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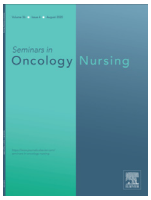

Scan-Associated Distress in People Affected by Cancer: A Qualitative Systematic Review

M. Hussain[a], S. Chau[b], M. Turner[a], C. Paterson[a,b,c,d,e,*]

[a] *Faculty of Health, University of Canberra, Bruce ACT, Australia*
[b] *Caring Futures Institute, Flinders University, Australia*
[c] *Central Adelaide Local Health Network, Adelaide*
[d] *Robert Gordon University, Aberdeen, Scotland, UK*
[e] *Flinders Medical Centre, Adelaide, Australia*

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ABSTRACT

Objective: The term "scanxiety" has been coined to describe the anxiety commonly associated with individuals undergoing cancer-related imaging. Despite the prevalence and severity of scanxiety across various clinical and demographic populations, there remains a significant lack of qualitative insights from existing studies that effectively capture patients' experiences of scanxiety in their own words. Therefore, this review addresses the following research question: What are the experiences of scanxiety distress among people affected by cancer across the cancer care continuum?
Data Sources: Following the PRISMA methodology, a meta-aggregation of qualitative studies was performed, encompassing patients of all age groups who had been diagnosed with cancer or were indicated for a cancer-related scan. Of the 556 articles screened, 15 were deemed eligible for inclusion in the analysis.
Conclusion: The three overarching themes of 1) experience of "scan-itis," 2) experience of "patient-clinician support," and 3) development of self-management strategies reveal the complex and interconnected factors that influence scanxiety in individuals undergoing cancer-related imaging. These findings emphasized distress experienced by patients during the waiting period for scan results, the act of viewing the results, and even the delivery of "bad" news. Consequently, patients expressed a strong desire for increased information, communication, and empathy from attending healthcare providers. Patients also report a myriad of self-coping strategies to manage their scanxiety well before, during, and after their scan appointment.
Implications for Nursing Practice: The study highlights the need for targeted interventions for those undergoing cancer-related scans, including increased awareness and education for health professionals regarding scanxiety.

Introduction

Globally, cancer is a significant cause of mortality. In 2020, cancer accounted for 10 million deaths, equating to nearly one in six people.[1] All patients affected by cancer will require medical imaging to stage their cancer at diagnosis and at subsequent time points to assess response to treatment and monitor for cancer recurrence. Evidence has underscored[2-6] that many patients in the lead-up to their scans, during and after their imaging, can experience significant distress, also known as "scanxiety."[7] The term scanxiety has been defined as a particular type of distress reported by patients who are scheduled for cancer imaging to assess their disease.[7] Patients report imaging distress due to a fear of treatment failure, disease progression, or disease recurrence, and this has been directly related to reduced quality of life.[3,8,9]

The prevalence and severity of scanxiety have been reported to a varying degree in different clinical and demographic populations,[10] and existing systematic reviews have collated quantitative comparisons over time. Overall, scanxiety prevalence has been shown to range from 0% to 83%.[10] Such large disparities have been explained by significant divergence in study designs and measurements used.[10] Noteworthy recent systematic reviews[10] did not provide qualitative insights from existing studies to understand patients' own individual accounts of scanxiety, through their words, which may provide valuable insights into the patients' experience of having cancer related scans during staging, diagnosis, and screening.[2,5,11,12]

Qualitative studies[2,5,11-13] have identified that patient experiences of distress around medical imaging can vary significantly, and patients articulated the need for reassurance, hope, improved understanding, and

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* Address for correspondence: Catherine Paterson, Professor of Cancer Nursing, PhD., Caring Futures Institute, Flinders University, Sturt Campus, Australia.
E-mail address: catherine.paterson@flinders.edu.au (C. Paterson).

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enhanced feelings of control over their condition from healthcare professionals. Supportive care is a term used to describe a person-centered holistic approach in relation to the provision of cancer services for those living with or affected by cancer.[14-16] This holistic lens to care encompasses the informational, social, psychological, spiritual, and physical needs during diagnosis, treatment, or follow-up phases, including interventions to optimize support to help patients affected by scanxiety to cope. Healthcare professionals and researchers are yet to fully understand the qualitative experiences of people affected by scanxiety.[10] Therefore, there is a clinical need to synthesize the qualitative experiences among patients affected by cancer-related scanxiety, to understand their experiences as articulated by them. Addressing the supportive care needs related to scanxiety distress is considered a modifiable factor in clinical practice because of the direct causal impact on quality of life.[17] Therefore, the aim of this systematic review is to understand qualitative experiences of scanxiety among people affected by cancer inclusive of all types, stages, and indications for having a cancer-related scan.

Research question: What are the experiences of scanxiety distress among people affected by cancer across the cancer care continuum?

Method

This systematic review was reported according to Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.[18] A meta-aggregation of qualitative studies was conducted to identify the experience of scanxiety among people affected by cancer. The presentation of findings conforms to the Enhancing Transparency in Reporting of the Synthesis of Qualitative Research (ENTREQ) statement[19] (see Supplementary Table 1). This review was conducted according to a priori protocol available from PROSPERO [CRD42023393039].

Preeligibility Screening Criteria

Inclusion criteria were all qualitative studies irrespective of research design, including qualitative components of mixed methods studies, and studies published in peer-reviewed journals.

Exclusion criteria were all quantitative publications, conference abstracts, commentaries, editorials, or studies which did not provide data to address the research question.

Participants were all patients (irrespective of age) who were diagnosed with cancer (all cancer types and stage) or had an indication for a cancer-related scan. Cancer-related reasons for noninvasive scans included screening (detection of cancer), diagnosis (cancer detection), staging (evidencing the stage of cancer), and surveillance (monitoring for detection or progression). The experience of scanxiety was the primary focus of the review.

Search Strategy

The APA PsycINFO, CINAHL, Cochrane Library (DSR and CENTRAL), MEDLINE, and Scopus databases were searched on January 30, 2023, and repeated using the same search on July 3, 2023, to identify all current relevant studies. To increase the inclusivity of results, no language or other limiters were placed on any of the database searches. Relevant systematic reviews were scrutinized for potentially relevant studies for screening. The search architecture was designed by an expert librarian, utilizing the efficient search method for systematic reviews developed at Erasmus Medical Center.[20] The management of citations was conducted using Endnote software. The search used a combination of key words and subject headings to increase the sensitivity and inclusiveness of the searches and capture the "sample" (people affected by cancer) and "phenomenon of interest" (scan-related anxiety). See Supplementary Table 2 for the full record of database searches.

Study Selection

All publications were imported into Covidence systematic review software for de-duplication and the study selection process. All titles, abstracts, and full-text publications were reviewed independently by two reviewers according to the inclusion and exclusion criteria. Any conflicts throughout the process were resolved by discussion. Full-text studies not meeting the inclusion criteria were excluded, and reasons for exclusion provided.

Assessment of Methodological Quality

Methodological quality assessment of all the included studies was completed using the JBI Critical Appraisal Checklist for Qualitative Research.[21] The quality assessment items were consolidated and represented in a final quality appraisal table. The included studies were assigned a score based on each question within the appraisal tool, with a rating of yes, no, or unclear.

Data Extraction

The data extracted specifically captured the population, context, geographical location, study methods, and the phenomenon of interest relevant to the review research question. The findings were extracted directly from the original studies, referring to specific quotations that justify the generation of each theme reported. The focus, therefore, was to extract the findings generated by the researchers of each study, without reinterpreting the actual data from the individual studies.

Analytical Approach

The JBI method of meta-aggregation was used to extract, synthesize, and categorize the data. All findings were assessed for congruence and were given a ConQual ranking of either "unequivocal" (clear association between the finding and illustration), "equivocal" (unclear association between the finding and illustration, leaving it open to challenge), or "not supported" (findings not supported by data).[21] In keeping with the JBI approach all unsupported findings were not included in the final synthesis. Two or more findings were grouped into categories and further synthesis undertaken to produce a single comprehensive description of the findings to represent each category. Qualitative research findings (subthemes and illustrative quotes) across the included studies were synthesized using a thematic analysis approach. Specifically, the synthesis of findings enabled the generation of a set of statements that represented similar findings, which were categorized based on the commonality of meaning.[21] Following careful and repeated assessment of the compiled data, two or more findings were grouped into categories and then were grouped together to form overall synthesized findings. The data synthesis involved three steps in this process:

Step 1: The data extraction (findings and illustrative quotes) from the main findings of the original studies were extracted in tabular format.
Step 2: The findings and associated illustrative quotes were group together based on similar meaning.
Step 3: The final step in the meta-aggregation synthesis involved the generation of categories and the final synthesized findings reviewing conclusions with primary sources.

This process in the data synthesis was carried out by one reviewer and quality checked by all review authors. Any disagreements were resolved by discussion.

Findings

Of 556 total publications screened, 15 publications were included (Fig 1). The studies represented different international settings

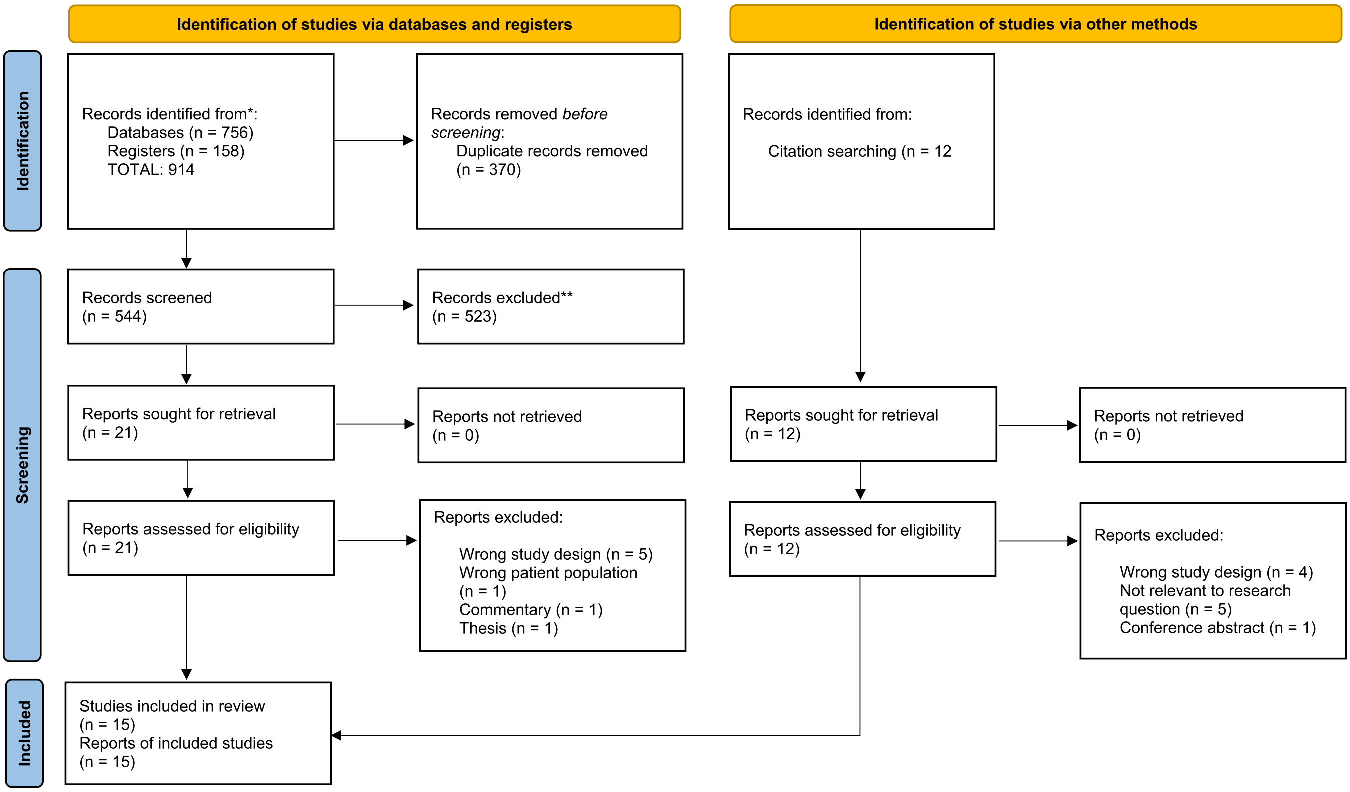

Fig 1. PRISMA diagram.

including Demark,[22] United Kingdom,[23-26] United States of America,[13,27-30] Australia,[2,31] Netherlands,[32,33] and Germany[34] (see Table 1 for overview of studies). This qualitative systematic review represented a total sample of 393, inclusive of breast,[13,22,29] lung,[23,27,31,34] advanced solid cancers,[2] brain,[25,26] mixed cancer samples,[30,32,33] and lymphoma,[28] and one study did not report on clinical characteristics.[24] Overall, the methodological quality was good but there was a notable lack of reporting of the congruity between the stated philosophical perspective and the research methodology across most of the included studies (see Table 2 for results of the quality assessment results).

There was a total of 90 individual findings included in this review (see Supplementary Table 3), which were synthesized into three findings: 1) experience of "scan-it is," 2) experience of "patient-clinician support," and 3) development of "self-management strategies"; see Fig 2 and Table 3 for overviews.

Synthesized Finding 1: Experiences of "Scan-itis"

Two subthemes emerged from synthesized finding 1: (1) patients' experience related to access scan results and (2) their preferences for types and frequencies of surveillance scans. Some of the participants reported to have online access to their scan results, which resulted in a continual dilemma to balance between waiting for the scan results to when their appointment was with their healthcare professional.[22,30] Many patients opted not to look at their online scan results due to the fear that the result was "bad" in the absence from their treating team, because so much rode on their scans.[2,32] Patients also commented on the differences in access to timely scan reporting, noting that computed tomography (CT) scans had longer reporting times compared to magnetic resonance imaging (MRI).[22] Patients also expressed negative experiences of undergoing an MRI scan, which caused both physical and psychological distress[2,13,23,26,31] and patients often preferred CT scans due the less invasive nature. In the time leading up to imaging scans, many patients reported a profound sense of dread with significant levels of anxiety[2,13,26,28-31,34] and described it as "scan-it is."[28]

> *"I dread it for a couple of weeks before. My anxiety builds as I get closer to the date"* (page 201[13])
>
> "*[. . .] there is a lot of anxiety around it, there is a lot of worry about scan-to scan, what's happening, what are we going to do, and um, what's next? And you know, how do you live your life knowing that at any moment, it's all going to come crashing down around you again?"* (page 5[29])

Noteworthy, only one recent study[30] reported as an emergent theme that not all patients affected by cancer experience scanxiety, "I'm not apprehensive. Just has to be done. So I'm at peace with it" (page 471[30]). However, for the most part scan-related distress was present following the procedure and during the time when they received their results,[2] which was heightened if the results were provided over a telephone consultation.[2] The presence of "scanxiety" was very real during consultations, and most people affected by cancer who were undergoing routine cancer imaging scans reported that they tried to main a positive outlook because they were continually challenged by a lack of control due to the uncertainly of the results.

> *"The stress comes out in – around the sleeping pattern. . . I get [a racing heart and sweaty hands] the minute I walk into the hospital. . . I'm tireder. That usually hits a few days before." In response to the scanxiety experience*. (page 7445[2])

Many of the participants reported several types and frequencies of surveillance scans and expressed their own preferences for such frequencies. This preference was linked to safety concerns related to an increased radiation exposure over time.[13] However, scan distress was lessened when patients and their oncologists shared the decision-making about the mode and frequency of their own individualized imaging surveillance protocols.[13] It was clear that the manifestation

Table 1

Characteristics of the Included Studies.

Study	Methods for Data Collection and Analysis	Country	Methodology	Phenomena of Interest	Setting/Context/Culture	Patient Characteristics and Sample Size	Description of Main Results
Baun et al (2020)	***Data Collection:*** Participants received electronic questionnaire about their knowledge and use of online health record. Semiconstructed interviews conducted with four women, elaborating on findings from questionnaire. ***Data analysis:*** Qualitative analysis: Thematic via interpretative phenomenological analysis. Quantitative analysis: Descriptive statistics with nonparametric Wilcoxon rank sum test.	Denmark	Not explicitly reported	**Aim:** increase knowledge regarding patient's experiences of online access to scan results, specifically in the context of the attitudes held by Danish women with metastatic breast cancer.	***Setting:*** single-center study at department of nuclear medicine, Odense University Hospital, Denmark. ***Context:*** patients all have metastatic breast cancer; compromised of first-time users, experienced users and women who had never used the health portal. ***Culture:*** All participants were white.	***Participants:*** participants were female patients with metastatic breast cancer receiving care at Odense University Hospital. Quantitative component: 38 patients (median age 66, SD 11.8, range 34–84 years) Qualitative component: 4 patients from the initial 38. ***Sample Size:*** 46 participants	Seven salient themes: (1) greater transparency and patient empowerment; (2) consequences of bad news; (3) creation of a dilemma, (4) medical terminology; (5) immediate access differs according to scan type; (6) increased need for contact with oncology team; (7) own responsibility. These themes reflected the preferences and facilitators of the patients who read their scans.
Bellhouse et al (2021)	***Data Collection*** – *Mixed Methods* Quantitative component: Validated questionnaires – State-trait Anxiety Inventory-state (STAI-S) assessed anxiety regarding scans. Claustrophobia Questionnaire used to assess feelings of suffocation and restriction. MR and CT imaging-specific questionnaires regarding anxiety Qualitative component: Semistructured interviews explored participants experience of CT and MRI scans. Interviews conducted by researcher via face-face or telephone. ***Data Analysis*** Quantitative component: Analysis of questionnaires performed using SPSS v.22. Descriptive statistics retrieved. Wilcoxon Signed rank test adopted to assess differences in state and scan-specific anxiety. Qualitative component: Data collection and analysis occurred simultaneously to assess saturation. Thematic analysis via framework approach used to analyze the transcripts. Iterative processes used to identify themes.	United Kingdom	Not explicitly reported	**Aim:** explore patient anxiety and claustrophobia when undergoing [cancer] treatment planning scans, specifically the difference between MRI and CT. Findings related to the greater scheme of how these experiences impacted on image quality and scan completion.	***Setting:*** single-center study at UK Specialist Cancer Centre ***Context:*** study involved lung cancer patients who were already involved in another study. Involved participants who were over 18 years of age, had radiotherapy treatment with curative intent planned. ***Culture:*** not reported.	***Participants:*** Quantitative component: 29 participants (mean age 69, range 54–89, SD: 9.2). 66% were female. Qualitative component: 16 interviews conducted, with 7 interviews conducted from individuals who withdrew/nonparticipated in quantitative component. (Mean age 68, range 54–83, SD: 9.7). 61% were female. ***Sample Size:*** 29 participants	Qualitative component: There were no differences in post-scan state anxiety between MRI 1 and MRI 2. One-third of patients did not tolerate the MRI scans; withdrawal decisions encompassed self-reported claustrophobia, limb pain. Completers and noncompleters both exhibited scan-specific anxiety. CT scan was favored over MRI due to less claustrophobia and shorter durations. Participants expressed more relief post-MRI compared to post-CT. Quantitative component: Interview data revealed evidence of preexamination anxiety, more common for MRI. More concerns reported for MRI compared to CT. Reasons for nonparticipation included feeling overwhelmed with the number of scans already required.

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Table 1 (*Continued*)

Study	Methods for Data Collection and Analysis	Country	Methodology	Phenomena of Interest	Setting/Context/Culture	Patient Characteristics and Sample Size	Description of Main Results
Brandzel et al (2017)	***Data Collection:*** Six focus groups created and led by the same facilitators throughout. Each participant had a 2-hour discussion with the investigators, via semi-structured interviews. The participants had their partners accompanying them in the interviews. Verbatim written transcriptions generated by stenographer present at each discussion. ***Data Analysis:*** A team of three experienced coders. Combination deductive and inductive thematic analysis to develop themes and subthemes. Coders discussed emergent themes. Qualitative software: Atlas.ti Version 7.5.2. was used.	United States of America	Phenomenological framework – ethnographic approach. "We assessed women's experiences and preferences about cancer surveillance imaging [...] determining where gaps in care knowledge could be filled by conducting qualitative study of women [...] in different geographic regions of the US."	**Aim:** to better understand women's perspectives about and experiences with surveillance imaging	***Setting:*** multicenter study; six focus groups among women were registered with the Breast Cancer Surveillance Consortium in California, North Carolina, and New Hampshire. ***Context:*** study involved women 18–75 years with history if stage 0–III breast cancer diagnosed within the prior 5 years. Women eligible must have completed initial treatment for breast cancer. ***Culture:*** not reported.	***Participants:*** 41 women with prior breast cancer (age range: 38–75). Breast cancer stages n=4 (stage 0) n=14 (stage 1) n=18 (stage 2) n= 3 (stage 3) n=2 (unknown) ***Sample Size:*** 41 participants.	This study revealed that women experience the processes of surveillance breast imaging in various positive and negative ways.The major themes included: · Type and frequency of surveillance breast imaging · Surveillance imaging and preferences · Trust in providers Knowledge and decision-making about surveillanceA finding included expression of intense worry at time of scan due to fears of cancer recurrence, which supports current literature findings. The interview data also suggests that clarification regarding justification for imaging recommendation will likely alleviate anxiety surrounding surveillance imaging.
Boele et al (2023)	***Data Collection:*** Semistructured interviews. Audio recorded and transcribed verbatim. ***Data Analysis:*** theoretical coding the relationships between categories were defined and a theory developed.	United Kingdom	Constructivist grounded theory	**Aim:** to understand how adults living with PMBTs experience and cope with interval scanning.	***Setting:*** two sites in the UK (Leeds Teaching Hospitals NHS Trust (LTHT) and Kings College Hospitals NHS Foundation Trust (KCH). ***Context:*** Adult (18 +) patients diagnosed with high-grade PMBT who were having interval scans (defined as "MRI scans at set intervals following completion of initial treatment") who were proficient in English were recruited. ***Culture:*** Not reported.	***Participants:*** 12 participants, 5 male, and 7 females. Age 40–75 years range, all received treatment for primary malignant brain cancer. Sample Size: 12 participants.	Findings related to 1) living with primary malignant brain cancer: surviving, 2) the interval scan process: varying levels of anxiety, 3) the MRI scan: managing anxieties and accepting the discomfort, 4) waiting for the results: getting through the difficult times, 5) the results: short-term relief vs. ongoing anxiety, and 6) Interval scans: provide a safety net.

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Table 1 (*Continued*)

Study	Methods for Data Collection and Analysis	Country	Methodology	Phenomena of Interest	Setting/Context/Culture	Patient Characteristics and Sample Size	Description of Main Results
Bui et al (2021)	***Data Collection:*** semistructured interviews. Audio recorded and transcribed verbatim. ***Data Analysis:*** Five steps of framework analysis; familiarization, constructing thematic framework, indexing, charting and mapping and interpretation. Double coding used.	Australia	Phenomenological – interpretivist approach.	**Aim:** to explore the experiences of scanxiety and the strategies used to manage it. Through qualitative study, researchers aimed to determine the lived experiences of people with cancer having cancer-related scans.	***Setting***: Concord Repatriation General Hospital. – substudy of a multicentre cross-sectional survey of scanxiety. ***Context:*** English-speaking adults who had advanced solid cancer and CT scan for monitoring. ***Culture:*** not reported	***Participants:*** 16 participants, 7 men and 9 women. Age range 46–82 years old. n=11 diagnosed with cancer more than 2 years ago. n=12 on active treatment for cancer. ***Sample Size:*** 16 participants	Five salient themes: 1. The scan experience – a routine part of cancer care/interactions with the clinical team 2. The scanxiety experience – manifestations of scanxiety/knowledge and uncertainty influences of scanxiety/timing of scanxiety. 3. Coping with scan – behaviors and attitudes around the time of a scan/the role of support networks. Interview data revealed that scanxiety was often associated with the results rather than the scan itself, and manifested psychocognitively in patients. It was found that the negative experiences around a scan were not readily recognized as scanxiety, and coping strategies described by patients were not recognized as coping strategies for scanxiety.
Golden et al (2017)	***Data Collection:*** semistructured interviews with use of thematic saturation. ***Data Analysis:*** Direct content analysis using ATLAS ti 7.1.7. to organize and analyze the interviews.	United States of America	Patient-centered communication theoretical model.	**Aim:** to qualitatively assess the experiences of patients who underwent either surgery or radiation therapy for early-stage non–small cell lung cancer (NSCLC), particularly with respect to patient-clinician communication	***Setting:*** multicenter study; three medical centers in the northwest US. ***Context:*** evaluated patients 1 month before NSCLC treatment, 1 month and 1 year after treatment. Two follow-up interviews. Participants had to be English-speaking. ***Culture:*** most participants were white (82%), 82% were former smokers.	***Participants:*** 11 participants (55% were female, mean age was 71 years). ***Sample Size:*** 11 participants	Three categories discussed: patient as a person; information exchange; and shared decision making. Interviews revealed that most patients were satisfied with the information received regarding their treatment for their NSCLC, although many still had knowledge gaps regarding their treatment outcome and follow-up.

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Table 1 (*Continued*)

Study	Methods for Data Collection and Analysis	Country	Methodology	Phenomena of Interest	Setting/Context/Culture	Patient Characteristics and Sample Size	Description of Main Results
Hall et al (2022)	***Data Collection:*** six focus groups were recorded and transcribed verbatim. Interviews stopped when initial analysis of themes demonstrated no new emerging themes, i.e., saturation. ***Data Analysis:*** Inductive thematic analysis in line with Braun and Clarke's methods.	United Kingdom	Not explicitly reported.	**Aim:** to explore the views of relevant stakeholders on the design of a device using stimulated affective touch to reduce procedural anxiety.	***Setting:*** Single-center study at the Royal Marsden Hospital ***Context:*** patient, carers, and health professionals involved in either the delivery of radiotherapy or imaging procedures. ***Culture:*** not reported	***Participants:*** Two participant groups – patient and cares; and health practitioners. 13 patients and 3 carers. 10 health professionals – n=9 were therapeutic radiographers, n=1 diagnostic radiographer ***Sample Size:*** 30 participants	Data revealed mixed opinions across the different patient cohorts regarding the design aspects of the device. Relevant findings include patient expressed desire to have control of device; patients appreciated the simulated affective touch aspect of the device.
Lai-Kwon et al (2021)	***Data Collection:*** semistructured interviews conducted by two researchers. Interviews were audio-recorded and transcribed verbatim. ***Data Analysis:*** Thematic analysis involving familiarization, coding, systematic refinement of current concepts and theme identification.	Australia	Not explicitly reported	**Aim:** to characterize the lived experiences of people with metastatic NSCLC receiving long-term immunotherapy or target therapy.	***Setting:*** single-center study conducted at tertiary cancer center in Australia. ***Context:*** Eligible participants included patients with metastatic, unresectable NSCLC. Only English-speaking patients aged >18 years. ***Culture:*** half of participants born in Australia or New Zealand.	***Participants:*** 20 participants interviewed. 13 were female. Median age 62 (range: 34–83). ***Sample Size:*** 20 participants.	Four overarching themes: experience of living on long-term IT and TT, psychological concerns, desire for assistance with practical issues and desire for specific information tailored to treatment. The findings of patients with NSCLC were like previous research in those lived experiences of patients with melanoma. Coping with the side effects of treatment, uncertainty of prognosis, and scan-related anxiety were common in the survivorship experience, as supported by previous research. Despite common themes, there were unique experiences/ challenges in patients with NSCLC, i.e., stigma regarding smoking.
Mannion et al (2023)	***Data Collection:*** semistructured interviews conducted by two researchers. Interviews were audio-recorded and transcribed verbatim. ***Data Analysis:*** Descriptive phenomenology framework was used for data analyses.	United States of America	Not explicitly reported	**Aim:** qualitative study sought to learn from patients with cancer in their own words about anxiety associated with medical testing	***Setting:*** single-center study conducted at tertiary cancer center in USA. ***Context:*** were broad and inclusive of any patient who had been diagnosed with cancer and received treatment. ***Culture:*** *Not reported*	***Participants:*** 20 participants, 11 female and 9 male, 68 years (range: 36, 83 years) with mixed cancer types. ***Sample Size:*** 20 participants.	Two emergent themes: 1) the first is that anxiety related to medical testing is a real entity, and 2) the second theme focused on coping with medical testing anxiety.

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Table 1 (*Continued*)

Study	Methods for Data Collection and Analysis	Country	Methodology	Phenomena of Interest	Setting/Context/Culture	Patient Characteristics and Sample Size	Description of Main Results
Moreno et al (2023)	***Data Collection:*** four 2-hour focus groups conducted by a trained clinical psychologist. Discussions were audio-recorded and transcribed verbatim. ***Data Analysis:*** Thematic analysis involving familiarization, coding, systematic refinement of current concepts and theme identification.	United States of America	Not explicitly reported.	**Aim:** to characterize supportive care needs among women with metastatic breast cancer.	***Setting:*** single-center study conducted at tertiary cancer center in Northwestern University Feinberg School of Medicine campus in Chicago. ***Context:*** Women living with metastatic breast cancer. Only English-speaking patients >18 years old. ***Culture:*** Women were primarily non-Hispanic/ Latina White (86.5%) with some representation of Asian (4.5%), Black/African American (4.5%), and Hispanic/ Latina (4.5%) women	***Participants:*** 22 participants. women were aged 60.32 years (SD 12.21, min 34, max 84). Women were currently receiving chemotherapy (59.1%), hormone therapy (50.0%), radiation (9.1%), and/or immunotherapy (4.5%). ***Sample size:*** 22 participants.	Four overarching themes related to supportive care need domains: (1) psychosocial, (2) physical and functional, (3) health system and information, and (4) sexuality and fertility needs. Supportive care needs unique to living with metastatic breast cancer included the cumulative effects of continuously undergoing cancer treatment on symptom burden, worry from scan-to-scan regarding response to cancer treatments, diagnosis-related stigma and social isolation, end-of-life concerns, and misconceptions regarding metastatic breast cancer.
Seibel et al (2023)	***Data Collection:*** semistructured interviews conducted by two researchers. Interviews were audio-recorded and transcribed verbatim. ***Data Analysis:*** Structured thematic content analysis procedure was triangulated with another text-hermeneutic method, the integrative basic method.	Germany	Not explicitly reported.	**Aim:** explored how lung cancer survivors and their caregivers experience follow-up examinations.	***Setting:*** two Comprehensive Cancer Centers, three clinics and seven primary care practices federal state of Baden-Wuerttemberg, Germany and was based at the Department of Palliative Medicine at the University Medical Center Freiburg. ***Context:*** Curative lung cancer treatment stage I–III. Only English-speaking patients >18 years old. ***Culture:*** not reported	***Participants:*** 25 participants. 13 females and 12 males, median age 67 (range 52–58). different histologic types of lung carcinoma (non–small cell lung carcinoma (NSCLC) and small cell lung carcinoma (SCLC) completed treatment. ***Sample size:*** 25 participants	Three themes related to 1) ongoing impact of curatively treated lung cancer in the family system: long-term and late effects, 2) meaning of follow-up care, and 3) psychosocial needs during follow-up care.

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Table 1 (*Continued*)

Study	Methods for Data Collection and Analysis	Country	Methodology	Phenomena of Interest	Setting/Context/Culture	Patient Characteristics and Sample Size	Description of Main Results
Schoenmaekers et al (2022)	***Data Collection:*** focus groups participated in discussions with four experienced and trained researchers. Discussions were audio recorded and transcribed verbatim. ***Data Analysis:*** content analysis through discussion and consensus of coding.	Netherlands	Not explicitly reported	**Aim:** to use focus group discussions to investigate the perspective of patients, their family members, and close friends regarding: how asymptomatic brain metastases affect the psychological well-being and quality of life.	***Setting:*** single-center study conducted at thoracic oncology outpatient clinic of the cancer center at Maastricht University Medical Centre. ***Context:*** 6 focus groups with 3-4 participants each. Researchers who conducted the interviews were not known by the participants. Participants were eligible if diagnosed having NSCLC and asymptomatic BM. One family member/friend who were highly involved of each patient was also invited for separate discussion. ***Culture:*** 80% of patients were married, 50% had children. Other cultural factors not reported.	***Participants:*** 13 patients – 60% were female, mean age was 66 years (55–75). Among participating relatives, 80% were partners of the patient, and 20% were close friends. ***Sample Size:*** 20 participants.	Four major themes were extracted from the data: coping with diagnosis of BM; impact of imaging to screen for and to follow up BM; difference between having BM vs having metastases at other sites; involvement of family and friends. The leading finding revealed that a diagnosis of asymptomatic BM leads to anxiety and distress for both patients and close relatives. Majority of patients expressed a preference when it came to follow-up imaging (MRI over CT) as they felt it was more sensitive in catching the disease. Both patients and relatives expressed a variety of coping strategies, which were attributed to their personality and staging of the disease.
Thompson et al (2010	***Data Collection:*** Qualitative component: Series of qualitative questions were asked in interview format. Responses were recorded, and transcribed. Quantitative component: survey instrument included patient-physician relationship scale items and STAI items. ***Data Analysis:*** Qualitative component: Analysis via grounded theory by of the two investigators Quantitative component: Multivariate analysis	United States of America	Not explicitly reported	**Aim:** to investigate the source of anxiety in lymphoma survivors.	***Setting:*** single-center study at the Weill Cornell Medical Centre. External participants contacted the principal investigator directly as it was advertised at clinicaltrials.gov. ***Context:*** Eligible participants were survivors of Hodgkin lymphoma and aggressive non-Hodgkin lymphoma. Participants had to meet criteria of being >18 years, last treatment >2 years, and English speaking. ***Culture:*** 83% of participants were Caucasian, 6% African American, 10% Hispanic, 1% Other. Other sociocultural demographics such as education level, yearly income and marital status were also obtained.	***Participants:*** Patients were a median age of 47 (range 23–80) and 64% were female. ***Sample Size:*** 70 participants.	Qualitative component: Patients reported fear of recurrence as major trigger for anxiety around time of follow-up scans, with feelings of relief immediately after disclosure of the results. Quantitative component: 37% incidence of clinically significant anxiety in the time leading up to surveillance scans. History of relapse, and poor doctor–patient rapport were the only factors that were independently associated with higher anxiety levels.

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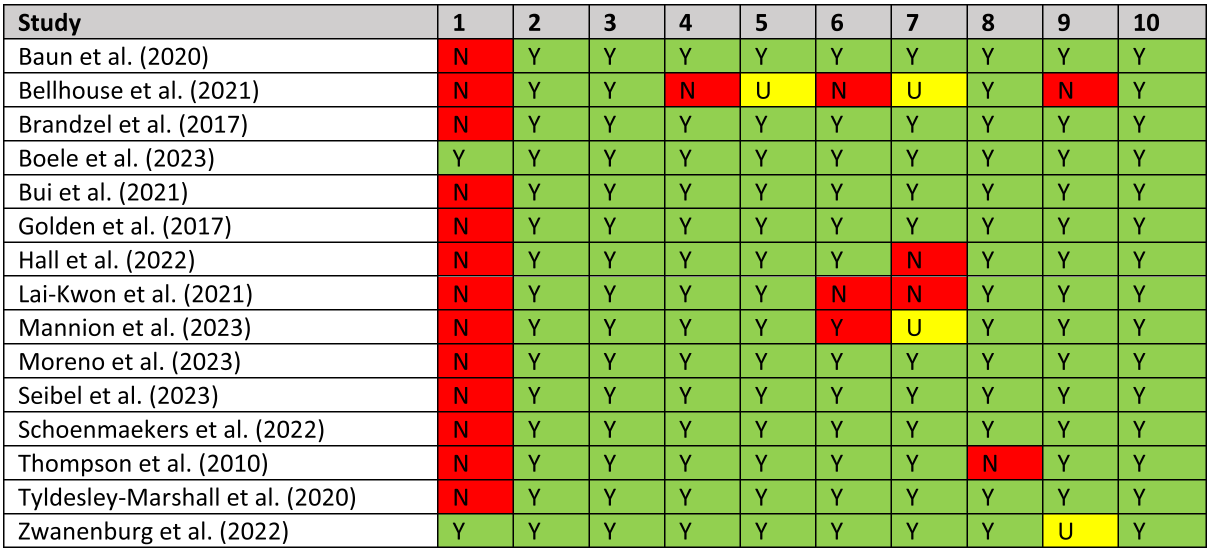
Table 1 (*Continued*)

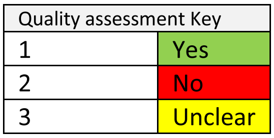
Study	Methods for Data Collection and Analysis	Country	Methodology	Phenomena of Interest	Setting/Context/Culture	Patient Characteristics and Sample Size	Description of Main Results
Tyldesley-Marshall et al (2020)	***Data Collection:*** interview questions + semistructured interview. Interviews were audiotaped and transcribed verbatim. ***Data Analysis:*** Thematic analysis in accordance with grounded theory and framework method	United Kingdom	Not explicitly reported	**Aim:** to gain perspectives from young patients and their parents about the value and emotional impact when viewing brain tumors. This allowed to explore what families understood from viewing MRIs.	***Setting:*** Single-center study at the neuro-oncology clinic at Birmingham Children's Hospital. ***Context:*** Patients were eligible if they had a brain tumor and were 3 months post-diagnosis and undergoing MRI surveillance. Patients with severe learning difficulties and under the age of 8 were not eligible. Though, their parents were eligible. ***Culture:*** sociocultural demographic variables were obtained, include ethnicity and socioeconomic status. Majority of patients were Caucasian.	***Participants:*** 15 parents (13 mothers) and 8 patients Patient's mean age was 12 (range 8−15). ***Sample Size:*** 14 participants.	Three major themes: Receiving results, emotional responses to MRI, Understanding of MRI, and Value of MRI. Each had a range of subthemes. Overall, the study gained perspectives from young cancer patients and their parents on how they emotionally respond to and understand their follow-up MRI. Responses were varied but parents and patients understood what could be seen in an MRI, though there was an assumption (mostly by parents) that size of tumor and fatality were linked.
Zwanenburg et al (2022)	***Data Collection:*** Semistructured interviews, audio recorded and transcribed verbatim. A summary of this was returned to interviewee for a member check. ***Data Analysis:*** Inductive thematic analysis	Netherlands	Naturalistic, interpretivist approach using subtle realism paradigm.	**Aim:** to fill the knowledge gap relating to patient's lived experiences with obtaining long-term response to treatment.	***Setting:*** single-center study at the Helen Dowling Institute. ***Context:*** patients diagnosed stage IV lung cancer/melanoma with confirmed response to long-term stable disease while on IT or TT. Eligibility included being over 18 and speaking Dutch. ***Culture:*** study reported sociodemographic and clinical characteristics, including employment, education level, martial status, cancer type and time since diagnosis.	***Participants:*** 17 participants: n=11 female. mean age: 56.4 years. ***Sample Size:*** 17 participants	The overarching themes included: (1) twilight zone, neither feeling a patient, nor feeling healthy. (2) living with uncertainty – going back and forth between hope and despair, (3) struggling to adapt to a life with cancer. The findings are in line with previous qualitative research in this field, however, bring forth uniqueness that has formed a new patient group. This new patient group has its own challenges, most notably being living with a uncertain life perspective as they a repeatedly confronted with possible disease progression.

Table 2
Results of Quality Assessment.



Study	1	2	3	4	5	6	7	8	9	10
Baun et al. (2020)	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
Bellhouse et al. (2021)	N	Y	Y	N	U	N	U	Y	N	Y
Brandzel et al. (2017)	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
Boele et al. (2023)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Bui et al. (2021)	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
Golden et al. (2017)	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
Hall et al. (2022)	N	Y	Y	Y	Y	Y	N	Y	Y	Y
Lai-Kwon et al. (2021)	N	Y	Y	Y	Y	N	N	Y	Y	Y
Mannion et al. (2023)	N	Y	Y	Y	Y	Y	U	Y	Y	Y
Moreno et al. (2023)	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
Seibel et al. (2023)	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
Schoenmaekers et al. (2022)	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
Thompson et al. (2010)	N	Y	Y	Y	Y	Y	Y	N	Y	Y
Tyldesley-Marshall et al. (2020)	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
Zwanenburg et al. (2022)	Y	Y	Y	Y	Y	Y	Y	Y	U	Y

Item number check list key*: **1** Is there congruity between the stated philosophical perspective and the research methodology? **2** Is there congruity between the research methodology and the research question or objectives? **3** Is there congruity between the research methodology and the methods used to collect data? **4** Is there congruity between the research methodology and the representation and analysis of data? **5** Is there congruity between the research methodology and the interpretation of results? **6** Is there a statement locating the researcher culturally or theoretically? **7** Is the influence of the researcher on the research, and vice versa, addressed? **8** Are participants, and their voices, adequately represented? **9** Is the research ethical according to current criteria for recent studies, and is there evidence of ethical approval by an appropriate body? **10** Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?



Quality assessment Key	
1	Yes
2	No
3	Unclear

of scanxiety was evident in the time leading up-to the scan, during, and after, at the time of sharing of results.[28,31] If the results showed a favorable outcome patients reported that they felt like they had their life back,[2] but in contrast, when the results showed disease progression patients expressed despair with no control.[33] There was only one qualitative study[24] which explored patients views of a simulated affective touch device to reduce imaging induced procedural anxiety. The findings identified mixed opinions in relation to the temperature, shape, and tactile sensation of the device.

Synthesized Finding 2: Experience of "Patient-Clinician Support"

All patients reported the need for patient-clinician support to manage their scanxiety. The dynamics of the patient-clinician relationship was important, and the relational attributes of shared knowledge and decision-making, transparency, trust,[23] patient empowerment,[22] and being seen as team[23] and a person were central.[2,27] During their scan, patients specifically reported that it would be useful if radiographers were sensitive and informed about their cancer diagnosis rather than conducting a "scan task," to acknowledge and understand the distress being experienced and provide comfort during that appointment[23] as it can be a lonely experience.[26] Patients did report, however, a lack of informational support to understand what to expect during their procedural imaging appointment from their care team, which resulted in nervousness and a sense of unease.[23,26] Following their scan, patients expressed an urgent need to discuss and receive timely support from their clinician to understand what their results showed[2,22,25,28,33] to inform next steps in their care and treatment. Patients also expressed value in being supported by a psychologist before their scan and they perceived benefit in managing their anxiety.[2] Patients expressed problems with medical jargon and terminology whereby they could not understand specifically what disease progression meant, and where metastasis were located in their consultations with healthcare professionals,[22,27] sometimes due to blunt communication.[23]

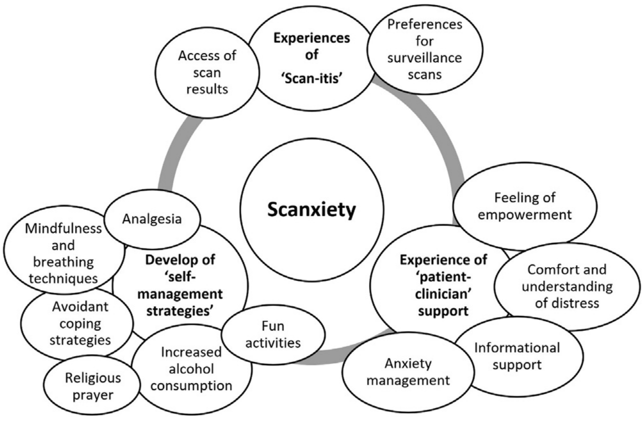


Fig 2. Findings.

> *"I don't like being told, 'no everything's fine.' (laughs) I'm like, we'll hang on, prove to me that it's fine first."* (page 169 [25])

Synthesized Finding 3: Development of "self-management strategies"

Across the included studies patients reported that they developed several self-management strategies to cope[26,30] with the significant scan-related distress that they experienced. Some patients reported to require administration of analgesia,[13,23] used mindfulness and breathing techniques,[23,32] used avoidant coping strategies

Table 3
Synthesized Findings.

Findings	Categories	Synthesized Finding
F1, F6, F7, F10, F13, F15, F17, F18, F19, F25, F27, F29, F30, F31, F32, F35, F36, F37, F38, F39, F40, F41, F45, F58, F59, F60, F61, F66, F67, F68, F69, F70, F71, F72, F73, F74, F86, F87, F88	Scan distress and anxiety Perceptions of aids Uncertainty	Experiences of "Scan-itis" Patients expressed tension in having online early access to their scan results in the absence of their care team. Many patients experience significant levels of anxiety leading up to their scan, during, and at the time of receiving their results. Some patients reported not to experience scan related anxiety and were at ease, as it was something had to be done. To alleviate scan related distress and uncertainly it was important to have individualized and shared decision-making with their healthcare professional regarding imaging protocols, given concerns of radiation exposure.
F2, F3, F4, F5, F8, F14, F20, F21, F22, F23, F26, F28, F33, F34, F43, F47, F54, F55, F57, F75, F77, F78, F79, F80, F83, F85	Patient-clinician support Shared decision-making Medical jargon Understanding images	Importance of "patient-clinician support" All patients reported the need for patient-clinician support to manage scan related anxiety and distress. Patient valued the relationship attributes of shared knowledge and decision-making, trust, transparency and been seen as a person and collective team with their clinician. Patient expressed a lack of empathy and care from radiographers during scans and valued support from psychologists.
F9, F11, F12, F16, F24, F42, F44, F46, F48, F49, F50, F51, F52, F53, F63, F64, F65, F67, F76, F81, F82, F90	Coping Practical help Family and friends	Development of "self-management strategies" Patients reported that they developed several different self-management strategies to cope with the scan-related distress in cancer imaging scans. It was important that patients also had a good support network available to them.

"denial,"[2,32] religious prayer,[2,30] increased alcohol consumption,[2] or tried to plan fun activities.[30,32]

> *"I had to find the right dose for Ativan just to get me comfortable enough to get my boobies in there"* (page 201[13])

> *"[. . .] I definitely drink a fair bit more [alcohol] than what I normally would. Especially the night before, or the day before ...I stop counting [how many drinks I have] . . . [it] helps me sleep, I think it just knocks me out . . ."* (page 7446[2])

Many of the patients represented in this review articulated that mobilizing their support network before their cancer scans was important to help them cope with anxiety,[27] and during consultations to help them process the information shared.[25,32]

Discussion

This qualitative systematic review set out to understand patients' experiences of scan-related anxiety in their own words. This current synthesis of evidence highlights three primary categories: 1) experiences of "scan-it is," 2) experience of "patient-clinician support," and 3) development of self-management strategies. These key areas indicate an intricate and interrelated web of factors that influence a patient's experience with cancer imaging/scans and the associated distress commonly referred to as "scanxiety." This systematic review has provided several new findings and implications for future directions of research. The experiences of "scan-itis" encapsulated the shared distress and anxiety that many patients experience leading up to, during, and after their scans. This study echoes the findings of previous research where scanxiety has been associated more with scan results rather than the scan itself.[10,35] Despite the normalcy and inevitability of scans in the cancer care continuum, the psychological distress associated with them is significant and in the main poorly, if at all, addressed in clinical practice. Notably, despite patients sharing similar symptoms or stages in their cancer journey, responses to scans and "scanxiety" experiences varied considerably among individuals. Patients have developed a range of adaptive coping strategies surrounding their scans, with differing views on the support roles played by family and friends. An interesting observation is that the ubiquity of scans and associated "scanxiety" might result in the underrecognition of negative experiences and coping strategies tied specifically to "scanxiety.".Particularly in advanced cancer cases, patients may accept these adverse experiences due to the critical role scans play in objectively assessing their condition and guiding optimal care strategies. Interestingly, no studies have reported formal or systematic approaches to mitigate "scanxiety" among patients.[10]

Consequently, due to a lack of supported self-management from healthcare professionals, patients have reported a variety of coping and self-management strategies developed on their own.[2,35] This observation highlights the need for a comprehensive approach to care that extends to include the cancer care team and to include family, friends, and other people living with cancer. This finding is in keeping with a recent study[36] that identified patients who were experiencing scanxiety engaged with social media platforms such as Facebook and Twitter for additional peer support. A scoping review[35] has further pointed toward helpful interventional approaches to assist the cancer multidisciplinary team in offering timely and tailored care to manage scanxiety. Firstly, future approaches may include implementing routine screening by using scan-specific measures to identify those individuals at risk to enable timely individualized care. Also, supported self-management strategies during stressful periods in the cancer care continuum, for example by designing and delivering interventions that alleviate procedural related scanxiety distress and supporting positive psychosocial coping strategies, should be targeted. Further cognitive and behavioral strategies might include optimizing coping skills, delivering stress-management skills, and providing psychological support and counseling services. Finally, clinical system strategies point toward timely delivery of results by reducing scan-to-results wait times, ensuring care coordination, and providing education in next steps in care.

A further important consideration was patient-clinician support, which is a central and critical factor in managing this scan-related anxiety and distress. Patients unanimously reported the importance of a supportive relationship with their clinicians, characterized by shared knowledge, mutual decision-making, trust, and transparency. The findings are in line with the broader literature that has consistently reported the positive effects of good physician-patient communication on patient outcomes, including anxiety.[37] Patients highly valued being recognized as a person and being part of the care team, rather than just a case number. Our synthesized findings suggest that patients often reported a perceived lack of empathy from radiographers during their scans, indicating a potential area for improvement and targeted education in undergraduate and post-graduate curriculums. The importance of psychological support from professionals like psychologists emphasized in the included qualitative studies in this review identifies the need for a multidisciplinary approach in managing scanxiety. Addressing scan associated distress within the health system requires all members of the multidisciplinary team (nurses, medical oncologists, radiation oncologists, surgeons, general practitioners, radiologists, radiographers, therapeutic radiographers, and allied healthcare professionals) to have specific targeted training and professional development to recognize this as important mainstay issue in routine cancer care.

This review brings new light to the ethical dilemma presented by the immediate access to test results in the digital health era. While rapid access can reduce the waiting anxiety, it may also escalate distress if not accompanied by adequate patient-clinician support. This draws attention to the need for a balanced approach that optimizes patient care while considering the emotional implications of immediate access to test results. It has been observed that individuals who frequently access their health records online tend to be more educated than those who do not.[22] It is recommended that healthcare providers proactively educate a broader range of patients about the benefits of digital health records. Additionally, it would be helpful to conduct further research to assess patients' experiences with online access and determine if they require additional support or information. Lastly, there is a clear need for improved communication about treatment outcomes and follow-up procedures. Thorough, personalized explanations could enhance patient understanding and trust, thereby potentially reducing scanxiety.

Strengths and Limitations

This qualitative systematic review followed the guidelines set out by the Joanna Briggs Institute for qualitative methodologies. This review included all qualitative studies irrespective of language of publication. The findings of this review are confined to the evidence presented in the included studies. Due to the small number of included studies (n=15) our findings may not accurately present all patients' experiences of scan-related anxiety in all clinical settings but has taken the most recent available literature to inform future directions and research. Prospective longitudinal research on scanxiety in patients with cancer is warranted to quantify the prevalence and severity of scan-associated distress, which will enable further understanding of this issue and therefore inform timely and tailored scanxiety interventions. Noteworthy, this qualitative systematic review represented people affected by cancer who underwent scans for disease progression and evaluation of response to treatment[2,13,22-29,31-34] exclusively, despite the inclusion criteria of this review being inclusive of all participants with cancer related scans across the entire cancer care continuum. Therefore, future qualitative research should be targeted to discern between potential differences in scanxiety across the entire cancer care continuum.

The eligibility screening criteria encompassed individuals of all age groups. This deliberate inclusion was motivated by the need to gather valuable data about the pediatric population coping with cancer-related scans, as they are considered an especially vulnerable group.[38] During the data extraction process, no articles were found that specifically targeted pediatric patients. As a result, this systematic review brought to light an additional and significant research gap regarding the representation of this demographic group.

Systematic reviews face a well-recognized challenge related to heterogeneity, which arises when combining the findings of diverse studies that involve varying patient characteristics, disease conditions, and enrolment criteria. This issue is often referred to as "mixing apples with oranges," highlighting the difficulty of comparing and combining disparate elements within the review process.[39] In this study, we have examined papers involving patients with different types of cancer and various stages of disease progression. It is therefore essential to remind oneself of the nuance within each individual patient and appreciate the unique challenges they encounter in relation to their cancer-related scans.

Implications for Practice

Despite the regularity and necessity of scans in cancer care, anxiety is widely experienced around them and varies across individuals. The review highlights the importance of the relationship between patients and clinicians and a multidisciplinary approach to effectively and efficiently address scanxiety. This review also warrants the need for tailored interventions, focusing on both psychological aspects of "scanxiety" and operational changes to enhance patient comfort. Such interventions could benefit from integrating the strength of the clinician-patient relationship and the supportive role of family and friends. The review also points towards the ethical dilemma of immediate access to test results in the digital health era, suggesting a need for a balanced approach that optimizes patient care while considering emotional implications. Last, the review supports the need for improved communication about treatment outcomes and follow-up procedures, which could potentially reduce scanxiety.

Conclusion

This qualitative systematic review captured the experiences of scanxiety distress among people affected by cancer in their cancer trajectory. In their own words and experiences, this review highlighted the three important themes of "scan-itis," "patient-clinician support," and the need for supported self-management strategies that accentuates the multidimensional nature of scanxiety and the importance of a patient-centered approach in addressing it. Future research should aim to develop and test interventions that address the individual experiences of scanxiety while considering the potential ethical implications of immediate access to test results.

Authors' Contributions

Catherine Paterson was responsible for conceptualization, methodology, data extraction, analysis, writing, editing, and supervision. Miami Hussain was responsible for methodology, data extraction, analysis, writing, and editing. Minh Chau was responsible for methodology, writing, and editing. Murray Turner was responsible for database searches, methodology, writing, and editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.soncn.2023.151502.

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Supplementary Table 2 – Search strategy

The APA PsycINFO, CINAHL, Cochrane Library (DSR and CENTRAL), Medline, and Scopus databases were searched on 3 July 2023 to identify relevant studies. No limiters were placed on any of the searches. Search terms and number of results by database:

APA PsycINFO via EBSCOhost (24)

((scanxiety OR scan-associated-anxiety OR scan-associated-distress OR scan-related-anxiety OR scan-related-distress OR medical-imaging-associated-anxiety OR medical-imaging-associated-distress OR medical-imaging-related-anxiety OR medical-imaging-related-distress OR ((imaging OR radionucl* OR scan* OR tomograpy OR ultraso*) N5 (anxi* OR distress* OR fear* OR worr*))) AND (neoplasm* OR cancer* OR malignan* OR tumour* OR oncolog* OR carcinoma*))

CINAHL via EBSCOhost (100)

((scanxiety OR scan-associated-anxiety OR scan-associated-distress OR scan-related-anxiety OR scan-related-distress OR medical-imaging-associated-anxiety OR medical-imaging-associated-distress OR medical-imaging-related-anxiety OR medical-imaging-related-distress OR ((imaging OR radionucl* OR scan* OR tomograpy OR ultraso*) N5 (anxi* OR distress* OR fear* OR worr*))) AND (neoplasm* OR cancer* OR malignan* OR tumour* OR oncolog* OR carcinoma* OR (MH "Neoplasms+")))

Cochrane Library: Database of Systematic Reviews (3) and CENTRAL (158)

#1	(scanxiety OR scan-associated-anxiety OR scan-associated-distress OR scan-related-anxiety OR scan-related-distress OR medical-imaging-associated-anxiety OR medical-imaging-associated-distress OR medical-imaging-related-anxiety OR medical-imaging-related-distress OR ((imaging OR radionucl* OR scan* OR tomograpy OR ultraso*) NEAR/5 (anxi* OR distress* OR fear* OR worr*))):ti,ab,kw	924
#2	(neoplasm* OR cancer* OR malignan* OR tumour* OR oncolog* OR carcinoma*):ti,ab,kw	248,732
#3	MeSH descriptor: [Neoplasms] explode all trees	111,737
#4	#2 OR #3	261,497
#5	#1 AND #4	161

Medline via EBSCOhost (326)

((scanxiety OR scan-associated-anxiety OR scan-associated-distress OR scan-related-anxiety OR scan-related-distress OR medical-imaging-associated-anxiety OR medical-imaging-associated-distress OR medical-imaging-related-anxiety OR medical-imaging-related-distress OR ((imaging OR radionucl* OR scan* OR tomograpy OR ultraso*) N5 (anxi* OR distress* OR fear* OR worr*))) AND (neoplasm* OR cancer* OR malignan* OR tumour* OR oncolog* OR carcinoma* OR (MH "Neoplasms+")))

Scopus (303)

((scanxiety OR scan-associated-anxiety OR scan-associated-distress OR scan-related-anxiety OR scan-related-distress OR medical-imaging-associated-anxiety OR medical-imaging-associated-distress OR medical-imaging-related-anxiety OR medical-imaging-related-distress OR ((imaging OR radionucl* OR scan* OR tomograpy OR ultraso*) W/5 (anxi* OR distress* OR fear* OR worr*))) AND (neoplasm* OR cancer* OR malignan* OR tumour* OR oncolog* OR carcinoma*))

Supplementary Table 1. ENTREQ checklist (Enhancing transparency in reporting the synthesis of qualitative research)

No. Item	Guide Questions/Description	Reported on Page
1. Aim	A meta-aggregation was conducted to identify the experience of scanxiety among people affected by cancer.	Page 2
2. Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology (e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis)	Page 3
3. Approach to searching	The search was pre-planned. Comprehensive search strategies were undertaken to seek all available studies.	Page 4 Supplementary 2
4. Inclusion criteria	Inclusion criteria All published studies exploring experiences of experience of scanxiety among people affected by cancer (inclusive of all cancer types and ages). Exclusion criteria This review excluded reviews, commentaries, editorials, or studies with no clear data related to review aim.	Page 2-3
5. Data sources	The APA PsycINFO, CINAHL, Cochrane Library (DSR and CENTRAL), Medline, and Scopus databases were searched on 30 January 2023 to identify relevant studies. No limiters were placed on any of the searches.	Page 4
6. Electronic search strategy	The search architecture was designed by an expert systematic review librarian and the management of citations was conducted using Endnote (Clarivate Analytics, PA, USA). The search used a wide range of keywords and free text items to increase the sensitivity and inclusiveness of the searches, see Supplementary Table 2.	Page 4 Supplementary 2
7. Study screening methods	Overview of the study screening methods	Page 5
8. Study characteristics	Table 1 presents the characteristics of the included studies (author(s), year of publication, country, population, number of participants, data collection, methodology, analysis and limitation of the studies).	Table 1
9. Study selection results	A flow diagram using PRISMA guidelines for reporting of systematic reviews is presented in Figure 1 in reporting of the selection process and results.	Figure 1 Page 6
10. Rational for appraisal	All studies meeting the PICo (participant, phenomenon of interest, context) inclusion criteria were assessed using the JBI Critical Appraisal	Page 4-5

	Checklist for Qualitative Research. The 10-item, Critical Appraisal Checklist instrument assesses congruity between the philosophical/theoretical position adopted in the study, study methodology, study methods, the research question, the representation of the data, and the interpretation of the findings of each of the selected studies. The item ratings of each appraisal were consolidated and represented in a final quality appraisal table as agreed by two reviewers.	
11. Appraisal Items	Appraisal Checklist for Qualitative Research. The 10-item, Critical Appraisal Checklist instrument assesses congruity between the philosophical/theoretical position adopted in the study, study methodology, study methods, the research question, the representation of the data, and the interpretation of the findings of each of the selected studies.	Page 5 Table 2
12. Appraisal Process	Appraisal was conducted independently by two independent reviewers. The two reviewers discussed if consensus was required.	Page 3-4
13. Appraisal Results	Appraisal Results presented in Table 2.	Table 2
14. Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies?	Page 4-5
15. Software	State the software used.	Page 4-5
16. Number of reviewers	Identify who was involved in coding and analysis.	Page 4-5
17. Coding	Describe the process for coding of data	Page 6-7
18. Study comparison	Describe how were comparisons made within and across studies	Page 4-5
19. Derivation of themes	Explain whether the process of deriving the themes	Page 5
20. Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author’s interpretation.	Table 3, Supplementary Table 3, and pages 6-8
21. Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies	Table 3, Supplementary Table 3, and pages 6-8

Supplementary Table 3. Study findings and illustrations

Study		**Evidence**				**Label** **Finding Number**
		Unequivocal	**Credible**	**Not supported**		
Study	**Baun et al. (2020)**					
Finding	**Creation of a dilemma**					
Illustration	“[…] my impatience to calm myself after a scan often drags me to look at the results on the online portal. But the problem is when it’s a ‘bad result,’ the waiting time to my appointment at the hospital feels even longer and worse! I practice NOT looking up the scanning results online – but it’s difficult not to do it“ P.6	X				F1
Finding	**Medical terminology**					
Illustration	“I know that progression means expansion, and I know that metastases are… when something is there… But what does it mean if they are in three or four bones or just in one? … Because that was how it was at the next scan; what does that mean?” P.6	X				F2
Finding	**Increased need for contact with oncology team**					
Illustration	“[patients] experienced an urgent need to discuss the results with their oncologists. […] this increased need for contact and reassurance from an oncologist was also clear in all 4 interviews.” P. 7.	X				F3
Finding	**Greater transparency and patient empowerment**					
Illustration	“I told them that I look up my own record and prepare my appointment with the physician. They know exactly what they don’t have to tell me […] the physician can say ‘what is your opinion about that?’ and this means I get more involved in things.” P.6	X				F4
Finding	**Consequence of bad news**					
Illustration	“one informant who had previously been a diligent user of the PAEHR and had regularly read her scan results […] she had read her scan results […] showed serious disease progression. She then has to spend the entire weekend with her family and the bad news, as she could not contact the hospital. Since then, she has changed her approach to only receiving information about her disease directly from her physician during hospital appointments.” P.6	X				F5
Finding	**Immediate access differs according to scan type**					
Illustration	“those having regular CT scans waited longer for their scan results to be realised online[…]” P.7	X				F6
Finding	**Own responsibility**					
Illustration	“it’s my responsibility to log in and it’s my responsibility to read the result…. There is a box to click where it asks, ‘are you sure you want to continue?’ … and the preselected answer is NO.” P.7	X				F7
Study	**Bellhouse et al. (2021)**					
Finding	**MRI scan experience**					
Illustration	“I was bit apprehensive, a bit nervous the first time around, because of not knowing	X				F8

	what to expect” P. 21					
Finding	**MRI scan experience**					
Illustration	“I decided that I’d take a couple of paracetamols before the scan to perhaps just take the edge off” P.21	X				F9
Finding	**MRI scan experience**					
	“I was alright like I said until I opened my eyes. And then of course the thing is right on top of you [MRI Machine]… and that’s when it hit me.” P.21	X				F10
Finding	**Coping strategies**					
Illustration	“It was just coping with it, breathing and pretending I’m on a beach” P.21	X				F11
	Coping strategies					
Illustration	“stiff but really relieved. That’s one of the first things I said” P.21	X				F12
Finding	**Scan preferences**					
Illustration	“you’re not as enclosed are you with the CT, it’s more open and… yeah, so it’s obviously not as bad as the MRI” P.21	X				F13
Finding	**Scan preferences**					
Illustration	“If they’d [the radiographers] have known in advance that the person they were dealing with had a medical issue, could have probably made it more comfortable experience from the outset” P.21	X				F14
Study	**Brandzel et al. (2017)**					
Finding	**Surveillance imaging experiences and preferences**					
Illustration	“I dread it for a couple of weeks before. My anxiety builds as I get closer to the date” P. 201	X				F15
Finding	**Surveillance imaging experiences and preferences**					
Illustration	“I had to find the right dose for Ativan just to get me comfortable enough to get my boobies in there” P.201	X				F16
Finding	**Surveillance imaging experiences and preferences**					
Illustration	“You have to situate to the machine in order to get the image, and it’s uncomfortable, and not only is it uncomfortable, but it’s dehumanizing.” P. 201	X				F17
Finding	**Surveillance imaging experiences and preferences**					
Illustration	“The worst point is between when you do your initial images and then you’re waiting to see if you need more. Because then as soon as they ask for more images, the mind just goes crazy about what they found and what they see […] She [provider] came in with her files close to her chest – is she holding it close to her chest because she’s going to tell me something terrible?” P. 201	X				F18
Finding	**Surveillance imaging experiences and preferences**					
Illustration	“If we had a safer imaging technique, I would get it twice, three times a year” P. 201	X				F19
Finding	**Trust in providers**					
Illustration	“I’ve begged my oncologist, I’m like I ‘I want an MRI’ and my oncologist says, ‘the mammogram did its job. Your cancer was found on the mammogram […]” P. 202		X			F20
Finding	**Trust in providers**					
Illustration	“You have to trust your doctor. That’s it. You have to trust that they know what they’re doing.” P.202.					F21
Finding	**Knowledge and decision-making about surveillance**					

Illustration	“Decision-making is really hard. You’re presented with all of these things. And I kept saying I’m not a doctor, I don’t know. I don’t know. You know, what should I do? What is the right course?” P.202	X				F22
Finding	**Knowledge and decision-making about surveillance**					
	“My oncologist let me change to just mammograms every six months without the MRI. […] She says what she believes is best, but then doesn’t argue or make you feel bad if you want to do something else” P.202.	X				F23
Study	**Boele et al., (2023)**					
Finding	**Living with a PMBT: surviving**					
Illustration	“I think it’s probably because, you know, it’s got to be done and you kind of just have to get on with it.” (Jane) P.4	X				F24
Finding	**The interval scan process: varying levels of anxiety**					
Illustration	“I’m still a little bit claustrophobic inside [those machines], and I have a few thoughts when I lie down that the machine’s going to stop working or it might crush me or something.” (Hannah) P.4 “Doing the scan makes me think about the tumor, which slightly raises my anxiety levels about the possibility of return, which is always there.” (Adam) P.4	X				F25
Finding	**The MRI scan: managing anxieties and accepting the discomfort**					
Illustration	“Just the fact that you’re lying in a scanner that, you know you’re all on your own it’s quite isolating, it’s quite lonely. So, just for them to say you’re doing well, or you know we’ll be in in a minute; last ten minutes, you know just something encouraging to make you think, oh okay I'm doing all right.” (Amy) P.5	X				F26
Finding	**Waiting for the results: getting through the difficult times**					
Illustration	“You’re never gonna know until you get the results but like, I think also, I don’t know for sure, but I think if it is bad news...maybe they’d call me earlier.” (Ben) P.5	X				F27
Finding	**The results: short-term relief vs. ongoing anxiety**					
Illustration	“No, it’s good. Good. And I usually feel on top of the world. And then, you know, you do realise that you know you’re gonna have to go through it all again in three months’ time.” (Sophie) P.5 “That’s when they sent me to different department, a different scan machine cause they weren’t sure about something. I got a bit worried. I thought they’d found something, or, you know, it grew back or some-but it wasn’t that; they wanted to see something on a different machine.” (Hannah) P.5	X				F28
Finding	**Interval scans: provide a safety net**					
Illustration	“Peace of mind; just a bit of security really that some one’s there. They're gonna check things, not just leave me until I get symptoms” (Hannah)	X				F29
Study	**Bui et al. (2021)**					
Finding	**The scan experience – a routine part of cancer care**					
Illustration	“necessary evil” in relation to routine scans. P.7443	X				F30

Finding	**The scan experience – a routine part of cancer care**					
	"you lie down, you get probed, you get experimented on and whatever the hell they do in there." P. 7443	X				F31
Finding	**The scan experience – a routine part of cancer care**					
Illustration	"they got to have the time to process the scan, read it, discuss it, dissect it, and stick it on a wall." P.7443	X				F32
Finding	**The scan experience – interactions with the clinical team**					
Illustration	"when the doctor first told me […] it was like a bomb – she was that blunt." P.7444	X				F33
Finding	**The scan experience – interactions with the clinical team**					
Illustration	"[…] [my oncologist] calls us a team. I think that's really important." P.7444	X				F34
Finding	**Presence of scanxiety**					
Illustration	"if someone calls you [with the result], it makes you nervous." P7444	X				F35
Finding	**Presence of scanxiety**					
Illustration	"I always go in there, thinking, it's ok, it's all ok. But in the back of my mind, I'm having another little devil sitting in my shoulder saying to me, they're going to tell you one day that it's not, it's not ok." P.7445	X				F36
Finding	**Knowledge and uncertainty influences scanxiety**					
Illustration	"a lot rode on those scans." In response to their scanxiety when on potentially curative treatment. P.7444		X			F37
Finding	**Knowledge and uncertainty influences scanxiety**					
Illustration	"I'm probably a bit more relaxed about it, knowing what it is." P.7445	X				F38
Finding	**Knowledge and uncertainty influences scanxiety**					
Illustration	"all I could think of was, am I going to be alive to see the baby?" P. 7445					F39
Finding	**Manifestations of scanxiety**					
Illustration	"The stress comes out in – around the sleeping pattern… I get [a racing heart and sweaty hands] the minute I walk into the hospital… I'm tireder. That usually hits a few days before." In response to the scanxiety experience. P.7445	X				F40
Finding	**Manifestations of scanxiety**					
Illustration	"Sleeping's hard, a couple of nights before… I feel a bit nauseous through them." In response to the scanxiety experience. P.7445	X				F41
Finding	**Timing of scanxiety**					
Illustration	"[It's] very much like a celebration. Thank goodness I've got my life back." In response to once the scan results were known. P.7445	X				F42
Finding	**Timing of scanxiety**					
Illustration	"waiting for the results is the most nerve-racking." P.7445	X				F43
	Timing of scanxiety					
Illustration	"[scans bring me] back to square one, because basically you're losing control again… sometimes you go in and you're feeling pretty good… and you have a scan and all of the sudden it comes back and you're not okay." P.7445	X				F44
Finding	**Timing of scanxiety**					
Illustration	"I knew it wasn't working, and that was really getting to me. Every time that I'd had to scan. We'd have a couple of millimetre spikes." P.7445	X				F45
Finding	**Behaviours and attitudes around the time of a scan**					
Illustration	"I'm probably a bit like an ostrich. I probably bury my head in the sand. Sometimes, the	X				F46

	less you know the better. Because the more you know, sometimes it can be stressful.” P.7556					
Finding	**Behaviours and attitudes around the time of a scan**					
Illustration	“I saw one of the psychologists at the hospital here for a while. And that definitely helped. And that was around scans and things like that.” P.7446	X				F47
Finding	**Behaviours and attitudes around the time of a scan**					
Illustration	“Pray. You can only pray” in relation to strategies to cope with scans. P.7446	X				F48
Finding	**Behaviours and attitudes around the time of a scan**					
Illustration	“I talk to myself… the cancer’s there and it’s not going away, so, you know. Calm down, you’re not helping yourself.” P.7446	X				F49
Finding	**Behaviours and attitudes around the time of a scan**					
Illustration	“[…] I definitely drink a fair bit more [alcohol] than what I normally would. Especially the night before, or the day before….I stop counting [how many drinks I have]…[it] helps me sleep, I think it just knocks me out…” P.7446	X				F50
Finding	**The role of support networks**					
Illustration	“[My family are] probably more anxious about the appointment coming up than I am.” P7446		X			F51
Finding	**The role of support networks**					
Illustration	“I’m more concerned about the people around me, just staring at me… I find that a lot of pressure… I’m quite happy to cope and talk with myself through things.” P.7447	X				F52
Finding	**The role of support networks**					
Illustration	“My wife usually comes with me [to get the result]… we discuss it afterwards, and there might be things that I’ve missed or that she can fill in… I just like the fact that she is there. I feel comforted by the fact that she is there.” P.7447	X				F53
Study	**Golden et al. (2017)**					
Finding	**Patient as person**					
Illustration	They [the clinicians] were very responsive […] It was one of the better experiences I had for surgery. It was well explained, what was going to happen beforehand […] On other surgeries they just told me what they we gonna do and then let me like, ferment there for a while.” P. 4	X				F54
Finding	**Information exchange**					
Illustration	“now if they’ve already got my lung, I was curious, can you tell me if they got it all on the lung or not?... Well, I don’t know because I don’t know what the results are. I don’t know if it slowed down or if it’s killed it or if was off target. I don’t know, I don’t have any of the information yet.” P.4	X				F55
Finding	**Shared decision making**					
Illustration	“I Still don’t see that I really had much of a choice. I learned a long time ago if you’re going to go to experts for their opinion, then listen to their opinion. There’s no point in going to them if you’re not going to listen to them […]” P.4	X				F56
Finding	**Shared decision making**					
Illustrations	“I mean they just sort of tell you, “this is what you need to do, and this is what we scheduled for you, is that going to work for you? And if not, we need to do something.” And so, I basically said it was going to work for me cause I pretty much didn’t have	X				F57

	anything else to do […] I have a tremendous amount of respect for [my doctor]. I kind of believe [them].” P.4					
Study	**Hall et al. (2022)**					
Finding	**Patient views – temperature of the device**					
Illustration	“it also temperature, when you hold someone’s hand, it’s a warm experience, whereas sometimes with some of the treatment you have you feel quite cold and distance, and that’s a bit f a strange one […]” Patient had experience of radiotherapy with affective touch device. P.4	X				F58
Finding	**Patient views – shape of the device**					
Illustration	“the ball, it would just give you a degree of confidence as someone who isn’t so secure in where they are.” Patient had experience of radiotherapy with affective touch device. P.4	X				F59
Finding	**Patient view – tactile sensation of device**					
Illustration	“if you get it in the right pulse, it’s just so calming […] modulating” Patient had experience of radiotherapy with affective touch device. P.4	X				F60
Study	**Lai-Kwon et al. (2021)**					
Finding	**Psychological concerns**					
Illustration	“Scan anxiety is always there, yeah there’s always there. A very recent scan proved it 110%, the lead up to that scan on a conscious level I was feeling wrecked completely.” P.395	X				F61
Finding	**Desire for assistance with practical issues**					
Illustration	“At max I can stay seven weeks because then I miss my blood test -but I do take medicine for the next cycle, but I can’t miss the CT scan” P.395		X			F62
Study:	**Schoenmaekers et al. (2022)**					
Finding	**Coping with the diagnosis of brain metastases**					
Illustration	“I simply can’t accept the diagnosis and can’t deal with it… I worry about it a lot, especially at night. I’m afraid for what the future will bring.” P.4	X				F63
Finding	**Coping with the diagnosis of brain metastases**					
Illustration	“I try to live in the moment and plan fun activities as much as possible. Sometimes I even take advantage of my disease.” P.4	X				F64
Finding	**Impact of imaging to screen for and to follow up brain metastases**					
Illustration	“Just lie down, close your eyes and focus on something else or think about fun stuff.” P.6	X				F65
Finding	**Difference between having BM versus having other metastases at other sites**					
Illustration	I’m afraid of bone metastases in the vertebra because you can get paralysed. I’m certainly not waiting for that” P. 6	X				F66
Finding	**Involvement of Family and Friends**					
Illustration	“we told everybody about the diagnosis. In the first months family and friends were very involved. However, over time their involvement diminished.” P.6	X				F67
Study	**Moreno et al., (2023)**					
Finding	**Uncertainty**					

Illustration	P8: I Think though, there is a lot of anxiety around it, there is a lot of worry about scan-to scan, what's happening, what are we going to do, and um, what's next? And you know, how do you live your life knowing that at any moment, it's all going to come crashing down around you again? (age 53; NHW; stage IV diagnosis at recurrence) P.5	X				F67
Finding	**General psychosocial challenges**					
Illustration	P20: I don't know why I need something like that, you know, 'cause you would think, with 'this kind of diagnosis, that you'd want to, you know, do everything you can, but… it's exhausting…I mean I'm down here every month, you know, for labs, and every 3 months, for my scans, and it gets old. (age 55; NHW; stage IV diagnosis at recurrence). P.5	X				F68
Study	**Seibel et al. (2023)**					
Finding	**Fear of and around scan**					
Illustration	Survivor 2: "In the beginning, it's always like you're going to a court hearing where a death sentence might be pronounced, right?" Survivor 14: "So, you wait again and by the time you are ready to get the injection [with the contrast medium, the authors] and lie down, an hour and a half has passed and the hour and a half is, in my opinion, the greatest poison for patients. Because the patient is so tense inside, to the point of no return and wonders: what's happening? You're not being told anything." Survivor 1: "The worst are the minutes when I'm waiting for the CT, when I'm waiting until it's my turn. Then I think, dear God in heaven, oh please please please let me be healthy, let it be gone …. it's just exhausting. I'm just brutally scared." P.6	X				F69
Study	Schoenmaekers et al., (2022)					
Finding	**Impact of Imaging to Screen for and to Follow Up Brain Metastasis**					
Illustration	"Even though the local therapy did not start immediately, and I did not have any symptoms of the discovered BM, I would still want to know that I have BM." Female, age 72 years. P.5 "Even though the local therapy did not start immediately, and I did not have any symptoms of the discovered BM, I would still want to know that I have BM." Female, age 72 years. P.	X				F70
Study	**Thompson et al. (2010)**					
Finding	**Fear of recurrence heightened at the time of follow-up scans**					
Illustration	"scan-itis" when referring to the scan experience. P.2264	X				F71
Finding	**Fear during the time between having the scan and waiting for results**					
Illustration	"whole other kind of fear." P.2264	X				F72
Finding	**Scan-related anxiety**					
Illustration	"The weeks leading up to it [the scan] is very nerve-racking, and it's a lot of the thoughts that I had when I was first diagnosed start to come back… once it's over, a sense of relief" P.2264	X				F73
Finding	**Scan-related anxiety**					

Illustration	“Even if you know that the statistics are in your favour, and you know that you’re feeling all right, you still have a huge amount of anxiety that goes away, oddly enough, it goes away immediately when you hear that it’s fine. It’s a complete relief.” P.2264	X				F74
Study	**Tyldesley-Marshall et al. (2020)**					
Finding	**Receiving results**					
Illustration	“I felt worries because there was a lump and worried what it would when I got older.” “There’s no hundred per cent in anything”. Patient & parent respectively. P169	X				F75
Finding	**Emotional responses to first seeing MRI**					
Illustrations	“I could see the scans and I knew what it meanttt. I’d… get a little bit worried and I would cry or something, cos it made me feel upset, cos obviously I knew what I’d have to go through again.” “I just remember my first thought, thinking, that’s it. There you go. [they’ll] um, erm…. That’s it. That the end of [child] and knowing that [they’ll] die. … because the tumour was massive”. Patient and parent respectively. P.169	X				F76
Finding	**Understanding of images**					
Illustration	“errmm, it [the MRI] can tell you, like what, they, what they need to get of, why it’s there … erm , how it’s caused, and things like that?” (transcription of patient). P.169	X				F77
Finding	**Understanding of images**					
Illustration	“But what els does it not tell me? Erm. I don’t know. I’m not sure… ya know, if it’s gone or whatever.” (transcription of parent). P.169	X				F78
Finding	**Understanding of images**					
Illustration	“I don’t like being told, ‘no everything’s fine.’ (laughs) I’m like, we’ll hang on, prove to me that it’s fine first.” (transcription of parent). P.169	X				F79
Finding	**Value of MRIs**					
Illustration	“as you get older… you realise, what can happen, and you realise the situation you’re in, like this scan shows what, what can ‘appen. So like it can still affect you.” (transcription of patient). P.170	X				F80
Finding	**Value of MRIs**					
Illustration	“And then obviously with the pictures, you see a lot clearer cos it’s like you know what’s going on cos otherwise if you didn’t know then you’d just be panicking, like ‘what’s going on? how are they doing stuff?’ So obviously you have to prepare yourselves as well so.” (transcription of parent). P.170	X				F81
Finding	**Value of MRIs**					
Illustration	“it’s nice ter, look at them and see that there’s no change.” (transcription of patient). P.170	X				F82
Study	**Zwanenburg et al. (2022)**					
Finding	**Twilight zone: neither feeling a patient, nor feeling healthy**					

Illustration	“If someone tells me I’m doing really well, that [the cancer] is surely over now, I think, ‘Well, no, it’s not over at all.’ But when someone starts om about how cancer is, then I think, ‘stop it, it’s not like that at all, look at me, I’m here and I can do this, and I can do that.’ So, it’s always in between, more nuanced.” P.6	X				F83
Finding	**Living with uncertainty: going back and forth between hope and despair**					
Illustration	“At the very beginning I got the scans every other month, and then over time every three months and then every six months. In the beginning when it was every other month, that was my life window, my outlook for life. I also told myself it was one month, then we’ll see. That was manageable for me.” P.6	X				F84
Finding	**Living with uncertainty: going back and forth between hope and despair**					
Illustration	“the scans and the conversations afterwards are the moments when it really comes to the forefront again. Very present. This creates tension and uncertainty. However, this became less, every time it went well.” P.7	X				F85
Finding	**Living with uncertainty: going back and forth between hope and despair**					
Illustration	“[…] It forced you to face reality again, like oh I have a scan again. On the other hand, it’s also nice to have that check. So, it is a bit of a double feeling actually” P.7	X				F86
Finding	**Struggling to adapt to a life with cancer**					
Illustration	“There was a time when I stopped buying clothes. When I was in the store, I thought: I’m going to die anyway, why would I buy something?” P.7	X				F87
Study	Mannion et al, 2023					
Finding	**Medical testing related anxiety as a real entity**					
Illustration	It’s the anticipation. And then “ once it’s done and the results, you know, it’s…it’s waiting for the results whether they’re good or bad that’s stressful” (patient 18). P.470 I don’t think it bothers me until I get near the time for testing. It’s just…you know, I’ve lived with it for 8 years. It’s just kinda part of my life …. (patient 18) P.470 I’ve got so many other stresses that there’s no room for another 1 right now” (patient 1). P.470	X				F88
Finding	**Not all patients describe experiencing this anxiety**					
Illustration	“I’m not apprehensive. Just has to be done. So I’m at peace with it.” (patient 3) P.471 “I’m not apprehensive. Just has to be done. So I’m at peace with it.” (patient 3) P.471	X				F89
Finding	**Some patients have found ways to mitigate this anxiety**					
Illustration	Well, yeah, and you start seeing th.. you don’t know what you’re … looking at. And you know, your imagination can run wild on you. And I just don’t wanna go there. I’d just rather and Dr. X is … really good. She always walks in, the first thing she says to me, ‘Everything looks good!’ (laughing) (patient 5). P. 473 “I’d rather do it with the doctor. I don’t know enough to know what I’m looking for” (patient 10). P.473 staying upbeat and don’t let myself sink into a pity pot ….” (patient 5) P.473	X				F90

	and relying on family, community, and meaningful pursuits, ("Um, family is huge. Family, my husband, friends, um church community, faith, um … music" (patient 20)) P.473.					

Evidence is allocated to a category based on quality level of finding:
Unequivocal (findings accompanied by an illustration that is beyond reasonable doubt and; therefore not open to challenge), **credible** (findings accompanied by an illustration lacking clear association with it and therefore open to challenge) and n**ot supported** (findings are not supported by the data)