

Current approaches to managing fear of cancer recurrence; a descriptive survey of psychosocial and clinical health professionals

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Abstract

Objective: Fear of cancer recurrence (FCR) is common amongst cancer survivors and help with this problem is the most frequently reported unmet need in this population. This study investigated how FCR is perceived and managed by clinical health professionals (medical and nursing staff) and psychosocial professionals in oncology settings.

Methods: Clinical health professionals and psychosocial professionals in oncology settings received emailed invitations from their professional organisation to participate in an online survey.

Results: Data from 77 clinical health professionals and 64 psychosocial professionals indicate that FCR is perceived as common and challenging to manage. Thirty-one percent of psychosocial professionals estimated FCR is present in >50% of cancer survivors seen in their practise. Only a minority (21%) of clinical staff reported always referring patients with high levels of FCR to psychosocial support. Strategies for managing FCR differed considerably amongst psychosocial professionals, and most reported that aspects of acceptance and commitment therapy and/or cognitive behaviour therapy were helpful. Greater than 99% of participants were interested in training to help patients manage FCR.

Conclusions: Fear of cancer recurrence is commonly identified in oncology settings and a common focus of discussion in follow-up care. However, patients with high levels of FCR are not routinely referred to psychosocial staff, and barriers to referral to psychosocial care should be investigated. The diversity of approaches reported by psychosocial professionals suggests lack of consensus regarding management of FCR, indicating that the development effective, theoretical-based intervention and evidence-based intervention for FCR is a matter of priority.

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Introduction

In the months and years of following cancer treatment, concern amongst survivors about cancer returning is very common. Given that all cancers are associated with a chance of recurrence, some uncertainty or concern about cancer returning is not unexpected amongst cancer survivors. Following treatment, some vigilance may be appropriate and use of available screening checks and monitoring for symptoms may be advised by medical practitioners. For many survivors, however, fear of cancer recurrence (FCR) is sufficiently intense to cause a significant psychological burden, characterised by chronic worry and hypervigilance for signs of disease return including excessive, frequent monitoring of bodily symptoms or sensations [1,2].

Fear of cancer recurrence has been defined as ‘the fear or worry that the cancer will return or progress in the same organ or in another part of the body’ [3]. Although a consensus on the level at which FCR becomes pathological

remains to be reached, recent studies show that a clinical or moderate-to-high level of FCR is present in 42% of cancer survivors with mixed diagnoses and up to 70% in vulnerable groups such as young survivors of early stage breast cancer [4–6]. The need for help with this problem is one of the most frequently reported unmet needs in this growing population [7–9]. Furthermore, FCR can persist for many years, even when risk of recurrence is low. For example, in a study of long-term testicular cancer survivors who were on average 11 years post-diagnosis, 24% reported FCR bothered them ‘quite a bit’ and 7% that it bothered them ‘very much’ during the past week [10].

A recent comprehensive systematic review of FCR in adult cancer survivors reported that only one out of 21 cross-sectional studies found an association between FCR severity and time since diagnosis or treatment and 18 out of 22 longitudinal studies found no change in FCR over time assessed. These findings suggest that FCR may remain relatively stable over time. Other patient or disease characteristics may, however, interact with time

since diagnosis to influence the course of FCR over time. Although 11 studies reported that indices of illness severity were positively associated with FCR, 16 studies did not find an association or reported that stage was unrelated to FCR. The results of this systematic review suggest that FCR is not restricted to cancer survivors recovering from recent treatment or those with greater severity of illness [11].

Fear of cancer recurrence is associated with higher levels of distress, [12,13] depression and anxiety, [14,15] post traumatic stress symptoms [16] and death anxiety [17]. Amongst breast cancer survivors with high levels of FCR, a quarter reported that it impacts considerably on their mood and 19% reported a considerable impact on their ability to make plans and set goals for the future [5].

Given the psychological burden associated with FCR, the identification of cancer survivors with clinical levels of FCR is a matter of priority, in order to manage FCR and reduce its negative impact on psychological well-being. However, despite being a well-described, prevalent and distressing phenomenon, very few interventions for the management of FCR have been reported [18] and there is a need for the design and evaluation of more FCR-specific interventions [19].

In the absence of an established body of evidence about optimal management of FCR by clinical health professionals and psychosocial professionals, the present research aimed to ascertain how FCR is currently managed by staff working in oncology settings. Better understanding of current practises and the challenges that clinicians face is likely to be useful and informative in the design and trial of future interventions to treat FCR. The specific aims of this descriptive study were:

1. To describe the experience of clinical health professionals working in oncology regarding FCR, including the identification of the:
 - a) frequency with which high levels of FCR are noticed in patients;
 - b) nature of current approaches to the management of FCR, including referral practises;
 - c) level of challenge associated with management of FCR; and
 - d) level of interest in receiving training for managing FCR.
2. To describe the experience of psychosocial professionals working in oncology settings regarding FCR including the identification of the:
 - a) frequency with which psychosocial professionals treat high levels of FCR;
 - b) key strategies, therapies, skills or approaches commonly used in managing FCR;

- c) level of challenge associated with management of FCR; and
- d) level of interest in receiving training for managing FCR.

Methods

Participants

This study targeted clinical health professionals (including surgeons, medical and radiation oncologists, nurses and general practitioners) and psychosocial professionals (including psychologists, social workers, psychiatrists and other psychosocial staff including counsellors and group therapists) currently in cancer care roles with adults with cancer in any clinical setting. Exclusion criteria included not being in practise currently or exclusive treatment of paediatric oncology.

Recruitment and procedures

Six peak professional organisations representing Australian clinical and psychosocial health professionals in cancer care roles across both rural and urban settings agreed to facilitate recruitment and endorse the study. These organisations included the Medical Oncology Group of Australia, Psycho-Oncology Co-operative Research Group, Psychosocial Oncology Group of the Clinical Oncology Society of Australia, New South Wales Psychologists in Oncology Group, Cancer Nursing Society of Australia and The Primary Care Collaborative Cancer Clinical Trials Group. Members of these organisations received emailed invitations to participate in our online survey from the executive offices of these professional organisations. In total, 162 invitations were emailed to clinical health professionals and 109 to psychosocial professionals. This recruitment strategy was used to ensure that the majority of possible participants were given the opportunity to participate and to attempt to recruit participants from a diverse range of clinical settings and geographic locations. Interested participants were provided with a link to complete the survey (in the same email), after completing the online consent form. Non-respondents were followed up by email by the organisations on two occasions to prompt completion. Ethics approval for this project was granted by The University of Sydney's Human Research Ethics Committee.

Materials

Two questionnaires were purpose-designed in order to appropriately survey clinical health professionals and psychosocial professionals. In both surveys, multiple choice items asked about professional background and FCR experience, the proportion of cancer survivors in the clinician's practise requiring professional help with FCR and the proportion of time spent in follow-up appointments discussing concerns about cancer spreading or returning.

FCR was defined in the survey as ‘fears of cancer spreading or returning’, which is the most commonly cited definition and was developed by Vickberg [3]. All participants were asked to respond on a 4-point ordinal scale to questions concerning the level of challenge associated with helping patients to cope with FCR and level of interest in receiving training for the management of FCR. Clinical health professionals were also asked to endorse one or more strategies they used to help patients reduce or manage fears of recurrence from a list of common strategies (including information giving, referral to psychosocial support or further tests, etc.). The psychosocial professionals were also asked which therapeutic techniques or strategies were considered useful for helping patients cope with or manage FCR using an open-ended question that allowed for one or more techniques or strategies to be reported.

Results

Participants

Of the 85 responses received from 162 invitations to clinical health professionals to participate in the study, data for one participant were ineligible due to their profession not matching those being targeted, and seven respondents either made invalid entries on the survey or declined participation, leaving 77 participants (a response rate of 49%). Data were incomplete for two participants, but their data were used where possible. The mean number of years since being trained for these 77 clinical health professionals was 18.43 years ($SD = 10.07$), and the majority were nurses (62%) or medical oncologists (25%) (see Table 1). Seventy-six psychosocial professionals working in oncology settings responded favourably to the invitation to participate (response rate of 71%). Twelve of these were ineligible due to their profession not matching that being targeted, leaving 64 participants. The majority were psychologists (61%) or social workers (17%) in the field of psycho-oncology (see Table 2). The majority of psychosocial professionals had completed training 6 or more years ago (70%) and almost a third (30%) had 5 or less years of experience since completing training.

Clinical health professionals' practises and challenges with fear of cancer recurrence

As shown in Table 1, 77% of clinical health professionals estimated that at least 10–25% of cancer survivors seen in their practise need professional help to cope with FCR and 33% estimated that such a need is present in more than 25% of patients. A third of all clinical health professionals surveyed (33%) reported that discussion of patient concerns about cancer recurrence took up more than 25% of the time in follow-up consultations. Information giving

Table 1. Clinical health professionals' practise details ($n = 77$)

	Mean	SD
Number of years since completion of professional training	18.35	10.0
	Frequency ^a	Percent
Professional background		
Medical oncologist	19	24.7
Radiation oncologist	3	3.9
Surgeon	1	1.3
Nurse	48	62.3
Palliative care	4	5.2
Other	2	2.6
Proportion of cancer survivors seen who require professional help for FCR		
Less than 10%	17	23.0
10–25%	34	45.9
26–50%	12	16.2
More than 50%	11	14.9
Proportion of time in follow-up appointments spent discussing concerns about cancer returning ($n = 74$)		
Less than 10%	17	23.0
10–25%	33	44.6
26–50%	21	28.4
More than 50%	3	4.1
Strategies used for management of FCR		
Information (e.g. Likelihood of remaining disease free)	71	92.2
Medical Investigations (e.g. Scans and blood tests)	19	24.7
Stress management techniques	41	53.2
Referral to psychosocial support (e.g. psychologist and social worker)	68	88.3
Psychotropic medications	4	5.2
Frequency of referral for high levels of FCR to psychosocial staff		
Never	3	4.0
Sometimes	33	44.0
Most of the time	23	30.7
Always	16	21.3
Level of challenge in helping patients to cope with FCR		
Not at all challenging	3	4.1
Somewhat challenging	39	52.7
Moderately challenging	24	32.4
Very challenging	8	10.8
Interest in receiving training for managing FCR		
Not interested at all	0	0.0
Somewhat interested	19	19.0
Moderately interested	14	14.0
Very interested	42	42.0

FCR, fear of cancer recurrence.

^aNumber varies slightly per item due to a small amount of missing data

(92%) and referral to psychosocial support (88%) were the top strategies endorsed by clinical health professionals when asked what would be carried out to help a patient who was extremely worried about cancer recurrence. When asked how often clinical health professionals currently refer patients with very high levels of FCR, however, only 52% responded most of the time or always; ‘sometimes’ was the most frequently endorsed option (42%) (Table 1). All but three clinical health professionals reported at least some challenge in dealing with FCR and all participants expressed some interest in further training with 42% stating they were ‘very interested’ in receiving further training.

Table 2. Psychosocial professionals' practise details (n = 64)

	Frequency	Percent
Professional background		
Psychologist	39	60.9
Social worker	11	17.2
Psychiatrist	1	1.6
Other Psychosocial	13	20.3
Number of years since completing professional training		
0–2 yrs	5	7.8
3–5 yrs	14	21.9
6–10 yrs	16	25.0
More than 10 yrs	29	45.3
Proportion of cancer survivors seen who require professional help for FCR		
Less than 10%	6	9.4
10–25%	22	34.4
26–50%	16	25.0
More than 50%	20	31.3
Description of therapies, strategies, skills or approaches which have been particularly helpful in the management of FCR		
ACT, Mindfulness and other ACT subcomponents	54	84.4
Cognitive Approach (including CBT and subcomponents)	48	75.0
Validation/normalising	12	18.8
Psychoeducation	10	15.6
Relaxation/meditation	5	7.8
Solution-focused therapy	5	7.8
Supportive counselling	5	7.8
Narrative therapy	5	7.8
Goal setting	3	4.7
Interpersonal therapy	3	4.7
Stress Reduction	3	4.7
Existential Therapy	2	3.1
Mindfulness Based Cognitive Therapy	2	3.1
Psychodynamic therapy	2	3.1
Tolerate difficult thoughts/feelings	2	3.1
Diary and write recovery story	1	1.6
Discussing/assessing risk	1	1.6
Encourage peer support group use	1	1.6
Hypnosis	1	1.6
Metacognitive strategies	1	1.6
Positive reframing	1	1.6
Review the cancer journey	1	1.6
Supportive/expressive group therapy	1	1.6
Level of challenge associated with managing FCR		
Not at all challenging	4	6.3
Somewhat challenging	30	46.9
Moderately challenging	27	42.2
Very challenging	3	4.7
Interest in receiving training for managing FCR		
Not interested at all	1	1.6
Somewhat interested	7	10.9
Moderately interested	13	20.3
Very interested	43	67.2

ACT, Acceptance and Commitment Therapy; FCR, fear of cancer recurrence; CBT, Cognitive Behaviour Therapy.

Psychosocial professionals' practises and challenges with fear of cancer recurrence

As shown in Table 2, 56% of psychosocial professionals estimated that clinical levels of FCR are present in more than 25% of cancer survivors seen in their practise, and 31% estimated FCR is present in more than 50%. In total

psychosocial professionals reported 23 different strategies or approaches used to manage FCR, with techniques derived from Acceptance and Commitment Therapy (ACT) and Cognitive Behaviour Therapy (CBT) being the most commonly reported approaches. To a lesser degree, psycho-education and validation of concerns/normalisation of the client's experience were also mentioned. In addition, the following strategies and approaches were mentioned more than five times as being helpful: exploring, acknowledging and allowing worries to exist, relaxation/meditation, solution focused therapy and supportive counselling. All but four psychosocial clinicians reported that they experienced some degree of challenge in dealing with FCR and only one was not interested in further training.

Discussion

The findings in the present study indicate that clinical health professionals and psychosocial professionals working in oncology settings often encounter high levels of FCR amongst cancer survivors and that it is challenging to manage. Strategies used for the management of FCR differ considerably amongst psychosocial professionals, indicating a lack of consensus in approach. Further professional training in techniques to help people with FCR is desired by the majority of health professionals, both clinical and psychosocial.

To our knowledge, this is the first time clinicians' estimates of the prevalence of FCR in their own practise have been reported. Clinical health professionals were asked to estimate the proportion of patients seen in their practise who require professional help with FCR using their individual clinical judgement. There is currently no consensus definition on what constitutes clinical FCR nor are formal methods for detecting clinical FCR widely used in current clinical practise. Therefore, gaining a better understanding of clinicians' estimates of the proportion of people requiring help with FCR based on their own judgement is important because it allows for contrast of this data with data from studies using self-report methods of assessment.

When compared with evidence derived from patient self-report measures, which indicate that clinical or moderate-to-high levels of FCR are present in 42% of survivors of mixed diagnoses and up to 70% of those from vulnerable groups such as younger survivors of breast cancer [4–6]; the estimates reported in our study suggest FCR may be under-recognised by many clinical health professionals, 68% of whom estimate that less than 26% of survivors are in need of professional help to cope with FCR. This is consistent with other studies in psycho-oncology literature, which demonstrate that recognition of psychological morbidity by clinical health professionals is lower than that reported by patients [20–22]. Such differences point to the need for increased use of screening tools to improve the detection of FCR in patient

care. The estimates of prevalence of high levels of FCR by psychosocial professionals were higher, perhaps because their clientele consists primarily of distressed patients and psychological issues are the focus of their discussion with these patients. These higher estimates from psychosocial professionals suggest that a large proportion of cancer survivors who seek or accept psychosocial support are in need of help in the management of FCR.

Although FCR is noticed by clinical health professionals and commonly dealt with by psychosocial professionals in their clinical practise, our findings suggest that managing FCR is a challenge for the majority of both psychosocial and clinical health professionals. Given this, it is unsurprising that further training in techniques to help patients with FCR was of interest to the vast majority of the professionals surveyed, including all of the clinical health professionals and over 98% of the psychosocial professionals.

Our results indicate that a moderate proportion of time in follow-up consultations is spent discussing the likelihood of cancer returning, suggesting that interventions to reduce FCR may have cost-benefits in reducing the length of follow-up consultations. Further research is needed to assess the health economic impact of treating FCR.

When prompted with options for the management of FCR, the majority of clinical health professionals surveyed reported that they would use referring patients with high levels of FCR to a psychosocial clinician as a treatment strategy, but self reported *actual* rates of referral to psychosocial staff were lower. This is consistent with other studies which have reported low levels of referral to psychosocial oncology care [23] which fall short of what is clinically indicated according to levels of distress [24]. Given that a cancer patient's healthcare team often consists of several individuals, there may be an expectation that another member of this team will refer patients to psychosocial services if necessary. A study investigating health professionals' experience of emotional distress in cancer patients in the UK reported that diffusion of responsibility and the lack of guidance on referral pathways to help staff decide when it is appropriate to refer patients are barriers to referral of distressed patients to psychosocial services [25]. More widespread use of screening for FCR during follow-up appointments to determine whether clinical levels of FCR are present has been recommended [5] and may help to overcome such barriers. Several screening tools for this purpose have been proposed [3,26], and more work is needed to establish the efficacy of their widespread use. Our findings highlight the need for a consensus definition of clinical FCR. Furthermore, our findings also support the use of routine screening to facilitate recognition of clinical levels of FCR and to assist in decisions about the need for referral to psychosocial support.

Another possible barrier to referral of cancer patients and survivors is that clinical health professionals may

have a limited idea of what might be carried out by psychosocial professionals to help such patients [27]. Without a specific intervention for FCR having been tested and put into widespread practise in hospitals, clinical health professionals may have limited faith in the likelihood that psychological treatment would help patients with FCR. Although the present survey did not investigate reasons for non-referral of patients high in FCR for psychosocial support, it is possible that the current lack of evidence-based interventions for FCR is a significant barrier. Further research into barriers to referring patients with high levels of FCR for specialist psychosocial care is needed.

Responses to the open-ended question asking psychosocial professionals to describe the approaches and strategies they find helpful in managing FCR were informative in the identification of the array of current treatment practises for FCR. The two major therapeutic approaches emerging from the open-ended question were components of ACT including mindfulness, connecting with values and other subcomponents of ACT, and cognitive approaches including CBT and components of CBT including cognitive restructuring and managing worry. Most psychosocial professionals mentioned both of these approaches as being helpful. Other strategies commonly cited, often in conjunction with ACT or CBT, included psycho-education, relaxation/mediation, solution-focused therapy and supportive counselling.

These results suggest that these clinicians are guided by their individual experience and there is currently enormous variability in the approaches taken to managing FCR in Australia. Although these results suggest that FCR accounts for a high proportion of cancer patients and survivors seeking or accepting psychological treatment, there does not appear to be a consensus on how it is best managed. It is likely that this is due to a lack of evidence-based interventions for FCR. Therapeutic approaches commonly include at least some components of CBT and/or ACT; however, the psychosocial professionals often cited several different strategies, and these strategies often represented more than one psychological tradition. The diversity of approach suggested by these results emphasises the need for the design of a specific intervention based on a clearly articulated model of the mechanisms underpinning FCR. There are currently several FCR-specific intervention trials underway internationally, which aim to help patients better manage their FCR; including a nationwide randomised controlled trial of an FCR intervention by members of our group (PB, LS, and BT) in Australia, [18,28–30] and the results of these trials are keenly awaited.

Limitations and strengths

The strategy of recruiting study participants by emailed invitation from a professional organisation introduces the possibility of a responder bias. For example, it is possible

that professionals with greater interest in FCR may have been more likely to participate which could possibly bias the results in favour of a greater interest in training for the management of FCR. It is also possible that the higher response rate of psychosocial professionals may be due to a greater interest in FCR compared with clinical health professionals. Because of ethical requirements, this study used an opt-in method of recruitment and did not collect data on non-responders. Furthermore, despite recruiting from peak professional organisations within Australia, with large and geographically spread membership bases including metropolitan, rural and regional staff, we did not collect detailed information on the clinics at which participants were employed or the nature of the population of patients and survivors seen at those clinics. We cannot, therefore, be certain of the degree to which these findings generalise to all oncology clinicians and cancer survivors in Australia. However, the response rate in the present study was relatively high compared with surveys of oncology professionals recruited using similar methods [31–33]. Despite these possible limitations, this is the first study to report on current treatment practises for FCR, and it includes staff from a diverse range of clinical disciplines.

The estimates reported of the number of patients requiring professional help for FCR are not necessarily based on the use of any standardised measures. These estimates, therefore, are not to be regarded as reliable indications of the actual prevalence of FCR amongst cancer survivors. As discussed, the estimates given by clinical health professionals are mostly lower than rates of moderate-to-high and clinical levels of FCR reported in studies using self-report measures. Clarifying the extent to which FCR is evident to clinicians in their everyday practise nonetheless provides an indication of how important the issue of FCR is to clinicians.

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Conclusions

Clinical health professionals and psychosocial professionals in cancer care roles often encounter high levels of FCR in their clinical practise and find it challenging to manage, and the majority of these clinicians are interested in further training in this area. High or clinical levels of FCR may be under-recognised by health professionals, and only a minority of clinical health professionals report always referring patients with high levels of FCR to psychosocial support. Therapeutic approaches for the management of FCR differ considerably amongst psychosocial professionals, many of whom have found aspects of ACT and/or CBT helpful in managing FCR. The wide variety of strategies reported suggests a lack of consensus in approach. The results of this study indicate that there is a strong need for a consensus definition of clinical FCR and routine use of screening tools to assess clinical FCR in follow-up care and for the development of effective, theoretical-based and evidence-based treatments for FCR.

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Conflict of interest

The authors have declared that there is no conflict of interest.

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