



Experiences with scans and scanxiety in people with advanced cancer: a qualitative study

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Abstract

Purpose Scan-associated anxiety (‘scanxiety’) in people with advanced cancer is a common clinical problem. This study aims to explore the experiences of scans and scanxiety in people with advanced cancer, including their strategies to reduce scanxiety.

Methods Semi-structured qualitative interviews were conducted with people with advanced cancers who had a computed tomography scan for monitoring of their cancer. Data was analysed with an interpretivist approach using framework analysis.

Results Interviews with 16 participants identified three key themes: the scan experience, the scanxiety experience and coping with scans. Scans were viewed as a routine and normal part of cancer care. Scanxiety was experienced differently by each person. Scanxiety often related to the scan result rather than the scan and led to psycho-cognitive manifestations. Adaptive coping strategies were often self-derived.

Conclusion People with advanced cancer experience scanxiety, but often accept scanxiety as a normal part of the cancer process. The findings fit within a transactional model of stress and coping, which influences the level of scanxiety for each individual. Quantitative research to determine the scope of scanxiety will be useful to develop formal approaches to reduce scanxiety.

Keywords Cancer · Anxiety · Scanxiety · Scans · Imaging · Qualitative study

Introduction

Distress leading up to, during and after an imaging scan has been termed ‘scanxiety’ [1]. While scans are performed regularly in cancer care, the scanxiety experience is likely to be different in people having scans for different reasons. People with advanced cancer, who often have regular scans to monitor their cancer, face a condition that is often incurable. Treatment resistance develops almost universally, though uncertainty about prognosis is created by emerging longer-term data about novel anticancer treatments such as immunotherapy and targeted treatment. Scan experiences may be negatively impacted by symptoms from cancer or side effects from treatment. Additionally, scan results provide an objective assessment of cancer that can prompt treatment changes and modify expectations about prognosis. People with advanced cancer are living longer and have more scans for monitoring over their cancer trajectory, but research on scan experiences and scanxiety in this population is limited.

Qualitative studies on the scan experience have included people having scans for cancer screening, surveillance,

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staging or diagnosis [2–6]. In these studies, participants described anxiety and discomfort around the time of the scan related to scan procedures, waiting for scan results, uncertainty and fear of cancer recurrence. In a recent systematic scoping review on the quantitative assessment of scanxiety in people having cancer-related scans, only three of 57 studies focused specifically on people having scans for monitoring of cancer. Overall, scanxiety prevalence ranged from 0 to 83%, and scanxiety severity varied due to heterogeneity in study design and scanxiety measurement [7].

We conducted a qualitative study to determine the lived experiences of people with advanced cancer having scans for cancer monitoring. The aims of this study were to explore the experiences of scanxiety and strategies used to manage scanxiety.

Methods

Study design and participants

We conducted semi-structured interviews as a sub-study of a multicentre cross-sectional survey of scanxiety. Participants eligible for the survey were consenting, English-speaking adults who had an advanced solid cancer and a computed tomography (CT) scan for cancer monitoring within the previous four months. Participants were excluded if they had only completed CT scans for the initial diagnosis or staging of cancer.

Participants who completed the survey at a single institution (Concord Repatriation General Hospital, CRGH) could opt into further research. Once the interview sub-study obtained ethical approval, a list of interested participants was generated. Treating oncologists confirmed it was appropriate to contact participants for the sub-study. Interviewees were recruited via a convenience sampling strategy, where participants were invited by telephone or email based on the proximity of their next date of attendance to the cancer service.

Interviews were planned to take up to 60 min and were conducted by one author (KTB) in person or via telephone. Participant interviews continued until saturation of themes was reached. The study was approved by the Sydney Local Health District Human Research Ethics Committee – CRGH (2019/ETH8007).

Data collection

Interviews were guided by a semi-structured schedule (Supplementary 1). Topics included the following: initial exploration of cancer diagnosis and treatment, how participants experienced scans in terms of procedural components of the scan and of obtaining results, how participants experienced

scans in terms of the psychological impact, how scanxiety may have changed over time, any functional impact of scanxiety and coping strategies and participant recommendations to manage scanxiety. Participant details such as their age, sex, cancer type, time since diagnosis and current treatment were recorded. All interviews were audio-recorded and transcribed verbatim. Interviews and transcripts were reviewed in real time and feedback provided on interview technique and adaptation of the interview schedule.

Data analysis

The interviews were analysed following an interpretivist approach [8] and using the five steps of framework analysis [9, 10]: familiarisation; constructing a thematic framework; indexing; charting; and mapping and interpretation. It involved simultaneous data collection and analysis and systematic review and refinement of developing categories of data. The thematic framework was developed iteratively through collaboration within the research team, which included medical oncologists and a behavioural scientist experienced in qualitative psychosocial research. Double-coding on 10–20% of transcripts was performed independently by two members of the research team to ensure consistency of findings and validity of themes. The data was summarised into a matrix in Microsoft Excel and was organised by participant and themes.

Methodological rigor was ensured by the following: creation of analytical memos by the interviewers and the transcript reviewers; transcription review by at least two researchers; verbal debriefing within the research team; multiple and cross-coding; iterative revision of the interview guide and categories of data; and member checking with participants naïve to the interview.

Results

Sixty-nine of 96 survey participants volunteered to be contacted about the interview sub-study. At the time of interview recruitment, 15 people were too unwell to participate. Contact was attempted for 30 people, of whom 20 agreed to be interviewed, one person declined without providing a reason and nine people were uncontactable. Data saturation was achieved after 16 interviews were completed.

In total, 16 people with advanced cancer participated in this study between October and December 2019 (Table 1). The age range was 46 to 82 years, with seven men and nine women. Most were diagnosed with advanced cancer more than 2 years ago ($n = 11$). Participants had a range of primary cancer types and were receiving a variety of treatments, with four participants not on active treatment.

Table 1 Demographics of study participants

ID	Age	Sex	Cancer	Time since diagnosis	Current treatment
P01	82	Male	Lung	3 year	Immunotherapy
P02	54	Male	Bowel	2 years	Chemotherapy
P03	68	Female	Bladder	< 1 year	Observation
P04	69	Female	Breast	2 years	CDK4/6 inhibitor and aromatase inhibitor
P05	69	Female	Ovarian	2 years	Observation
P06	79	Male	Mesothelioma	3 years	Chemotherapy
P07	77	Male	Unknown primary	1 year	Chemotherapy
P08	73	Female	Lung	1 year	Immunotherapy
P09	81	Female	Lung	< 1 year	Chemotherapy
P10	76	Female	Renal	13 years	Immunotherapy
P11	63	Female	Bowel	4 years	Observation
P12	46	Male	Bladder	7 years	Chemotherapy
P13	49	Female	Breast	4 years	Chemotherapy
P14	52	Male	Bowel	4 years	Observation
P15	68	Female	Lung	4 years	Epidermal growth factor receptor tyrosine kinase inhibitor
P16	58	Male	Basal cell carcinoma	4 years	Immunotherapy

The median interview duration was 20 min (range 6 to 31). Three major themes were identified: the scan experience, the scanxiety experience and coping with scans. Tables 2, 3, 4 and 5 provide exemplar quotations in relation to these themes.

Theme 1: the scan experience

A routine part of cancer care

Scans were considered a routine part of cancer management and were considered ‘part of the process’ and a ‘necessary evil’. One participant stated they were ‘up to scan 544 or something’ (P14), with the hyperbole of the number of scans reflecting the frequency of regular scans for people living with advanced cancer. Participants described individualised routines around the time of a scan and demonstrated variability in their focus on the different aspects of the experience (Table 2). Problems with contrast and intravenous cannulation were recurring issues, but often accepted as an unavoidable part of the scan. Participants preferred using their central lines for intravenous access

where possible to avoid ‘...pricking and prodding trying to find [the vein]’ (P04). One participant (P16) had ‘horrific’ scan experiences due to treatment side effects of tremors and muscle cramps in combination with the required positioning during the scan.

The process of receiving results was considered part of the routine, with participants generally expecting and preferring to receive their results at their next face-to-face oncology appointment, so they would ‘get a better reaction... [and] see how concerned [their doctor] is’ (P12). Few participants were open to receiving their results by phone or email, though it was preferred if it could shorten the period waiting for the scan and thus shorten the period of anxiety. There was variability in preferences for receiving scan results via verbal report, physical hardcopy and/or by viewing the images on a computer screen.

Interactions with the clinical team (Table 3)

All participants reported trust in their oncologists’ expertise, noting that scan results required medical interpretation. They described the clinical team in positive terms

Table 2 Participants focused on different parts of the scan procedure - quotations

Domain	Quotations
Lead up to the scan	<i>I always come earlier, go over to the coffee shop there at the gate, take my first [contrast], and have something to eat, and then come up to the scan place and take the second preparation (P08)</i>
The scan itself	<i>You lie down, you get probed, you get experimented on and whatever the hell they do in there (P02); You go through the machine, you come out again (P06)</i>
Procedures after a scan	<i>They’ve got to have time to process the scan, read it, discuss it, dissect it and stick it on a wall (P02) I do [the scan] on the Monday... Tuesday lunchtime afternoon, I go to [my GP] ... I ask him to give me some simple words to explain [the scan result, then] I tried to Google English... I see [my oncologist] always on a Thursday (P15)</i>

Table 3 Clinical team themes - quotations

Domain	Quotations
Trust in medical expertise	<i>I've got complete faith in the doctors and nursing staff</i> (P05)
Attributes of hospital staff	<i>The staff are wonderful, friendly and helpful</i> (P06) <i>Staff are doing their best, they smile at you, they help you be comfortable</i> (P04)
Relationships with oncologist	<i>I have complete faith in [my oncologist], and he calls us a team. I think that's really important</i> (P16)
Communication from the clinical team to participants—positive	<i>They come over the speaker and say, we're going to do this again – which is good</i> (P03)
Communication from the clinical team to participants—negative	<i>When the doctor first told me [more than two years ago], it was like a bomb – she was that blunt</i> (P04)
Communication within the clinical team	<i>[My GP] seems to have all the information downloaded to his computer, it's quite handy... I'm very pleased that he's in the loop</i> (P07) <i>She's been my GP for 23, 24 years... I do know she feels that she is left out of the loop... the last letter [from the oncologist] was [10 months ago]</i> (P10)

and had developed meaningful professional relationships with them. One participant favourably recounted working as a team with his radiographer to improve his scan experience, which included an effective handover between radiographers when the personnel changed (P16). Participants valued effective communication from their doctors and effective communication between their doctors, which they felt was sometimes lacking. When negative interactions with the clinical team occurred, they were recalled by participants' years after the event.

Theme 2: the scanxiety experience (Table 4)

The experience of scanxiety varied, reported by some participants and not others, often with a psychological impact, sometimes generating physical symptoms, and with differing triggers.

Presence of scanxiety

Most described the scan itself as 'alright', 'fine', 'okay', 'not a problem' or 'pretty easy', though some participants did experience scanxiety in relation to specific steps in the procedure: 'The worst part is going, oh god, I hope they can find the vein' (P05). For most participants, the scan result appeared to be the main driver of scanxiety. Scanxiety was also described when there was a deviation in the expected process: 'If someone calls you [with the result], it makes you nervous' (P13).

Manifestations of scanxiety

Participants described intrusive thoughts about scan results and their future, changes in mood such as irritability, impaired concentration and reduced motivation to complete

usual activities. They also experienced physical symptoms of insomnia, fatigue and nausea.

Knowledge and uncertainty influences scanxiety

Participants recognised and welcomed the concrete assessment of their cancer provided by scans. Scans were understood to have implications for treatment decisions and prognosis: 'It puts me in a position where I can make decisions going forward' (P02), which triggered uncertainty and scanxiety, particularly when participants felt unwell or treatment was not controlling the cancer. Familiarity with scan procedures did reduce scanxiety, especially as participants learnt how to improve the experience. Despite this, additional upfront information about scan procedures was not thought to help: 'They probably tell you the process, but it hasn't sunk in yet because it's the first thing' (P13).

The context of the scan and individual belief systems also influenced scanxiety, though in a variable way. For the initial scan, one participant had more scanxiety because the diagnosis had not been made, while another felt less anxious because he did not know what was ahead of him in terms of the diagnosis and treatment. For participants who initially received potentially curative treatment before transitioning to a palliative intent of care, one participant reported more scanxiety early on when 'a lot rode on those scans' (P14), while another felt more scanxiety later on: 'I was very brave at the beginning. But as the time and the experiences have accumulated, it's almost like cumulative trauma... [the cancer is] ongoing in your life [and] you lose hope' (P11).

Timing of scanxiety

The onset and peak of scanxiety varied among participants. Some reported onset a few days before the scan (P10), a few weeks before the scan (P11) or during the scan itself

Table 4 The scanxiety experience - quotations

Domain	Quotations
Manifestations of scanxiety	
Intrusive thoughts: about the result	<i>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 (P16)</i> <i>It goes through your head, you're having the scan for a reason and the reason is to find out whether the cancer is progressed, or what the state of it is (P02)</i>
Intrusive thoughts: about the future	<i>All I could think of was, am I going to be alive to see the baby? (P03)</i>
Mood: irritability	<i>I'm a bit short with [my family]. A bit cranky (P03)</i> <i>I'm probably a bit short... I don't suffer fools as much as I usually do (P11)</i>
Mood: sensitive	<i>It can be very emotional (P14)</i>
Reduced concentration	<i>I'm distracted far easier. I don't seem to be able to withhold as much information in my head. As soon as I get the result, that's all clear, and I'm back to normal (P11)</i>
Reduced motivation	<i>I probably take much longer doing what I do... I'm a carer for some of the older sisters, sometimes it's very difficult to get into the car to go and visit them (P10)</i>
'Uncertainty paralysis'	<i>I feel as if I can't make plans (P03)</i>
Physical symptoms	<i>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 tired. That usually hits a few days before (P11)</i> <i>Sleeping's hard, a couple of nights before... I feel a bit nauseous through them (P14)</i>
Anxiety triggered by a scan	
In relation to any scan	<i>[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 a sudden it comes back and you're not okay (P11)</i> <i>I feel like my life is on hold until I get the result... (P03)</i>
In relation to wellness	<i>I'm not expecting anything drastic because I'm not feeling unwell (P01)</i> <i>If I have a back pain, then I'll be thinking, ooh is something wrong. If I don't have any pain, then I'm not really worried about the scan coming (P12)</i>
In relation to treatment efficacy	<i>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 (P16)</i>
Anxiety over time	
First scan caused more scanxiety	<i>I'm waiting and I'm waiting and I'm waiting. I'm thinking, what's going on, what's been happening? (P03)</i>
Subsequent scans caused less scanxiety	<i>When you go back for your third, you know you're going to be okay 'cause it's exactly the same (P02)</i> <i>I'm probably a bit more relaxed about it, knowing what it is (P06)</i>
Adapting to scan procedure	<i>You've learnt to have [clothes] that didn't have metal there... so you didn't have to undress... if I'm feeling cold, I feel comfortable to say, could I have a blanket? (P05)</i>

(P13). Scanxiety generally abated once the scan results were known: '[it's] very much a celebration... thank goodness I've got my life back again' (P03).

Participants often found the period between the scan and receiving their results the most difficult: 'having the scan to the result bothers me terribly' (P03); 'waiting for the result is the most nerve-racking' (P13). Some perceived this period to be a clear contributor to scanxiety and preferred receiving scan results 'within the hour, but I know that's impossible' (P11). Others were casual about the timing between the scan and receiving the result, accepting that 'usually about a week [is] probably about right' (P10) or that 'one or two weeks... [is] fine' (P13). The day of the appointment for the result was sometimes associated with a peak in scanxiety: 'The worst part is waiting in the room to get my result' (P03); for another, it calmed him: 'you know you're getting the result. You know that it's coming... It puts my mind at ease' (P14).

Theme 3: coping with scans

Participants employed a range of strategies to improve their scan experiences, though these were not uniformly described or recognised as ways to reduce scanxiety.

Behaviours and attitudes around the time of a scan (Table 5)

Participants engaged in specific behaviours around the time of the scan, including normalisation, distraction, relaxation, taking ownership over their health care, positive self-talk and seeking professional help. Some negative health behaviours, such as excessive alcohol consumption, manifest in participant reports. Anti-anxiolytic medications, when used, were considered helpful (P02, P16), though other participants reported feeling 'dopey' (P14), were concerned about

Table 5 Strategies to cope with scans—quotations

Coping strategy	Quotations
Coping behaviours	
Normalisation	<i>I just go back to doing what I do. That's living (P02)</i> <i>'I'm able to live in the moment and put it to the back of my mind... (P11)</i> <i>I do a lot of business as usual. Like, you know, I do work, to keep my mind away from it (P13)</i>
Distraction	<i>I'm wanting to do stuff so I'm not sitting thinking, sitting worrying... I'll have distractions, family around... Read a lot. Cryptic crosswords. Shopping... As long as I'm around people (P03)</i> <i>I try to involve myself in a book or a good movie that I want to watch, take myself away from the situation (P16)</i> <i>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... there's probably a thousand things I should be doing that'd help, but you fall back to the things you know (P14)</i>
Relaxation	<i>Meditating, to a degree, and deep breathing exercises (P02)</i> <i>My cross-stitching... is therapeutic and calming (P09)</i>
Self-management of care	<i>[Booking your own scan gives] you something to do... owning your treatment... owning it yourself. [It means] you know when you're walking in to have the scan, you know where you're going (P05)</i> <i>I choose early morning, or later afternoon, [when there's] not so many people (P15) on seeing GP for the result</i>
Positive self-talk	<i>I talk to myself... the cancer's there and it's not going away, so, you know. Calm down, you're not helping yourself (P05)</i>
Seeking professional help	<i>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 (P14)</i>
Staying active	<i>[I] garden... I've joined the Survivorship Gym (P10)</i>
Religion	<i>[I] pray. You can only pray (P13)</i>
Coping attitudes	
Methodological	<i>I'm a bit of a step person. That's one step over, two steps over. Then I'm going home (P09)</i> <i>I'm a day to day person... I just take it as it comes (P12)</i>
Defiant	<i>I can't let it affect every other day (P02)</i> <i>I'm not going to let it ruin what quality of life I have left (P09)</i>
Problem-solving	<i>[The radiographer] knew about [my side effects from treatment] and really worked well as a team to get through [the scan]... We both thought of [a strategy] together (P16)</i>
Pragmatic	<i>I'm probably always a little prepared for the worst... We can't all live forever, that's the bottom line, so we've just go to accept what's going to happen (P08)</i> <i>[My time is] limited. So why would I waste a lot of time worrying about something I have no control over (P09)</i>
Contextualising	<i>You look at somebody who's got arthritis and they've got it badly – they suffer every day. What have I got to complain about? (P04)</i> <i>When you look at the different people, you go, he's worse than me. I can tell, just their face, how they're looking... Or they'll be someone younger... So it sort of takes it away from you (P05)</i>
Information-seeking	<i>Whether they're good or bad, or whatever the case... it's important to know for me... I'm happy to know, to deal with things on the basis of the more information the better... [being evasive] would worry me more (P02)</i>
Avoidant	<i>I'm probably a bit like, an ostrich. I probably bury my head in the sand. Sometimes, the less you know the better. Because, the more you know, sometimes it can be very stressful (P04)</i> <i>I don't mind being a bit ignorant sometimes about those things... I just want to go along as I am, until it catches up with me. I'm not going to waste half a day worrying about a report, sitting over a report (P09)</i>

'being drugged up' (P11), or 'just [didn't] think it's necessary' (P03). These strategies were often used in the lead up to the scan or while waiting for the result, rather than during the scan itself. The one exception was a participant who stated, 'I closed my eyes through the whole thing' (P16).

Participants also described their inherent approach to life and to their cancer which helped them manage around the time of a scan.

The role of support networks (Table 6)

Most participants had a clear preference on whether they wanted family or friends to be present while they received

scan results. Some wanted to be alone, feeling that family or friends would be anxious and require support themselves rather than supporting the participants. Others preferred the moral support and assistance retaining and understanding information.

Family and friends also provided support through logistics, positive encouragement, empathy and by being a confidante. The lack of support was also noted: 'Others would kind of say, "oh, you'll be alright"... There's a voice in my head that says, "you don't know the half of it!"' (P10). Family and friends were also observed to experience scanxiety: '[My family are] probably more anxious about the appointment coming up than I am' (P12).

Table 6 Support networks - quotations

Domain	Quotations
Participant prefers to be alone to receive scan results	<p><i>I like to do that sort of stuff solo... [My family's] not living this process every day. So if [my sister] were to sit down with me and the doctor every 3 months when we're looking at the scans, then she would be hyper-anxious about what's going to happen... I don't think it's fair on them. Even though they're there to support me, I feel like I'm supporting them (P02)</i></p> <p><i>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 (P11)</i></p> <p><i>Even though [my family are] thinking positive, they're always frightened... It was nice to have them there. But they weren't much help (P16)</i></p>
Participant prefers to have support people present to receive scan results	<p><i>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 (P07)</i></p>
How family and friends provided support	<p><i>He's always there to kind of, drop me off, pick me up, do whatever's necessary (P04)</i></p> <p><i>If I say something that's negative, he'll say, no don't talk like that, that's not going to happen (P03)</i></p> <p><i>Friends and family sort of understand that some days I'm not real good. If I can't make [a prior commitment], they're not judgemental (P14)</i></p> <p><i>It does help to talk to someone... it's good to have that calm presence there (P05)</i></p>

Participants did not always recognise that scanxiety was experienced by others: 'It didn't occur to me that it happened to anyone else. I thought it was just me being me' (P03); however, they were generally not interested in external supports: '[The person from the Cancer Council] said sometimes some of the members [of the support group] won't be there because they've died. And I said, no, that's just not for me... I don't want to sit around with people and talk about, oh mine's worse than yours' (P03).

Discussion

This novel qualitative study explored scan experiences and scanxiety in people with advanced cancer, a population who are living longer with cancer and who have regular scans that can profoundly affect treatment and prognosis. The principal findings were that scans and associated discomfort and anxiety were accepted as a normal and unavoidable part of cancer care. Scanxiety was often associated with scan results rather than the scan itself and had psycho-cognitive effects on participants. The scanxiety experience was individual; even when participants reported similar symptoms or being at a similar part of their cancer journey, they had different reactions to their scans over time. Participants developed adaptive coping strategies around a scan, and there were differences in how family and friends were viewed as supports.

The normalcy of scans and scanxiety was apparent by the fact that negative experiences around a scan were not always recognised as scanxiety and coping strategies were not recognised as coping strategies for scanxiety. People with advanced cancer may accept these negative experiences because of the higher stakes involved, where scans provide

an objective assessment of their cancer and can direct optimal care to improve prognosis. Further, while scanxiety may be an expected occurrence, it was evident that participants experienced scanxiety in different ways and with different severity. In the larger cross-sectional survey ($n=222$), from which participants were drawn, 55% of people with advanced cancer self-reported scanxiety, with a mean severity score of 6 out of 10 on the distress thermometer (possible range 0–10) (Bui, under review). The lack of recognition of scanxiety in some participants raises the possibility it may have been underreported, and that increased awareness and education about scanxiety is needed.

There were no identified formal or systematic approaches to reduce scanxiety in our interviewed participants, with most coping strategies self-derived by participants. Interventions to reduce scanxiety in people with advanced cancer remains an area of interest, with none of the 10 intervention studies identified from the systematic scoping review focused on this population [7]. Given the individualised experiences of our participants, there may be benefit to tailored interventions addressing psychological manifestations of scanxiety through psycho-therapeutic or educational interventions or participant comfort during scan procedures by streamlining procedures for intravenous cannulation (especially as people with advanced cancer may be more likely to have a central line). Given the increased in reported scanxiety in the lead-up to scan results, the impact of scanxiety may also be reduced through systematic changes to delivering results, such as streamlined scan and follow-up scheduling to reduce the wait for results. Discussing the possible scan results and their implications before the scan may also be helpful. The strength of the doctor-patient relationship

and the supportive role of family and friends could be incorporated into interventions to improve their efficacy.

Scanxiety can be viewed within the transactional theory of stress and coping proposed by Lazarus and Folkman[11], where scanxiety becomes a product of an individual and their environment (Fig. 1). Primary appraisal occurs when individuals consider whether a scan is a threat, contemplating understanding of their cancer and previous experiences with scans. Secondary appraisal occurs when individuals consider aspects around the scan experience and their ability to navigate these problems. In the feedback loop between primary and secondary appraisal, scanxiety levels can increase and decrease. Re-appraisal of the scan as a threat may occur through a scan period or between scan periods.

The main strength of this study is the detailed information obtained about scanxiety in people with advanced cancer, an understudied population. As recognised by participants, scans are a necessary means to assess the progress of cancer and response to treatment. Scans are often the preferred method of objectively assessing cancer and are a common thread across cancers and treatments. The burden of scans is likely to increase as people with advanced cancer

live longer, and therefore the issues raised around the scan experience and scanxiety in this study are likely to resonate with many people. The practice implications for members of the multidisciplinary teams providing cancer care hence become increasingly relevant. The adaptation of scanxiety to the threat appraisal model provides an understanding of the factors contributing to scanxiety and could guide potential intervention to reduce scanxiety.

The limitations of this study relate to its generalisability. We recruited a small sample who have characteristics that may not be typical of the general population of people with advanced cancer. They were English-speaking, had CT scans for monitoring of their cancer, had good relationships with their doctors and who mostly had been living with advanced cancer for more than 2 years. Our participants were also older, so our findings may be less applicable to younger people who have different circumstances around work, relationships, family and child-rearing, support networks and financial situations. The majority of interviewees also did not report high levels of scanxiety, which contributed to interview durations that were shorter than anticipated, and which was discordant with the quantitative scanxiety assessment

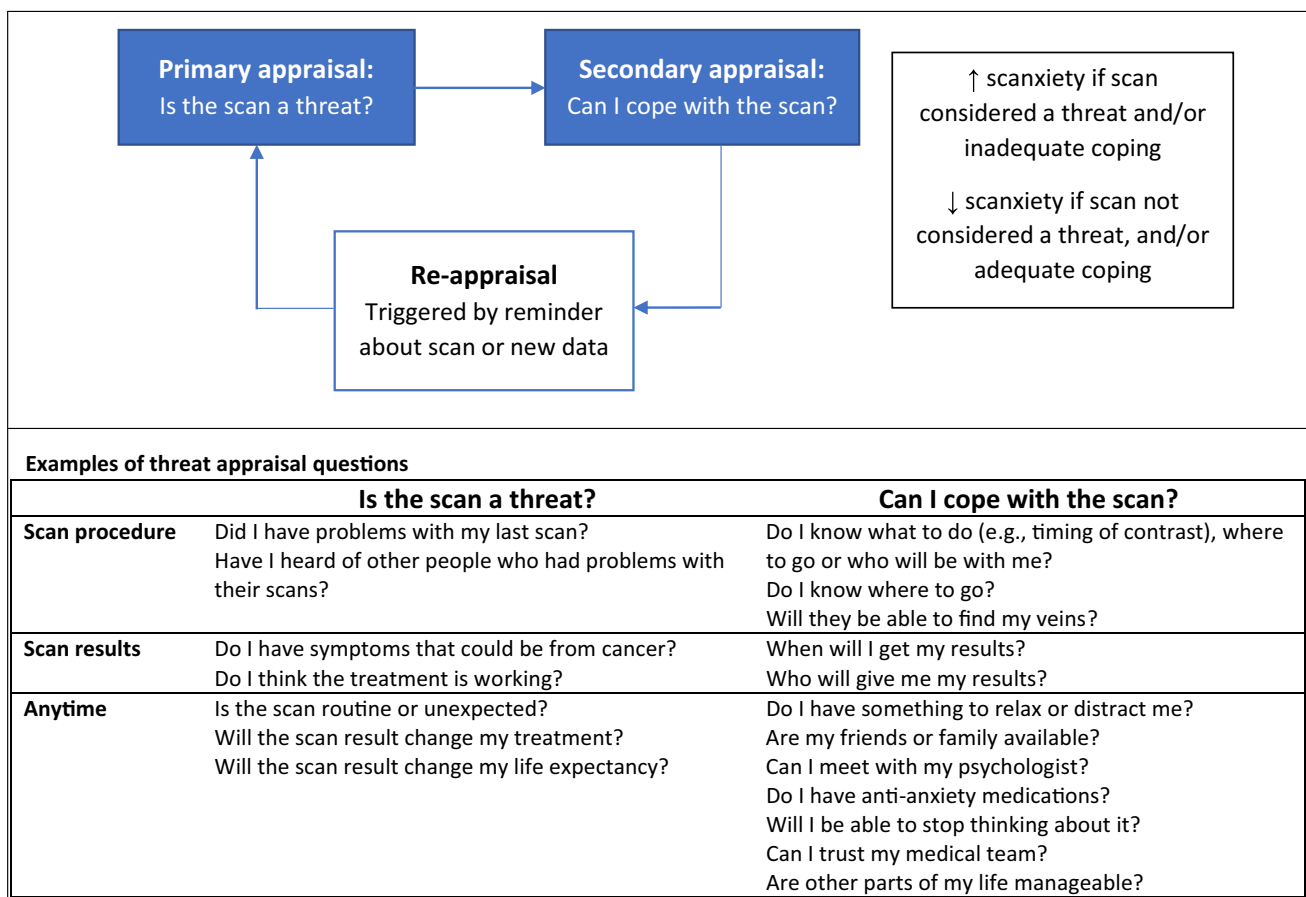


Fig. 1 Threat appraisal model of scanxiety

in the partner survey study. The qualitative nature of our study also limits the generalisability of our results, while the cross-sectional methodology introduced recall bias. It is unclear whether scans and associated scanxiety caused intrusive thoughts or behaviours in participants' lives.

Prospective longitudinal research on scanxiety in people with advanced cancer is currently underway and is important in quantifying the prevalence and severity of scanxiety to properly define the scope of this problem and to inform the optimal timing of scanxiety interventions.

Conclusions

People with advanced cancer do experience scanxiety, but it may be under-described due to the belief that scanxiety is a normal phenomenon. Varying self-derived coping strategies are used around a scan, and formal approaches to reduce scanxiety are needed.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s00520-021-06319-1>.

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Author contribution All authors contributed to the study conception and design. Interviews were conducted and transcribed by KTB. HMD reviewed recordings and transcripts throughout interview phase. Initial data analysis was performed independently by KTB and HMD, with final themes determined in collaboration with PB and BEK. The manuscript was written by KTB, and all authors reviewed and edited the manuscript. All authors read and approved the final manuscript.

Data availability Data from this study is available from Kim Tam Bui upon reasonable request.

Code availability Not applicable.

Declarations

Ethics approval This study was approved by the Sydney Local Health District Human Research Ethics Committee – Concord Repatriation General Hospital (2019/ETH8007). The study was performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments. Reporting followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement.

Consent to participate Informed consent was obtained from all individual participants included in the study.

Consent for publication Not applicable.

Conflict of interests Financial interests: BEK reports receipt of honoraria for advisory boards and educational presentations as well as

travel and meeting expenses from Roche; and receipt of honoraria for educational presentations from Novartis. HMD reports honoraria paid to their institution for educational presentations from MSD and BMS and advisory board by MSD. KTB, PB and CB declare they have no relevant financial interests to disclose. Non-financial interests: All authors declare they have no non-financial interests to disclose.

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