

Experiences of fear of recurrence in patients with sarcoma

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Abstract

Background: Fear of cancer recurrence (FCR) is often described as the most distressing consequence of cancer and has a negative impact on quality of life. There have been few investigations into the FCR in patients with sarcomas. We sought to explore the patient's FCR after a sarcoma diagnosis to determine when these fears were presented and the strategies patients used to address these fears.

Methods: This was a secondary analysis of qualitative semi-structured interview data from patients with sarcoma, as part of a study to develop a patient-reported outcome measure. This study included 121 patients from across the United Kingdom aged 13–82 years. Telephone and face-to-face interviews focused on the experiences of living with and beyond a sarcoma diagnosis, based on the domains of quality of life (physical, emotional, and social well-being). A secondary analysis was performed using the Common-Sense Model.

Results: The following four key themes were identified: triggers for FCR (symptoms and events), discussion of FCR, consequences of FCR (negative impact on quality of life), and strategies used to deal with FCR.

Conclusion: Patients with sarcoma reported a FCR at different stages of treatment and how these fears played a role in their daily lives. Despite these experiences, the identification and management of FCR have not been reported as a core component of routine clinical practice.

Keywords: fear of recurrence, sarcoma, scanxiety

1. Introduction

Fear of cancer recurrence (FCR) is defined as “fear, worry, or concern relating to the possibility that cancer will come back or progress.”¹ It is reported to occur in 39%–97% of patients living with and beyond diagnosis, the prevalence dependent on how it is measured and the definition of clinical levels of FCR.^{2,3} FCR is considered one of the most distressing consequences of cancer,

having a negative impact on quality of life and psychological wellbeing.² It has been reported as an area where there is the most unmet supportive care needs.⁴ A nationwide consultation in the United Kingdom (UK) with patients, carers, and professionals identified “what are the best ways to cope with the fear and anxiety about cancer returning (combining self-management approaches, treatments, and psychological support)?” among the top 20 research priorities for those living with and beyond cancer.⁵

Sarcoma is a rare cancer of connective tissue, which can occur in any part of the body. Although there are over 100 different subtypes, sarcoma is often classified as bone tumor, soft tissue sarcoma, and gastrointestinal stromal tumors (GIST). Survival for sarcoma is lower than other cancers; in the UK, this is reported as between 40%–70% for the 5-year survival depending on the subtype.⁶ There is high treatment burden requiring all or a combination of surgery, chemotherapy, radiotherapy, and proton beam therapy. In addition, there is a high risk of developing metastases (18%–50%)⁷ and high rate of recurrence (15%–40%).^{8,9} To ensure these are detected early, patients remain in follow-up with annual scan for many years.

There has been much work undertaken in other cancers to determine the factors associated with FCR; evidence is inconclusive for most demographic factors, including sex, education, marital status, and ethnicity,^{2,3,10} although there may be a relationship with age, as younger patients report higher FCR.^{11,12} Similarly, studies mostly show no association with cancer-related factors and the number of physical symptoms,⁶ but a recent review reported more studies showing a positive association between FCR and fatigue, pain, and body image than studies showing no association. Other determinants of reduced FCR include optimism and good social support.^{2,3,10}

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Existing research has focused predominantly on patients with breast, colorectal, and prostate cancers; few studies have specifically explored FCR in patients with sarcomas. A study looking at cancer worry in patients with soft tissue sarcoma and bone tumors noted that 45% of respondents reported having FCR, which occurred more frequently in female patients, those with comorbidities and receiving treatment other than surgery, and those on active follow-up.¹³ The most recent study noted that patients with all types of sarcoma reported a higher prevalence of FCR than patients with other cancer types. However, there were no differences according to the type of sarcoma, and the key factors associated with FCR were time since diagnosis, having previously experienced a recurrence, and perceiving cancer had a psychological impact.¹⁴

Rather than adopting quantitative methods, qualitative methods enable a more in-depth exploration of the meaning patients attribute to a specific situation. There has also been much qualitative work performed around FCR, which Almeida et al. summarized thoroughly in a meta-synthesis.¹⁵ Again patients with sarcoma were not represented in this literature nor in studies conducted subsequently.^{16,17} Patient's experience of FCR has not been explored explicitly in previous qualitative studies in sarcoma, but in Reissman's personal narrative of living with sarcoma, she noted "fear of recurrence is a constant companion." Although the psychological impacts were a significant negative consequence for patients treated with osteosarcoma, only three of eight participants specifically mentioned FCR.¹⁸ However, five of seven patients in a study with soft tissue sarcoma noted that FCR was constant, debilitating, and impeded how they lived their lives.¹⁹

The sarcoma population is distinct in that recurrence rates are higher than most other solid cancers,¹⁴ and therefore, the prevalence of FCR could be higher based on this clinical reality.²⁰ The experiences of FCR in patients with sarcoma and the strategies they develop to deal with the fear remain an unexplored but an important area of research. It cannot be assumed that generic interventions used to help patients cope with FCR would be suitable for patients with sarcoma, as this population reports experiences unlike patients with other cancer types.^{21,22} Furthermore, qualitative research has been recommended for an in-depth exploration of sarcoma patients' most feared phenomenon.¹³

The study builds on UK research priorities: the specific gap for sarcoma and the need for qualitative research. The aim of this study was a first step toward this recommendation by reporting secondary analysis of a data set generated in the development of a sarcoma-specific outcome measure²³ to provide an initial understanding of FCR in patients with all types of sarcoma. The objectives were to explore patients' experiences of FCR, determine when these fears normally presented themselves, describe the strategies they (and health care professionals) developed to address these fears, and identify the factors associated with FCR.

1.1. Conceptual basis

The Common-Sense Model of self-regulation of health and illness (CSM) provides a comprehensive framework for understanding the FCR and provided the basis for the analysis. According to this model, individuals actively construct their own understanding of health threats,^{24,25} such as FCR, based on their cognitive and emotional responses. FCR is driven by the interplay between an individual's perceptions of the illness, their emotional reactions, and their efforts to manage these feelings. The model proposes that people develop mental representations of illness, including its causes, consequences, and controllability. Fear arises when there is

a perceived lack of control over the recurrence, leading to heightened emotional distress.²⁶ The model also suggests that individuals engage in coping strategies to reduce this fear, such as seeking information, engaging in health behaviors, and seeking social support. Overall, the CSM highlights how psychological processes, including cognitive appraisals and emotional responses, contribute to the experience of fear related to cancer recurrence.

2. Methods

2.1. Study design

This was a secondary analysis of qualitative interview data from patients with sarcoma who described their experiences of living with and beyond a cancer diagnosis.^{21–23,27} These data were used in accordance with the original aim of the Sarcoma Assessment Measure (SAM) study to gain a deeper understanding of patients' experience of living with a sarcoma diagnosis.²³

2.2. Sample and setting

This study was conducted across the UK and recruited patients based on a purposive sampling framework.²² Owing to the heterogeneity of the population, it was necessary to include participants with a range of clinical and patient characteristics, which were agreed on by health care professionals with expertise in sarcoma as having potential influences on the impact and experience of a sarcoma diagnosis. Sampling considered demographic factors (eg, age, sex), location of care (eg, geographical region, specialist sarcoma center), sarcoma type (eg, bone, soft tissue, GIST, primary site), treatment intent, treatment type (eg, surgery, radiotherapy, chemotherapy), time since diagnosis, and other factors (including recurrence, clinical trial participation, and metastases).

Patients were eligible to participate in the study if they were 13 years or older, had a confirmed sarcoma diagnosis, and were able to communicate in English. The lower age of 13 was used to reflect the configuration of cancer services in the UK, which has specialist cancer units for teenagers and young adults. The lower age limit for admission into these units ranges from 13 to 16 years. Some of the sarcoma subtypes are common during adolescence and young adulthood, so the original study was designed to facilitate recruitment through these units and adult sarcoma units. Participants were recruited through multiple mechanisms: by health care teams in the participating hospital, through contact with sarcoma charities, and through participation in sarcoma support groups. This study was approved by the London-Stammore NHS Research Ethics Committee (reference 16/LO/2152).

2.3. Data collection

The details of data collection have been reported elsewhere, but in summary, telephone and face-to-face interviews were conducted using a semi-structured schedule based on the domains of quality of life (emotional, physical, and social wellbeing).²³ This was not used as a prescriptive tool and was purposefully flexible to enable the researcher to explore new and emerging experiences.²⁸ The interviews were digitally recorded and transcribed verbatim.

2.4. Data analysis

The interview transcripts were analyzed using framework analysis,²⁹ informed by the CSM model as well as additional

categories emerging from the data. The data analysis process involved an early stage of familiarization with the data, where salient topics were identified in the transcripts, and a draft codebook was developed. The codebook was piloted using a random sample of five transcripts. This was then consistently applied across all transcripts. Categories based on the CSM five attributes were used as a starting point, but the other topics emerging from the data were added. These categories were grouped into CSM and additional categories. The analysis was mainly performed by the lead author (C.V.-P.), but the codebook was revised based on discussions with the wider team. Two codes were added to the codebook because of these discussions, and three definitions of codes were revised. A second researcher (R.M.T.) also reviewed the codes and their application to the full data set.

3. Results

In total, 121 patients participated in the interviews (Table 1). There was an equal representation of sexes, with participants aged from adolescence to adulthood. Most participants had a diagnosis of soft tissue sarcoma, presentation in the extremities, and had completed treatment up to 38 years before participating in this study. We identified the following themes: factors acting as

triggers, consequences of FCR, patients' views on discussing FCR, and strategies developed for managing FCR.

3.1. Triggers

Symptoms associated with the disease lead to FCR. Feeling pain or any other symptoms that reminded them of the lead up to the original diagnosis led to suspicion of recurrence: *"I think, what happens is-, you start to get a bit worried. Any lumps, bumps, that kind of thing, you start to think, 'Oh no, what if that's another recurrence?' or that kind of thing. So, I think in the back of your mind, you always have that, 'What if?' going through your mind."*

In some cases, patients described changes in their identity and the way they saw themselves because of living through the disease and treatment, where they became hypervigilant of their bodies: *"I wouldn't call myself a hypochondriac or anything, well definitely not before, but now every little thing just worries me intensely and I'm trying not to let it affect me, but sometimes it does."*

Although we did not identify substantial differences in FCR depending on the treatment trajectory of the participants, one patient made an association between FCR and the amount of time after treatment had passed: *"I think the further away from your treatment you get, the more I find that I start to worry a little bit about recurrence and secondary effects from the treatment in terms of, like, secondary cancers, but it doesn't occupy me on a, sort of, daily basis. It's just, kind of, sitting there, but I'm not obsessing over it."*

Needing to attend a scan appointment was mentioned as a trigger and participants described an increase in their anxiety while waiting for the results of the scan: *"Every time before you get a scan, you always anxiety, you always get worried, it's just a known thing to panic over nothing, like, when you know you've got a scan coming up."* In some ways, the scan could confirm fears that the cancer had come back: *"It's the week between the scan and the results that the fear starts to set in again. 'Am I going to be told it's come back?' It's that not knowing."*

3.2. Discussing FCR

When participants mentioned FCR, they were asked whether they had discussed this fear with anyone. In general, participants did not want to discuss this with family members as they felt it created an emotional burden and would bring back memories of diagnosis and treatment. In some instances, participants indicated discussing it with health care professionals: *"I could talk to a CLIC nurse [clinical nurse specialist]. She comes round my house every week to, like, do blood tests, so I can talk to her then."* In other cases, they said that they did not discuss it with anyone else.

3.3. Consequences

The consequences of FCR were mainly described as having a negative impact on daily life, where participants reported not being able to enjoy the activities they used to enjoy (eg, socializing, gardening). Some participants also mentioned not being able to go back to the hospital or participate in consultations with the medical team because of the fear that they might tell them that the cancer has come back: *"The last time I saw my consultant I was in a state in the sense that I was so on edge and anxious and I couldn't think straight. All I wanted to do was run out of the consulting room we were in and I just told her that I couldn't deal with being there."*

Characteristic	Interview participants (n = 121)
Sex, number (%)	
Male	60 (50)
Female	61 (50)
Age (years), median (range)	53 (13–82)
Ethnicity, number (%)	
White	103 (85)
Non-White	18 (15)
Type of sarcoma, number (%)	
Soft tissue	75 (62)
Bone	34 (28)
GIST	12 (10)
Time since diagnosis (years), median (range)	4 (<1–38)
Site of tumor, number (%)	
Lower limb	46 (38)
Head and neck	15 (12)
Upper limb	13 (11)
Abdominal organ	13 (11)
Chest	6 (5)
Pelvis	9 (7)
Spine	3 (3)
Other	16 (13)
Amputation, number (%)	
Yes	14 (12)
No	107 (84)
Status at the time of participation, number (%)	
On treatment	34 (28)
Off treatment	87 (72)
Marital status, number (%)	
Married/cohabiting	82 (70)
Single	24 (20)
Other	12 (10)
Employment status, number (%)	
Employed	49 (42)
Retired	38 (33)
In education	7 (6)
Other	22 (19)

Participants also mentioned associating their FCR with worries of what they would do if the cancer came back and how the recurrence would affect their work, family life, and finances: *“I do quite often try to remind myself that ‘what if?’ Am I going to be struggling so much financially and am I going to be struggling to get myself through what would be more medical intervention? So, I do seem to sometimes think ‘what if?’”*

3.4. Strategies for dealing with FCR

When asked about coping with FCR, the participants mentioned activities that helped them relax and take their mind off fear. Some of the younger participants mentioned the use of “apps” such as headspace to meditate. Older participants mentioned activities such as gardening and playing bridge: *“Yes, I go and bury myself in the garden. I love gardening, so I go and take it out in the garden.”*

The participants mentioned a known and direct point of contact within the medical team as a useful way to work through their FCR. Even if they did not discuss their fears in detail with them, knowing there could be someone they could contact, who knew them, and their clinical history was identified as a factor that provided reassurance: *“Someone who knows, you know, the name of all your family, sort of thing, that familiarity, to just be able to put your mind at rest, particularly if you find, like, another swelling which you think might be a recurrence, you know? It’s just useful to have that point of contact, and it has been throughout the treatment.”*

A few participants indicated that health care professionals developed strategies to help them deal with their FCR and reduce anxiety generated through tests and consultations. These included emailing the patient the scan results in advance of the consultation and moving the consultation from the oncology clinic to a separate clinic, so it takes place in a different environment: *“[the consultant] has come up with strategies to help, she now emails me before the appointment to tell me my results, my scan results, so at least I’m not just sitting there waiting for them.”* Participants also noted that health care professionals mentioned the availability of support groups where patients could share their concerns, but not all patients felt that these group conversations would be useful (they feared having to listen to other patients in a worse condition): *“I’ve got a lot of interests, so I don’t feel that I need to be involved in a group, I think that would make me feel even more upset if there’s people worse than me and I’m looking at them and their cases are worse than mine.”*

4. Discussion

There is a dearth of evidence regarding FCR in patients with sarcomas. A secondary analysis of the existing data provided us with the opportunity to explore this qualitatively using patient narratives. We set out below the findings in relation to what is already known about FCR and what seems to be specific to the sarcoma population. Exploration of sarcoma patients’ experiences with FCR highlighted the impact of these fears and the strategies they used to address them. Similar to other studies on FCR in cancer survivors, we found reports of scanxiety, where patients reported an increase in distress associated with scheduled imaging appointments.^{15,30} This anxiety was persistent throughout different stages of treatment, and as reported in other studies,³¹ we found examples of scanxiety even in cases where several years had passed since diagnosis. Unlike other cancers, the follow-up of patients with sarcoma in the UK requires frequent

scans to monitor for recurrence and/or metastases. Although this is important for ensuring good physical health, the management of subsequent scanxiety is something that needs to be addressed.

Repeated hospital appointments were one trigger for FCR; however, the presentation of symptoms also gave rise to fear and anxiety. Physical symptoms, particularly those associated with the original sarcoma presentation, acted as triggers of FCR and patients reported being hypervigilant in relation to signs in their bodies that could indicate that “the cancer had come back.” FCR permeated patients’ perspectives of their illness and even their own identities, representing themselves as patients constantly searching for symptoms to show that the cancer had returned.^{24,26} Interestingly, in other cancer types, FCR was found to be the mediator between physical symptoms and quality of life rather than physical symptoms *per se* being the antecedent of poorer quality of life.³² This could have important implications for treatment, for example, necessitating a focus on managing FCR in addition to symptom management.

We found that one consequence of FCR was a negative impact on quality of life and ability to perform activities of daily living. Although our study supports the literature showing that a FCR affects daily life^{15,17} and is associated with poor quality of life,^{3,11,32,33} we were unable to explore in detail the other psychological consequences that have been reported in the literature, and this warrants further investigation. FCR shaped the interactions that patients had with health care professionals during follow-up appointments and scans. Although follow-up appointments and the time before the appointment have been previously shown to be related to higher FCR in patients with sarcoma,¹³ the nature of the fear was not explored. We found that fears experienced by patients took on different forms in the sense that some feared having to go through treatment again and potential death, while others also discussed fearing the impact of recurrence on their daily lives and financial situation.

Patients have developed strategies to keep their minds off these fears and reduce their anxiety when visiting the hospital, such as gardening and using meditation. This has been shown in studies exploring FCR in other types of cancer, but rather than being presented positively, distraction has been reported as avoidant coping. Types of coping style warrant further exploration in our population. Some patients also indicated that professionals from their medical teams worked with them to help manage their fears by providing them with information on the results of their scans before appointments and suggesting that they could visit support groups. These strategies seemed to be developed on a personal basis, and as others have reported,³⁴ we did not find evidence that tools for identifying and managing FCR are embedded in routine practice. Interventions for the management of FCR, such as the identification of triggers, use of restructuring techniques to alleviate catastrophic thinking, and the replacement of maladaptive coping strategies, have been used in the case of other cancers.³⁵ Additional work is required to determine their suitability for the experiences of patients with sarcoma.

Our study has several limitations. First, this was a secondary analysis of an existing data set, and while FCR was referred to in the patients’ reported experiences, the interview topic guide covered several topics about treatment trajectories and patient experiences, limiting the depth of discussions on FCR. Recurrence and the development of metastases are common in sarcoma, but we did not collect information on where recurrence had occurred in this study.²³ This information would be important to obtain in future studies to confirm whether this influenced the patient

experience. While our study has several limitations, it is the first qualitative exploration of FCR in patients with sarcoma. Our analysis included a large number of participants who were recruited nationally and included patients with all types of sarcomas. We also used one of the main theories related to FCR to inform the analysis,²⁴ which is important for informing future quantitative investigations and subsequent intervention development.³⁶ These results will inform future, more detailed studies in this area.

4.1. Conclusion

Patients with sarcoma report FCR at different stages of treatment and describe how these fears play a role in their daily lives and their continuous interaction with the health care system. Despite these experiences, the identification and management of FCR have not been reported as a component of routine clinical practice. Future research needs to explore sarcoma patients' experiences with FCR in greater depth, identifying the factors that need to be considered in the design and implementation of interventions to help manage these fears. The CSM was helpful in directing the analysis for this study, but future work would benefit from a more comprehensive model that would give a more detailed theoretical explanation of FCR.³⁷

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Conflicts of Interest

The authors have no conflict of interest.

Data sharing statement

Data are available on request from the corresponding author.

*Nicholas J. Hulbert-Williams holds the position of Associate Editor for Journal of Psychosocial Oncology Research and Practice.

Author contributions

Participated in research design: L.A.F., C.G., M.L., L.S., M.W., R.W., J.W., and R.M.T.; participated in the performance of the research: L.A.F., C.G., M.L., L.S., M.W., R.W., J.W., and

R.M.T.; participated in the data analysis; C.V.; participated in the writing of the paper: all authors.

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