015), such as sexual dysfunction and low libido. Patients also had issues with experiencing hot flushes from their treatment, frequent urination and incontinence, fatigue, as well as loss of muscle strength (Ames et al., 2008; Maguire et al., 2017). Patients suffered pain, as well as

reporting low levels of physical well-being (Ames et al., 2008, 2011).

Psychological Issues

Patients commonly reported high levels of anxiety (Ames et al., 2008; Lehto et al., 2015) due not only to the recurrence itself, but to PSA testing and subsequent results and related to their physical issues. Some patients reported anger and bitterness (Ames et al., 2008; Lehto et al., 2015) regarding their situation, as well as a frustration at the lack of a cure. One study (Lehto et al., 2015) described patients with depressive thoughts and fluctuating mood that were more pronounced than general prostate cancer patients. Though, Ames et al. (2011) found generally, participants had relatively low levels of anxiety, stress, and mental health issues, as well as reasonably raised mood. Moreover, an inconsistent picture emerged in the study by Ames et al. (2008) wherein participants rated their mood as high when measured qualitatively, which contrasted when measured quantitatively. Ullrich et al. (2003) found that recurrence in itself was not associated with greater mood disturbance or cancer-related fear. However, when patients with recurrence also had urinary symptoms they displayed high psychological distress; suggesting that these symptoms may be a more important factor.

Psychosocial Issues

Issues that arose in the study by Lehto et al. (2015) related broadly to the relationship between patients and their healthcare professionals. Several patients felt unhappy with the information given to them at diagnosis of recurrence. Some reported dissatisfaction at the way in which they learned of their condition in that some felt it too impersonal. Others deemed the behaviour and communication of healthcare professionals to be unsatisfactory, and half of their participants reported unhappiness with the care received (Lehto et al., 2015); however, experiences varied between the treatments undertaken. Maguire et al. (2017) noted that most of their sample were satisfied with the information they received about their condition and largely felt low regret over their choices regarding treatment. The participants in one

(Ames et al., 2008) study reported generally good relationships with their doctors. In terms of social relationships, participants in the same study reported the maintenance of good social relationships as an important marker of their QoL, and social support from friends and family was commonly reported as a useful method of coping with the cancer (Ames et al., 2008; Lehto et al., 2015). In the study by Lehto et al. (2015) most participants regarded their condition as having no effect on the relationship with their partner. One study (Ames et al., 2008) found that men with a recurrence of prostate cancer had worse health-related and prostate cancer-specific QoL than patients without recurrence, though the general QoL of recurrent patients in this study was higher than patients with other chronic illnesses. Pietrow et al. (2001) found small negative differences in health-related QoL in patients with recurrence vs. those without, but deemed overall QoL to be very similar in these two groups.

Comparison Between Breast and Prostate Cancer

Despite differences in the physical manifestation of breast and prostate cancer, some physical symptoms were highly prevalent in both types of cancer: pain; fatigue; problems with sexual activity; and bowel and bladder issues. Psychological morbidity was common for both cancer types. Some negative emotions, common with either type of cancer recurrence, were: sadness, worry, irritability, anxiety, uncertainty, and stress. Several, though not the majority of patients of both cancer types expressed dissatisfaction with medical professionals. The importance of social relationships as a means of emotional support was commonly reported across both cancer types. Noting differences is complex due to the disparity in the number of breast and prostate cancer studies. For example, as opposed to breast cancer (Okamura et al., 2000, 2005), no studies assessed prostate cancer patients for formal criteria of psychological disorders. More physical problems were associated with breast cancer recurrence, though the above issue may in part account for this.

Quality Appraisal

The MMAT includes five criteria of quality to judge studies (Hong et al., 2018). Included studies' quality scores ranged from meeting three out of the five criteria to meeting all five criteria. These criteria differ based upon the design of each study. Most studies were found to be of moderate quality. Of the 15 studies with a quantitative design it was observed that quality differed, with only five judged to meet all five criteria (Okamura et al., 2000; Northouse et al., 2002; Oh et al., 2004; Lehto et al., 2015; Maguire et al., 2017). The two studies with a qualitative design (Hall et al., 1996; Sarenmalm et al., 2009) were judged to meet all five criteria. The two studies with mixed-methods methodology were judged to only meet three criteria (Turner et al., 2005; Ames et al., 2008). An issue with both of these studies was that the authors did not outline explicitly how each research component integrated with the other. Many studies had small sample sizes as well as being at risk of non-response bias, which lowered the generalisability of the results. **Table 4** contains full details of the quality assessment of the included studies; and for ease of comparison, quality scores are displayed in **Tables 1**, **2** alongside study details.

DISCUSSION

From the available evidence, there appears to be several similarities in the experience of recurrent breast and prostate cancer. Moreover, most disparities appear within cancer types, with mixed results for certain outcomes across studies. The reported psychological factors indicate the biggest differences between studies (and not between cancer types). It is worth consideration that this could be in part related to the different outcome measures used to capture the experience of recurrent cancer. This is perhaps best demonstrated by the disparity already identified within Ames et al. (2011), wherein participants rated their mood highly when measured qualitatively but low when measured quantitatively.

The prostate cancer study (Ames et al., 2011) that reported generally positive mood of patients with recurrence was rated moderately, meeting 3 out of 5 quality criteria. The same rating was given to the study (Ames et al., 2008) where participants' mood rated high when measured qualitatively, but not quantitatively. Little difference in QoL between patients with recurrence and those with primary diagnosis was found by Pietrow et al. (2001), and this study was judged to meet 4 out of 5 quality criteria; a rating also given to the study (Ullrich et al., 2003) which found that recurrence in itself was not a significant factor on cancer fear and mood disturbance. However, fear was considered higher in patients with recurrence than without in the study by Maguire et al. (2017). This set of results initially suggests that the quality of studies may be important in interpreting results. However, the findings from the breast cancer studies may counter this opinion with one study (Oh et al., 2004) finding generally good mood and low levels of cancer specific-stress. This particular study was judged to meet all 5 quality criteria.

As this review was not examining the efficacy of a treatment or intervention, but rather examining the experiences of included patients, the process of distinguishing between RCTs and other study designs, in terms of levels of evidence, would not be as pertinent as it may otherwise be. Hence, the study featuring an RCT was a prostate cancer study (Ames et al., 2011) and diverged most from the other prostate cancer studies. It is interesting that this was a pilot study and therefore had a relatively small sample size. Inconsistent results were found within other study designs which suggests therefore that these design features do not necessarily explain differences found between studies.

The articles reviewed infer that gender may not explain differences in the recurrence experience. Interestingly, a recent meta-analysis suggests that fear of cancer recurrence is stronger in women than men, but whether this applies to emotional distress after actually experiencing a recurrence is unclear from this review. There is some suggestion that gender plays a role in how primary cancer is experienced (Pud, 2011; Linden et al., 2012); however, the literature is mixed in

that some research has found little difference or inconsistent results in relation to various aspects of the cancer experience between genders (Miaskowski, 2004; Garrett et al., 2011; Ahmed et al., 2017).

It has been suggested that the fear of cancer recurring decreases with age (Lim and Humphris, 2020), so that younger cancer survivors will be more concerned about this possibility.

TABLE 4 | Quality appraisal.

Qualitative	Is the qualitative approach appropriate to answer the research question?	Are the qualitative data collection methods adequate to address the research question?	Are the findings adequately derived from the data?	Is the interpretation of results sufficiently substantiated by data?	Is there coherence between qualitative data sources, collection, analysis and interpretation?
Hall et al. (1996)	Yes	Yes	Yes	Yes	Yes
Sarenmalm et al. (2009)	Yes	Yes	Yes	Yes	Yes
Quantitative randomised controlled trials	Is randomisation appropriately performed?	Are the groups comparable at baseline?	Are there complete outcome data?	Are outcome assessors blinded to the intervention provided?	Did the participants adhere to the assigned intervention?
Ames et al. (2011)	Can't tell	Yes	Yes	No	Yes
Quantitative non-randomised	Are the participants representative of the target population?	Are measurements appropriate regarding both the outcome and intervention (or exposure)?	Are there complete outcome data?	Are the confounders accounted for in the design and analysis?	During the study period, is the intervention administered (or exposure occurred) as intended?
Andersen et al. (2005)	Can't tell	Yes	Yes	Yes	Yes
Cleeland et al. (2014)	Yes	Yes	No	Yes	No
Cohen (2002)	Yes	Yes	Yes	Yes	Yes
Northouse et al. (2002)	Yes	Yes	Yes	Yes	Yes
Oh et al. (2004)	Yes	Yes	Yes	Yes	Yes
Pietrow et al. (2001)	Yes	No	Yes	Yes	Yes
Ullrich et al. (2003)	Yes	No	Yes	Yes	Yes
Quantitative descriptive	Is the sampling strategy relevant to address the research question?	Is the sample representative of the target population?	Are the measurements appropriate?	Is the risk of non-response bias low?	Is the statistical analysis appropriate to answer the research question?
Brady and Helgeson (2000)	Yes	Yes	No	Yes	Yes
Bull et al. (1999)	Yes	Yes	Yes	No	Yes
Lehto et al. (2015)	Yes	Yes	Yes	Yes	Yes
Maguire et al. (2017)	Yes	Yes	Yes	Yes	Yes
Okamura et al. (2000)	Yes	Yes	Yes	Yes	Yes
Okamura et al. (2005)	Yes	Yes	Yes	No	Yes
Sarenmalm et al. (2007)	Yes	Yes	Yes	No	Yes
Sarenmalm et al. (2008)	Yes	Yes	Yes	No	Yes
Thornton et al. (2005)	Yes	Yes	Yes	No	No
Mixed methods	Is there an adequate rationale for using a mixed methods design to address the research question?	Are the different components of the study effectively integrated to answer the research question?	Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?
Ames et al. (2008)	No	No	Yes	Yes	Yes
Turner et al. (2005)	Yes	No	Yes	No	Yes

This is plausibly explained by younger people having a longer life expectancy. In the current review breast cancer patients with recurrence were generally younger than those with prostate cancer, and so this could apply to the lived experience of recurrence rather than just the fear. However, with minimal difference found between the cancer types this suggestion is not supported.

In summary, findings from this review point to differences in the recurrent cancer experience being based upon individual factors, rather than having either recurrent breast or recurrent prostate cancer. There is evidence in this review to support this interpretation. As indicated previously, social support was important to patients at the time of recurrence. Previous research (Yoo et al., 2017) has found a link between higher perceived social support and higher quality of life and lower depressive symptoms among patients with a primary diagnosis of cancer, thus logically this may apply at the time of recurrence. Further, there was indication that treatment received may be an important factor in quality of life. It has been suggested that differing treatment in primary prostate cancer patients led to different physical problems (Bacon et al., 2001), and this could therefore subsequently impact on psychological well-being. Thus, it is possible that the experiences of patients may differ based on factors such as these, and would be would be worthy of further investigation.

Comparison to Previous Research

Within the literature, it is firmly established that fear of cancer recurrence, as well as an actual recurrence of cancer, are sources of emotional distress (Simard et al., 2013; Schouten et al., 2019); as such, this review is consistent with findings from the metaethnography carried out by Wanat et al. (2016) and the earlier narrative review by Vivar et al. (2009), which both described a wide range of negative issues that accompany cancer recurrence. This review adds to this research by conducting a comparison of cancer types, based upon the available literature. As noted, breast and prostate cancer were chosen as they differ in a number of ways, not least as they effect males and

females (almost) exclusively, but future research could be designed to capture a wider range of cancer types than just breast and prostate cancers. Such research would help to clarify these findings.

Limitations

Though the review was exploratory in nature, the cancer type comparison conducted should be read with the caveat that there were far fewer studies included examining the experience of patients with recurrent prostate cancer as opposed to breast cancer. All prostate cancer studies were quantitative, and whilst the integrative nature of this review means the study design is less important, it is perhaps indicative of the relative lack of research into the experience of recurrent prostate cancer patients. As such, there were some aspects of the patient experience that were measured solely in breast cancer patients and therefore cannot be compared. Whilst a gender difference is an interesting comparison point, with the two cancer types selected it is not possible to delineate between cancer type and gender as factors in how cancer recurrence is experienced, this is a major limitation of the review. This is partially offset by being only one of a number of factors discussed, but to further distinguish between gender and cancer type it would be beneficial in any future comparison to include another cancer type that affects men and women on a fairly equal proportion. In addition, several of the studies were not primarily exploring the experience of patients with recurrent cancer but had some patients who had recurred included in their analysis. Another limitation is the variety of timing when patients were investigated. For example, there were different time points when data were collected, as well as the time between initial diagnosis and recurrence varying across studies.

Recommendations

An exploratory, longitudinal study directly comparing cancer types at the time of a recurrence would greatly add to the findings of this review. Ensuring high methodological quality of such research would address

concerns raised in this review. This review has touched on factors that may result in lower quality of life in recurrent cancer patients (such as age, disease stage, and treatment received) that were not easily compared here. As such these could be explored as moderating variables in this new suggested research.

Clinical Implications

Healthcare professionals may find this review of assistance to clarify what patients may experience at the time of a cancer recurrence with two prevalent cancer types. It was demonstrated that between these cancers, the experience of cancer recurrence might have many similarities, and as such due consideration is needed toward the care and support of the individual at the time of a cancer recurrence.

CONCLUSIONS

This review primarily sought to identify if, based on evidence from the published literature, the type of cancer a patient had at the time of a recurrence had an impact on how cancer recurrence is experienced-based upon physical, psychological, and psychosocial indices of QoL in recurrent breast and prostate cancer patients. It highlights the multifarious issues created for cancer patients at the time of a cancer recurrence, thereby building upon findings from such previous research (Vivar et al., 2009; Wanat et al., 2016). Based upon the comparison conducted, findings suggest that it is likely that any differences in the experience of recurrent cancer are more heavily influenced by individual factors, rather than cancer type, though concerns have been raised about available study quality and differing outcome measures in this interpretation. Adding to the literature, this review is the first to specifically explore and compare the experience of patients with recurrent prostate or breast cancer; the most common cancers in males and females, respectively. As such, it has been possible to explore potential reasons for differences in experience.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author/s.

AUTHOR CONTRIBUTIONS

RS, SC, JD, and GH conceived of the review. RS and SC were responsible for study screening and quality assessment.

RS conducted data analysis and drafting of the manuscript. SC, JD, and GH made important revisions to the paper. All authors contributed to the article and approved the submitted version.

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Appendix 2- Study recruitment poster

CAN YOU HELP OUR RESEARCH?

Cancer Progression: Capturing the Concerns of Patients Living with Cancer Recurrence

What is the purpose of the study?

We want to explore the experiences of patients with a recurrence of cancer. We would like to you to describe your quality of life, your emotional well-being, including how much concern you have that your cancer will progress. We would also like to ask you some questions to see if the Covid-19 pandemic concerns you in relation to your cancer and your treatment.

Who can take part?

Anybody who has experienced a recurrence of their cancer within the last 3 years can take part.

Why participate?

Taking part can help patients in future. The results of this study will help to identify needs at the time of a recurrence of cancer. The results of this study may provide health care professionals with greater understanding about these needs and tailor care based upon this.

What will happen if I take part?

You will complete a questionnaire, and this should take approximately 20 minutes. You will be asked to complete these questionnaires on two more occasions after this on a monthly basis, by telephone/video call, or we can post these to you. You will ask you to share your thoughts about your diagnosis and care, any concerns you may have about the cancer progressing as well as any impact the Covid-19 pandemic has had on you.

FOR MORE INFORMATION

If you are interested or have any questions please don't hesitate to contact:

- **Ross Stewart** r.j.stewart@stir.ac.uk
- **Susanne Cruickshank** susanne.cruickshank@rmh.nhs.uk

The ROYAL MARSDEN

NHS Foundation Trust

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Participant Information Sheet

Cancer Progression: Capturing the Concerns of Patients Living with Cancer Recurrence.

You are being asked to take part in a research study called *Cancer Progression: Capturing the Concerns of Patients Living with Cancer Recurrence* . We are a research team based at the University of Stirling. The purpose of this information sheet is to help you decide if you want to be in the research study. Please read this information sheet carefully. You can choose whether or not you want to be in this study. Before you can make your decision, you need to know what the study is about, the possible risks and benefits of being in this study, and what you will have to do in this study. You may wish to talk to others about the study before taking part.

What is the purpose of the study?

The purpose of the study is to explore the experiences of patients with a recurrence of cancer. We would like to you to describe your quality of life, your emotional well-being, including how much concern you have that your cancer will progress. We would also like to ask you some questions to see if the current Covid-19 pandemic concerns you in relation to your cancer and your treatment.

Why am I being asked to participate?

You are being asked to participate as you have experienced a recurrence of cancer and we would like to examine your experience of the disease.

Do I have to take part?

No, you do not have to take part. Participation is entirely voluntary and you will be free to withdraw at any time without giving a reason, and withdrawal would have no impact on your care. You will be given this information sheet to keep and be asked to sign a consent form. Should you wish to withdraw from the study at any time, you are at liberty to do so and we will not collect any more data from you. However, any data collected up until the point that you withdraw will be kept and used in the data analysis.

What will happen if I take part?

There are two phases of the study. For the initial phase of the study you will need to complete a questionnaire, and this should take approximately 10 minutes. You will be asked to complete these questionnaires on two more occasions after this on a monthly basis, by telephone/video call, or we can post these to you.

The second phase of the study involves one interview (also over the phone or by video call) about your experiences, which will be recorded, and this will take approximately 30 minutes. You will be able to indicate on the consent form if you wish to be contacted to take part in the next phase of the study, though not everybody will take part in this phase.

Are there any potential risks in taking part?

There is minimal risk for you by taking part in this study:

- There is minimal risk of loss of privacy/confidentiality. We will lessen this risk by removing your identifying information from any documents before data is analysed. All questionnaires and interview transcripts will be stored securely in a locked container.
- You may feel uncomfortable answering some of the questions asked in the questionnaire and/or the interview. You can stop the conversation at any point and if you feel you require any support after the interview we will advise you of who will be suitable to contact to discuss this further.

Are there any benefits in taking part?

There will be no direct benefit to you from taking part in this research. However, the results of this study will help to identify the needs of patients at the time of a recurrence of cancer. The results of this study may provide health care professionals with greater understanding about these needs and tailor care based upon this.

Legal basis for processing personal data

As part of the project we will be recording personal data relating to you. This will be processed in accordance with the General Data Protection Regulation (GDPR). Under GDPR the legal basis for processing your personal data will be public interest/the official authority of the University.

We will also be processing your sensitive categories of personal information relating to your health for research purposes in the public interest.

What happens to the data I provide?

We will need to collect some information about you for the research project. This information will include your name, contact details and details about your cancer. Nobody except the research team will be able to see your name or contact details. Your data will have a code number instead. We will keep all personal information secure.

Once the study is finished, we will keep some of the data so we can check the results. Our write-up will be done in a way that nobody can work out that you took part in the study. We may also use the information collected in this study for future research studies. The research data will be stored securely and kept anonymous with identifying information removed from any documents before data is analysed. Research data will be kept for a minimum of 10 years.

Your personal data will be kept on Research Drive (a secure data centre on the Stirling campus), until the project is complete, no longer than 3 years- and then will be securely destroyed. If taking part in the interview, we will ask all participants for their permission to record this and use direct quotes in our write-up.

Will the research be published?

The research is intended to be published in an academic journal. You will not be identifiable in any report/publication. The University of Stirling is committed to making the outputs of research publicly accessible and supports this commitment through our online open access repository STORRE. Unless funder/publisher requirements prevent us, this research will be publicly disseminated through our open access repository.

Who has reviewed this research project?

The ethical approaches of this project have been approved via The University of Stirling NHS, Invasive & Clinical Research Ethics Committee, and the NHS London - Stanmore Research Ethics Committee.

Your rights

You have the right to request to see a copy of the information we hold about you and to request corrections or deletions of the information that is no longer required.

You have the right to withdraw from this project at any time without giving reasons and without consequences to you. You also have the right to object to us processing relevant personal data however, please note that once the data are being analysed and/or results published it may not be possible to remove your data from the study.

Who do I contact if I have concerns about this study or I wish to complain?

Members of the research team will be pleased to answer any question you may have and can be contacted at:

Contact	Telephone	Email
Ross Stewart	07754368225	r.j.stewart@stir.ac.uk
Sue Cruickshank	020 78118516	susanne.cruickshank@rmh.nhs.uk

If you would like to discuss the research with someone independent of the study, then please contact Dr. Ashley Shepherd. You can email Ashley at ashley.shepherd@stir.ac.uk or call her at 01786466334

You have the right to lodge a complaint against the University regarding data protection issues with the Information Commissioner's Office (https://ico.org.uk/concerns/).
The University's Data Protection Officer is Joanna Morrow, Deputy Secretary. If you have any questions relating to data protection these can be addressed to data.protection@stir.ac.uk in the first instance.

Full list of Investigators:

Mr. Ross Stewart

Health Sciences and Sport

University of Stirling

Stirling, UK

Prof. Gerald Humphris

School of Medicine

University of St. Andrews

St. Andrews, UK

Prof. Jayne Donaldson

Health Sciences and Sport

University of Stirling

Stirling, UK

Dr. Susanne Cruickshank

Strategic Lead for Applied Health Research

The Royal Marsden NHS Foundation Trust

London, UK

Thank you for your participation.

Appendix 4: Participant consent form

Participant Consent Form

NICR Approval Number: 19/20 – 095   Participant number:

Research Project Title: Cancer Progression: Capturing the Concerns of Patients Living with Cancer Recurrence.

Do you consent to be contacted about the follow-up study as described in the information sheet

dated [insert date]? Yes ☐ No ☐

	Please initial box
I confirm that I have read and understood the information sheet dated [insert date] explaining the above research project and I have had the opportunity to ask questions about the project	
I understand that my participation is voluntary and that I am free to withdraw at any time during the study at any time without giving a reason, and without any penalty. I understand that data already collected with consent would be retained and used in the study, and that no further data would be collected or any other research procedures carried out in relation to myself.	
I understand that my responses will be kept anonymous and I give permission for members of the research team to have access to my anonymised responses.	
I consent to being audio recorded.	
I understand how audio will be used in research outputs. I am aware that I will not be named in any research outputs but I could be identified by people I know through the stories I tell.	
I give permission to be quoted directly in the research publication anonymously.	
I agree to my personal data being kept securely for a maximum of 3 years before being destroyed.	
I agree to my anonymous data to be stored for 10 years and to be shared for additional analysis by other researchers with similar research interest.	
I agree to take part in this study	

Name of Participant   **Signature:**

Date: Click here to enter a date

Name of Researcher   **Signature:**

Date: Click here to enter a date

Appendix 5: Letters of ethical approval

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Mr Ross Stewart

Faculty of Health Sciences and Sport

Email: approvals@hra.nhs.uk

HCRW.approvals@wales.nhs.uk

University of Stirling

Stirling

FK9 4LA

08 February 2021

Dear Mr Stewart

HRA and Health and Care

Study title:	**Cancer Progression: Capturing the Concerns of Patients Living with Breast and Prostate Cancers**
IRAS project ID:	**287677**
Protocol number:	**N/A**
REC reference:	**20/PR/0852**
Sponsor	**University of Stirling**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:
- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **287677**. Please quote this on all correspondence.

Yours sincerely,

Kathryn Davies

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: Ms. Rachel Beaton

Ross Stewart

Faculty of Health Sciences and Sport

University of Stirling FK9 4LA

NHS, Invasive or Clinical
Research (NICR)
Panel

Research and Innovation Services
3B1 Cottrell Building
University of Stirling
Stirling   FK9 4LA

Tel: +44 (0) 1786 466233
Email: nicr@stir.ac.uk

01 July 2020

Dear Ross,

Cancer Progression: Capturing the Concerns of Patients Living with Breast and Prostate Cancers - NICR 19/20 – 095

Thank you for your recent submission, which was discussed at the Panel meeting on 30 June 2020.

The ethical approaches of your project have been approved for submission to NHS IRAS, subject to the following:

1 There is not enough detail in the IRAS form and this may result in rejection or request for resubmission. You should ensure that all of the key points are addressed in the form rather than just be reported in the protocol. You should pay particular attention to detailing the ethical issues in full within that section of the form. You also need to thoroughly read the two documents side by side to identify and remove a number of inconsistencies. For instance, on the IRAS form it is stated that a GP will not be informed, while the protocol states that consent will be sought to inform GP of participants taking part in study

2 There is insufficient justification/rationale for a comparison between breast and prostate cancer. This should be made clearer.

3 A6-1 requires some further elaboration about what you will do and how, since this will go on the HRA website. Clarify that you do not mean to recruit people with breast AND prostate cancer.

4 More detail needs to be given on recruitment and consenting processes. A18 – There should be 24h between discussing the study and obtaining consent after giving the participant the opportunity to ask questions about the study. A27-1 More information is required on how/when participant details will be accessed through hospital electronic systems

5   An estimate of the sample needs to be given for both the qualitative and quantitative parts of the study.

6   A33-1 states that 'reasonable measures' would be put in place to facilitate participation. Please elaborate on what these might be.

7   A35 – consent to retain data even if a participant withdraws needs to be specifically obtained at the outset and should be reflected in the consent form.

8   A53 – since participants will be informed of findings this needs to be reflected in section A14-1

9   A59 – more information is required on how the interview subgroup will be identified

10 A76-2/3 – Add details on insurance arrangements, presumably they are through the University

11 Participant information sheet mentions a question regarding how COVID-19 affected their concerns regarding cancer but there's no mention of this in the IRAS form

12 In the PIS it is stated that they will sign a consent form but in IRAS form it is stated that it will be verbal

May I remind you of the need to inform NICR (nicr@stir.ac.uk) prior to making any amendments to this protocol, or any changes to the duration of the project and provide notification of study completion.

The University of Stirling is recognised as a Scottish Charity with number SC 011159

Learning and Development information is available on the NHS HRA website: https://www.hra.nhs.uk/planning-and-improving-research/learning/

Please bear in mind that your study could be audited for adherence to research governance and research ethics protocols.

NICR 19/20 – 095
Please quote this number on all correspondence

Yours sincerely,

J. Harris

On behalf of NICR

Dr Fiona Harris Deputy Chair of NICR

Appendix 6: Research questionnaire

Hospital Anxiety and Depression Scale

Tick the box beside the reply that is closest to how you have been feeling in the past week.

I feel tense or 'wound up'

- Most of the time □
- A lot of the time □
- From time to time, occasionally □
- Not at all □

I still enjoy the things I used to enjoy:

- Definitely as much □
- Not quite so much □
- Only a little □
- Hardly at all □

I get a sort of frightened feeling as if something awful is about to happen:

- Very definitely and quite badly □
- Yes, but not too badly □
- A little, but it doesn't worry me □
- Not at all □

I can laugh and see the funny side of things:

- As much as I always could □
- Not quite so much now □
- Definitely not so much now □
- Not at all □

Worrying thoughts go through my mind:

- A great deal of the time □
- A lot of the time □
- From time to time, but not too often □
- Only occasionally □

I feel cheerful

- Not at all □
- Not often □
- Sometimes □
- Most of the time □

I can sit at ease and feel relaxed

- Definitely ☐
- Usually ☐
- Not Often ☐
- Not at all ☐

I feel as if I am slowed down

- Nearly all of the time ☐
- Often ☐
- Sometimes ☐
- Not at all ☐

I get a sort of frightened feeling like 'butterflies in the stomach'

- Not at all ☐
- Occasionally ☐
- Quite often ☐
- Very often ☐

I have lost interest in my appearance

- Definitely ☐
- I don't take as much care as I should ☐
- I may not take quite as much care ☐
- I take just as much care as ever ☐

I feel restless as if I have to be on the move

- Very much indeed ☐
- Quite a lot ☐
- Not very much ☐
- Not at all ☐

I look forward with enjoyment to things

- As much as I ever did ☐
- Rather less than I used to ☐
- Definitely less than I used to ☐
- Hardly at all ☐

I get sudden feelings of panic

- Very often indeed ☐

- Quite often ☐
- Not very often ☐
- Not at all ☐

I can enjoy a good book or radio or TV programme

- Often ☐
- Sometimes ☐
- Not often ☐
- Seldom ☐

EQ5-D-5-L

For each group below, please place a tick in one box that best describes your health today.

Mobility

I have no problems in walking about ☐

I have slight problems in walking about ☐

I have moderate problems in walking about ☐

I have severe problems in walking about ☐

I am unable to walk about ☐

Self-Care

I have no problems washing or dressing myself ☐

I have slight problems washing or dressing myself ☐

I have moderate problems washing or dressing myself ☐

I have severe problems washing or dressing myself ☐

I am unable to wash or dress myself ☐

Usual Activities *(e.g. work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ☐

I have slight problems doing my usual activities ☐

I have moderate problems doing my usual activities ☐

I have severe problems doing my usual activities ☐

I am unable to do my usual activities ☐

Pain/Discomfort

I have no pain or discomfort ☐

I have slight pain or discomfort ☐

I have moderate pain or discomfort ☐

I have severe pain or discomfort ☐

I have extreme pain or discomfort ☐

Anxiety/Depression

I am not anxious or depressed ☐

I am slightly anxious or depressed ☐

I am moderately anxious or depressed ☐

I am severely anxious or depressed ☐

I am extremely anxious or depressed ☐

Fear of Cancer Progression 12 & 4 Item.

Fear of Progression	Never				Very Often
	1	2	3	4	5
1. Being afraid of disease progression					
2. Being nervous prior to doctor's appointments or periodic examinations					
3. Being afraid of pain					
4. Being afraid of becoming less productive at work					
5. Having physical symptoms (e.g., rapid heartbeat, stomach ache)					
6. Being afraid by the possibility that the children could contract the disease					
7. Being afraid of relying on strangers for activities of daily living					
8. Being afraid of no longer being able to pursue hobbies					
9. Being afraid of severe medical treatments in course of illness					
10. Worrying that medications could damage the body					
11. Worrying what will become of family if something happens to me					
12. Being afraid of not being able to work anymore					

1. I am afraid that my cancer may progress.

Not at all ☐ A little ☐ Sometimes ☐ A lot ☐ All the time ☐

2. I am worried about the possibility of cancer progression.

Not at all ☐ A little ☐ Sometimes ☐ A lot ☐ All the time ☐

3. How often have you worried about the possibility of cancer progressing?

None of the time ☐ Rarely ☐ Occasionally ☐ Often ☐ All the time ☐

4. I get waves of strong feelings about the cancer progressing.

Not at all ☐ A little ☐ Sometimes ☐ A lot ☐ All the time ☐

Cancer and the COVID-19 Anxiety Scale (CCAS)

1. Are you anxious that you will receive timely treatment (if required)?

Not at all ☐ A little ☐ Sometimes ☐ A lot ☐ All the time ☐

2. Are you anxious that you will be offered the most effective treatment (if required)?

Not at all ☐ A little ☐ Sometimes ☐ A lot ☐ All the time ☐

3. Are you anxious that you will catch the Coronavirus?

Not at all ☐ A little ☐ Sometimes ☐ A lot ☐ All the time ☐

4. Are you anxious that you will survive the Coronavirus?

Not at all ☐ A little ☐ Sometimes ☐ A lot ☐ All the time ☐

Appendix 7: Interview schedule

KEY QUESTIONS	ADDITIONAL PROMPTS
Could you tell me about your experience of recurrent cancer?	How was it diagnosed? Had you been expecting it? How did you feel at the time?
How has your follow-up care been?	Do you feel you have support from your care team? What about social support?
How would you describe your health right now?	Are you having any issues with mobility? How about issues with self-care? And in relation to your usual activities? Are you experiencing pain?
How anxious have you been feeling?	Do you often feel 'butterflies' in your stomach? Are you able to relax and feel at ease?
Have you been feeling down since the diagnosis?	Do you still enjoy things you did before your diagnosis? Do you look forward to things coming up?
Do you worry about your condition worsening?	Are you nervous before hospital appointments?
Would you say that your worries about your condition progressing are strong?	How often do you think about it worsening? Do you find these worries affect you getting on with your daily life?
Has any support been offered to you to address these worries?	Have your healthcare professionals mentioned any support available?
Do you feel the COVID-19 pandemic has affected your care?	In relation to treatment? In relation to communicating with your usual care team?
In relation to your cancer are you particularly worried about contracting COVID-19?	Do you feel more at risk of serious symptoms?