

Not as simple as "fear of the unknown": A qualitative study exploring anxiety in the radiotherapy department

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Abstract

Objective: Little is understood about the anxiety experienced by cancer patients undergoing radiotherapy or investigative imaging. Our aim was to identify sources of anxiety, the points along the cancer journey where anxiety occurred and methods to alleviate it.

Methods: Six focus groups were conducted with cancer patients ($n = 17$), caregivers ($n = 3$) and healthcare practitioners (HCPs; $n = 10$) in the radiotherapy department. Patients described specific elements in the care pathway which induced anxiety, while HCPs focused on their perception of the patient experience. Thematic analysis was used to analyse data.

Results: Three broad themes emerged: The Environment, The Individual and The Unknown. The physical environment of the hospital, inside the scanner for example, emerged as a key source of anxiety. The impact of cancer on patients' individual lives was significant, with many feeling isolated. The majority of participants described anxiety associated with the unknown. HCPs reported difficulty in identifying the anxious patient.

Conclusions: Anxiety is experienced throughout the cancer pathway. Common sources include the physical environment and the uncertainty associated with having cancer. Identifying both anxiety-inducing factors, and the anxious patients themselves, is crucial to enable targeted interventions to alleviate anxiety.

KEYWORDS

anxiety, cancer, healthcare, qualitative, radiotherapy, unknown

Maria Greca Dottori and Eliza Gimson should be considered joint first author.

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1 | INTRODUCTION

The prevalence of cancer-related anxiety varies between studies depending on the measures used and the population studied (Niedzwiedz et al., 2019). There is consensus, however, that pathological anxiety is more common in people with cancer (Zhu et al., 2017). Anxiety is associated with impaired social functioning and fatigue and can markedly impact quality of life (Brenes, 2007). Cancer patients with anxiety often withdraw from friends and family, are less compliant with treatment or less likely to continue healthy habits (Nikbakhsh et al., 2014). This, in turn, can enhance patients' stress (Nikbakhsh et al., 2014). The repeated lockdowns and shielding experienced by many patients as a result of the COVID-19 pandemic have further compounded these mental health difficulties (Neal et al., 2020).

Twenty-seven percent of all cancer patients in the United Kingdom undergo radiotherapy, and the majority will have investigative imaging (Public Health England, 2017). Of 100 patients undergoing radiotherapy, 21% of patients experienced anxiety exceeding normal levels (Holmes & Williamson, 2008), with some tumour sites exacerbating anxiety further. Head and neck cancer patients, for example, are required to wear a mask fixing them to the treatment couch. Twenty-four percent of initial treatment sessions in this group were disrupted due to claustrophobia and anxiety attacks (Clover et al., 2011).

Prior research has focused on prevalence, diagnostic criteria and benefits of psychological interventions regarding cancer-related anxiety (Niedzwiedz et al., 2019). Qualitative studies have explored patients' experiences of living with specific cancer types, identifying cancer specific needs as well as those of the wider cancer population (Ho et al., 2016; Martins et al., 2019). There remains, however, a paucity of published research exploring patients' views on factors in the cancer pathway that induce anxiety. Identifying these triggers will allow for targeted interventions to address this.

Previous research has highlighted discrepancies between patient and staff perceptions of cancer care (Chan et al., 2019; Gouveia et al., 2015). One study of 153 cancer patients and 70 nurses found that nurses significantly underestimated depression, anxiety and the need for assistance (Hladschik-Kermer et al., 2013). Further consideration is needed about how these differences impact care.

The aim of this study was to explore the anxieties experienced by cancer patients attending for investigative imaging or radiotherapy. Focus groups were used to identify situations along the cancer journey where anxiety occurred, what feelings of anxiety the patient experienced and any methods which may alleviate such anxiety. Focus groups were also conducted with healthcare practitioners (HCPs) to compare with patients' views.

2 | METHODS

2.1 | Study design

This was an exploratory qualitative study involving cancer patients, their caregivers and clinical staff working in the radiotherapy and imaging department. A focus group methodology was utilised to allow

sharing of in-depth knowledge between participants and encourage the emergence of new ideas through group discussion (Monographs of the Society for Research in Child Development, 2012). It was conducted as part of a larger study, using a co-design approach to develop a reassurance device prototype for a radiotherapy treatment session.

An interview guide was developed, the first part designed to explore where in the cancer care pathway anxiety occurs, and any triggers. Patients were instructed to describe their feelings while HCPs were asked to focus on their perception of the patient experience. The second part focused on the top design features for the reassurance device prototype; this dataset will be analysed in a separate paper.

2.2 | Participants

Participants were recruited from a suburban specialist cancer NHS Foundation Trust in London. The study was advertised in the radiotherapy department to eligible participants and verbal consent was obtained. Eligible participants were over 18 years of age and had a good command of the English language. Participants had themselves undergone radiotherapy or investigative imaging as part of their cancer care or were the caregiver of a participant who had. HCP participants were diagnostic ($n = 1$) or therapeutic radiographers ($n = 9$).

2.3 | Study procedure

Focus groups were conducted at participants' convenience in the hospital. Patients and HCPs were placed in different groups. Each focus group was conducted by two facilitators (HM and GC or HM and TW) with a less experienced researcher observing (EJ).

2.4 | Data analysis

Focus group meetings were audio-recorded and transcribed verbatim. QRS International's NVivo v.10 software was used to store transcripts and analyse data. Inductive thematic analysis was used to code the original patient transcripts by two researchers (EG and MGD), independently. Investigator triangulation was used, and initial coding was reviewed to confirm interpretation. This process was followed by discussion between the original coders to reach consensus on the final themes. Once themes were established, codes were re-assessed and finalised. From the themes extracted in the patient transcripts, deductive analysis was used to code HCPs transcripts for comparison. Final analysis of both was cross-checked with existing literature and data provided by personal communication with Cancer Research UK.

2.5 | Rigour and ethics

Facilitators (HM, GC and TW) comprised a research radiographer with recent qualitative research training, a speech and language

therapist and PhD candidate with experience in conducting qualitative research and focus group interviews, and a professor of applied health research and expert in qualitative research. The coders (EG and MGD) comprised two final-year medical students with previous experience and training in coding qualitative interview data. Facilitators and coders were female, none of whom were known to participants. Facilitators used a reflexive diary throughout the focus group period. Study reporting was informed by the consolidated criteria for reporting qualitative research (COREQ) checklist (Tong et al., 2007). The project received ethical approval from the North West - Greater Manchester South Research Ethics Committee, HRA and Health and Care Research Wales (#19/NW/0607).

3 | RESULTS

3.1 | Characteristics of focus groups

Six focus groups were conducted between November 2019 and February 2020; four with cancer patients and their caregivers, and two with HCPs working in the radiotherapy or radiology department. Each focus group lasted from 46 to 108 min, with four to seven participants. Following completion of the fourth focus group, no new

themes emerged, and data saturation was deemed to be reached. Sampling of the HCP groups was pragmatic and limited by the size of the institution.

Among 17 cancer patients and three caregivers 12 were women, with an age range of 46–85 years. The majority of patients were early stage (0 and 1) breast cancer ($n = 5$), prostate cancer ($n = 6$) or head and neck cancer ($n = 2$). The remainder were stage 2b cervical cancer ($n = 1$), stage 2 rectal cancer ($n = 1$), stage 4 lung cancer ($n = 1$) and stage 4 chondrosarcoma ($n = 1$). Thirteen of the 17 cancer patients underwent radiotherapy, and the remaining four underwent investigative imaging (MRI or CT) as part of their cancer care. All 10 HCPs were women, ranging in age from 18 to 55 years.

3.2 | Description of main themes

Three key themes emerged from our focus groups (Figure 1): (1) The Environment, (2) The Individual and (3) The Unknown.

3.2.1 | The environment

This theme encompasses the anxiety encountered by patients during hospital visits. This anxiety was characteristically, as one participant

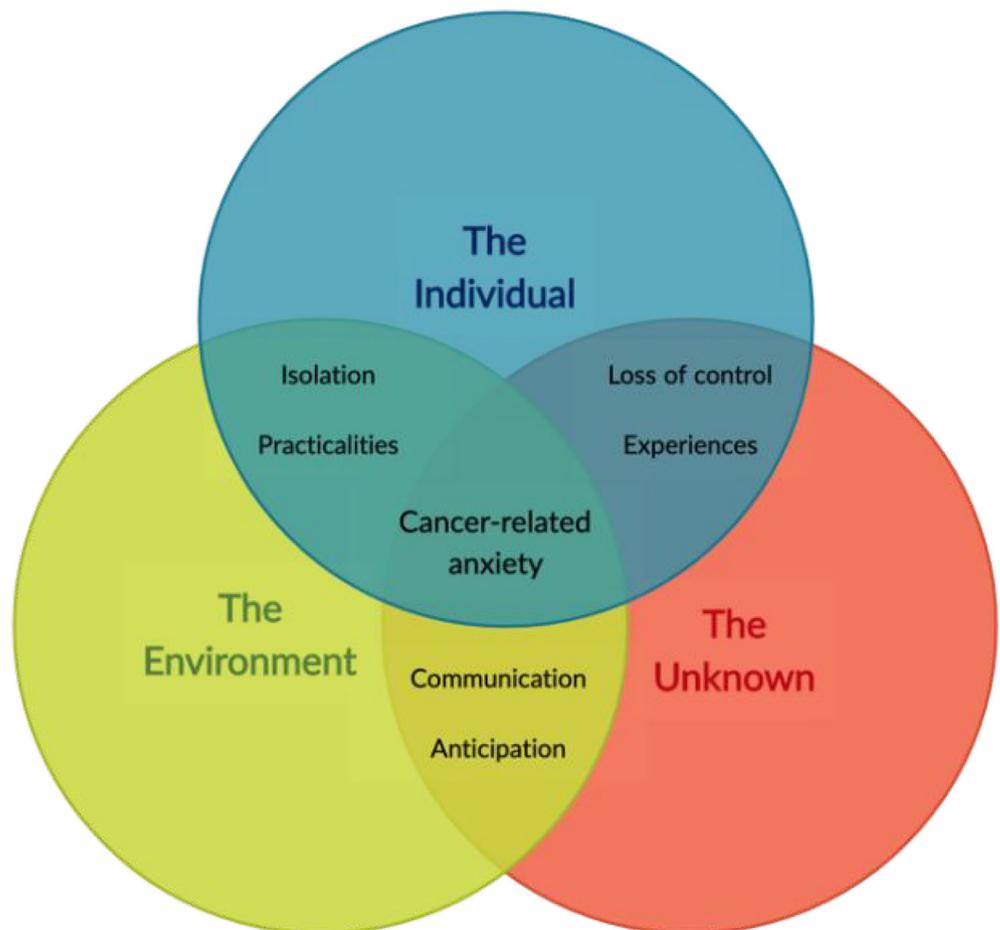


FIGURE 1 Summary of how key themes and subthemes overlap and converge to influence cancer-related anxiety

remarked, 'much more of a physical anxiety than a head one'. It was the only theme where references to anxiety medication for were made, for example, immediately before an MRI. The Environment was subdivided into places and people.

Places

Most of the cohort described feeling 'scanxiety'. Immobility, cold, noise, time and claustrophobia all contributed to anxiety in the MRI scanner. For some, the MRI was the only place where they experienced anxiety and even participants who had not experienced 'scanxiety' were aware of its effects on others.

When you are pinned down, all you have got is your thoughts because the only distraction is that you can see the patterned, flower wallpaper, and you can hear the machine operating and a bit of music, but you cannot do anything else.

Although the scan was the main place participants felt anxious, a combination of anxiety-inducing physical factors was experienced during treatment and in waiting rooms. Time spent in hospital and near-daily commitment to treatment were main contributors to anxiety in these settings.

People

Isolation was the main burden of The Environment, and most references to people in the hospital (staff, other patients and support network) were made in light of whether they could dispel this feeling.

Yes, absolutely. So that personal touch dispels huge amounts of it (the anxiety). And it does not happen enough. And it's not a complaint. It's just the way things are.

Regarding staff, the main sources of anxiety were feeling rushed, patronised and lack of experience, which increased patients' feelings of not being seen.

The consultant came in. She was literally in so fast, she spoke so fast, I could not take in anything that she said. Just rushed. I mean, bless her, I wasn't judging her, but it wasn't what we needed at the time.

Coping mechanisms

Although the majority of patients spoke about the negative effects of the Environment, alleviating factors also emerged.

Emotional support from loved ones both in the hospital and at home was an important way of lessening anxiety. Help with practicalities such as getting to and from appointments was also key. In the hospital, some participants referred to the importance of having a loved one present in consultations.

But that's the danger though, is not it, because you need somebody with you, because you are not listening in those stages.

Many described strategies are employed to help reduce scanxiety. A particularly common strategy was distracting oneself. Methods varied but included breathing exercises, listening to music and imagining one was elsewhere. Keeping track of time when having a scan emerged as a coping mechanism for several participants.

But the way I felt I got through the radiotherapy, I know it's a silly way, but I used to count one to sixty, six times. And I know that when I got to the end, oh, it's finished. And I did that every time throughout my treatment, and it worked for me.

The environment itself could also alleviate anxiety:

And things like the waiting area here, it's very spacious out there, it's a really good environment, it's almost like being in a foyer of a hotel. I just found that the whole environment was conducive to making me feel much happier.

3.2.2 | The individual

This theme encompasses the patient as an individual and their life outside cancer as well as the interplay between patients' lives and their cancer journey. Two subthemes emerged: encompassing emotional and practical elements.

Emotional

Many participants felt isolated at various points. The isolation was sometimes felt as a result of not being able to carry out their normal activities as well as a lack of understanding from people. This differs from the physical isolation induced by the hospital environment.

Because around that time, even though I had people around, I was beginning to feel isolated and nobody cared, nobody understood.

Emotional strain was experienced when communicating with loved ones. Participants found talking to be a helpful method of alleviating anxiety. However, often those closest to them found this too distressing.

Sometimes talking about it ... Sometimes people do not know how to talk about it ... but I did find sometimes I quite liked to talk about it ... But sometimes it's knowing who to talk to. I do not tend to with my husband because he gets too ... He'll tend to shut the

conversation down ... Some people, you cannot talk to them about it because they just get too upset by it.

Many participants embodied a strong sense of stoicism to get through what were often gruelling experiences, with most feeling they just had to 'get on with it'.

Practical

For a small proportion of our sample, work and financial concerns were a significant source of stress. This was particularly felt by those with caring responsibilities. A lack of understanding from employers and reductions in pay added to the anxiety.

No, but at that time you feel you are alone. And when I'm on my own with two children, I need to go to work. And now, they have cut down my money, and it's, when are you coming back? And I feel pressure.

For others, work served as a distraction and gave them purpose.

I found I had to have a purpose. Get up, go to work ... And it really did work for me.

The logistics associated with travelling to appointments as well as appointment preparation also emerged as a practical source of anxiety for some participants. This was sometimes eased through being accompanied.

On the stress front, if you are coming on your own and you are coming by car, sometimes you can spend 15 minutes in the queue and I think if you are on your own the stress levels go really high.

3.2.3 | The unknown

The Unknown refers to psychological anxiety and encompasses the uncertainty which flows through the patient journey. 'The Unknown' was a phrase used by most participants and when mentioned by one, was often immediately echoed by others. This theme is divided into three subthemes: anticipation, communication and experience.

Anticipation

A significant proportion of the anxiety surrounding The Unknown was associated with anticipation. Participants experienced anxiety anticipating results, next steps in management and side effects.

For some, the anxiety associated with treatment was felt most strongly at the start of their cancer journey. This was generally relieved once participants had a clear plan, although this could induce anxiety through an awareness of treatment options becoming limited as the disease progressed.

The time I felt most anxious was when I was very first told. Obviously, all sorts go through your mind at that stage. But then once I was told what's going to happen, what treatment I was having, I thought, well, this is what I've got to do.

Participants also experienced significant anxiety anticipating the side effects they might suffer, which was particularly tough due to their unpredictable nature. There was fear that some side effects might be permanent.

Also they are [side effects] potentially permanent, you know, some of them are potentially irreversible.

This anxiety did not necessarily translate into participants wanting to know all the potential side effects they might experience.

Actually they have [staff] been plugging away on how awful the side effects can be ... It's extremely negative.

When staff communicated side effects well, however, anxiety was eased.

They did explain very early on what the side effects could be, but made it very clear you might not get them or you might get some of them ... it was very positive.

Communication

Communication was a key factor in The Unknown. Poor communication emerged as a source of anxiety while effective communication was consistently described as a way to alleviate it. There was a mixed reaction to information booklets or flyers with most participants preferring to be spoken to face to face. Many participants felt a loss of control over their lives as a result of cancer. Poor communication exacerbated this.

It wasn't said unkindly, but it felt, kind of ... you know, he knew best. But you feel almost like a child. I've always been very in control and I'm used to being very in control and ... I only recently, a year before, had given up work and everything ... but suddenly I found myself saying, in an almost childlike way, is this going to hurt because you do not know.

Experience

Since the world of cancer is a new one for most patients, experience plays a major part in The Unknown. All participants agreed that the first time was the most anxiety-inducing.

But I think often it's the unknown. Even though you get leaflets and things, you do not ... Until you do it, you do not know what it's really like.

Interestingly, having loved ones who had had cancer or a previous personal experience did not alleviate this initial anxiety, and in some cases heightened it, as patients prepared for the worst.

My mum had radiotherapy donkey's years ago and she ended up with quite bad sores because she had breast cancer and I suppose you think, I could end up with great big sores everywhere.

HCPs' views

Most HCPs agreed that the experience of anxiety was patient-dependent.

Regarding The Environment, HCPs seemed aware of the increased anxiety in scans and during treatment, although there was little knowledge of specific triggers. Claustrophobia, isolation and time commitment associated with treatment were the most agreed upon.

Some of them have quite lengthy scans. It's very important that they keep extremely still. And they can be quite anxious about narrow tunnels.

When it comes to treatment, they are being left alone inside the treatment room. That's the time they probably can be flat and then think that thing.

Staff demonstrated an understanding of personal factors such as childcare or work which might exacerbate cancer anxiety.

The Unknown was the theme with most references in this dataset. HCPs recognised anxiety in patients regarding anticipation, treatment efficacy and the future, as well as first time experiences.

I was just about to say, fear of the unknown.

And about the efficacy of the treatment as well. There's anxiety about, is it working? Especially whilst on treatment.

Before [the anxiety] is worse, potentially, because it's the anticipation.

Most HCPs thought anxiety lessened after the first few treatments, although there was discussion regarding side effects and other factors that could potentially induce anxiety again. HCPs also thought patients might be anxious at the end of their treatment as support from staff decreases.

Regarding communication, all were aware of language, specifically how wording and explanations can alleviate anxiety.

I guess we all instinctively use very calming and distracting language I think.

Especially when they are first on their treatment, you are explaining literally everything. Everything that you

are doing. Not over the top, obviously, because there's lots of information in one go. But I think it's just giving them information before you are doing anything. Just letting them know what's happening.

Interestingly, there was some discussion regarding identification of the anxious patient with most HCPs agreeing that it is difficult sometimes to spot the ones that are not overtly anxious and are just 'carrying on with it'.

There are those that are anxious that we do not pick up.

4 | DISCUSSION

Three themes emerged from our study: The Environment, The Individual and The Unknown, encompassing the factors which induced anxiety throughout the cancer journey.

Loneliness is a known risk factor for poor mental health in the general population (Adams et al., 2017). It also plays a key role in cancer-related anxiety. The emotional isolation experienced by our participants stemmed from a desire not to burden loved ones with cancer-related conversations which they found too distressing. These feelings are common among cancer patients (Adams et al., 2017). It is important for staff to recognise this potential source of anxiety and offer to assist difficult conversations.

In keeping with previous research, loneliness as an anxiety trigger showcases the need for a strong support network (Nikbakhsh et al., 2014). Several other personal coping mechanisms emerged, which have been previously reported (Martins et al., 2019; Walshe et al., 2017). Björklund et al. noted that optimal psychological flow in cancer patients was achieved when they were completely immersed in hobbies, work or family (Björklund et al., 2019). This highlights that the most effective strategies to tackle cancer anxiety seem to be those that distract patients. It may also explain why physical isolation when undergoing radiotherapy or imaging was a main trigger for anxiety, as patients could not help but think of cancer.

This physical isolation described by participants in the hospital is a unique finding, although HCPs were aware it could be a source of anxiety. Cancer charities such as Maggie's recognise this isolation and provide architecturally calming spaces where patients can escape the hospital environment and interact with others. The restrictions placed on loved ones during COVID-19 may have further increased patient anxiety. A German study in the context of COVID-19 found participants were more likely to suffer from depression and anxiety due to physical separation from their peers (Benke et al., 2020).

One of the main spaces where hospital anxiety was felt was inside the MRI—where both physical isolation and a restricted space induced a phenomenon named 'scanxiety'. The reported prevalence of 'scanxiety' in the literature varies widely—from 0% to 64%—although it has been shown that there are interventions such as

meditation effective at reducing it (Bui et al., 2021). This further showcases the need for better and more unified approaches to manage and recognise anxiety in cancer patients undergoing interventions such as imaging or radiotherapy.

Our findings demonstrate the importance of easing physical isolation. This may be achieved through modifications to the hospital environment. At the individual level, reassurance from staff and providing distractions during interventions may help. Current evidence also calls for psycho-oncological care to be patient-centred, with anxiety-relieving approaches based on the patient's individual coping strategies, although these are common among cancer patients and could be streamlined across different groups (Sanjida et al., 2018).

Many of the issues raised regarding The Unknown have been identified as high priority areas for other cancer patients. Metastatic non-small cell lung cancer patients, for example, reported that uncertainty and anticipation of physical symptoms were key factors contributing to anxiety (Hendriksen et al., 2015). Similar findings were reported by patients with cancer of unknown primary, where uncertainty played a key role (Richardson et al., 2015). For our participants, personal, effective and timely communication were essential in mitigating anxiety. A unique finding from this study is that previous experience of the cancer pathway can sometimes heighten the fear of the unknown.

In the context of anxiety, participants employed a stoic attitude. This finding may partly explain why several HCPs agreed identifying anxious patients is difficult and why the prevalence of anxiety is reportedly underestimated by staff (Lampic & Sjöden, 2000; Widmark-Petersson et al., 2000). HCPs also described feelings of inadequacy regarding communication, mainly due to the differences in information needs among patients. A study of gastrointestinal cancer patients highlights this as a common worry (Yang et al., 2018). Of particular interest was the difference in opinions among HCPs, in particular regarding where in the pathway patients are more likely to need support, demonstrating the need for further research and training in psycho-oncology.

There are limitations to this work. Firstly, no data were collected on the time elapsed since diagnosis, therefore comparison between patients at different stages of treatment was not possible. Patients' perceptions may also have changed as they progressed through treatment, potentially introducing recall bias. The mean age of our participants was 65 years, limiting the generalisability of our findings and the exploration of other concerns reported in the literature, such as financial or childcare; generally attributed to a younger population. While previous studies have investigated the concerns of patients with specific types of cancer, the heterogeneity of cancer within our sample may increase the transferability of findings to the broader cancer population. Concerns relating to specific tumour types, however, may have been missed. Our study employed convenience sampling and thus may fail to reflect the perspectives of difficult-to-reach groups. Involvement of a larger and more diverse number of individuals—with specific attempts to engage difficult-to-reach groups—stratified according to tumour and treatment type with focus groups throughout the cancer journey, would strengthen our findings.

Our findings point to anxiety being experienced throughout the cancer journey, at different time points for different people. This highlights the importance of effective communication to understand how patients are feeling. Strategies for recognising the anxious patient must be embedded throughout the care pathway, enabling staff to provide the necessary support.

As the number of people living with cancer rises, future studies should focus on anxiety experienced by cancer patients from a range of ages and backgrounds. Such studies will assist the design of tailored interventions to alleviate anxiety and improve patient care.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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