ORIGINAL ARTICLE



A qualitative exploration of fear of cancer recurrence (FCR) amongst Australian and Canadian breast cancer survivors

B. Thewes^{1,2} · S. Lebel^{3,4} · C. Seguin Leclair³ · P. Butow²

Received: 12 August 2015 / Accepted: 8 November 2015 / Published online: 19 November 2015 © The Author(s) 2015. This article is published with open access at Springerlink.com

Abstract

Purpose Few studies have explored coping strategies used by cancer survivors to deal with fear of cancer recurrence (FCR), and little research has been conducted on the specific content of recurrence fears. This study aims to qualitatively explore the strategies used by younger breast cancer survivors to cope with FCR and whether women with low, medium and high levels of FCR employ different coping strategies. An additional aim was to understand the specific content of worst recurrence fears.

Method Twenty Australian and 10 Canadian women aged ≤45 years diagnosed with stages 0–II disease at least 1 year prior completed telephone interviews. The transcripts of audio-taped interviews were analysed using the qualitative methodology of transcendental realism.

Results Women with higher FCR described using distraction and avoidance and fewer coping skills. The fear of death was a common worst fear at all levels of FCR. However, participants with higher FCR described more elaborate fears of death often involving themes of pain and suffering. Cross-cultural differences were not observed.

Conclusions Women with higher FCR report using fewer and more avoidance-based coping techniques. Whilst many participants feared death, those with higher FCR reported more

 elaborate death fears. Women with high levels of FCR may benefit from learning a greater repertoire of coping skills. Understanding the specific content of FCR can help refine existing psychological treatment protocols for FCR. Implications for FCR treatment are discussed.

Keywords Breast cancer \cdot Oncology \cdot Fear of recurrence \cdot FCR \cdot Coping \cdot Worst fear

Introduction

Fear of cancer recurrence (FCR) has been defined as "the fear that cancer could return or progress in the same place or in another part of the body" [1]. Elevated FCR is characterised by functional impairment, psychological symptoms, poor quality-of-life and excessive efforts to monitor for potential recurrence and/or attempts to avoid cancer reminders [2]. FCR has been associated with greater utilisation of healthcare [3], unwillingness to be discharged from follow-up [4, 5] and increased healthcare costs [6].

Young breast cancer survivors (defined here as women under 45 years at diagnosis) are a cancer patient sub-group particularly vulnerable to FCR [1, 7–17]. However, few studies have explored the factors influencing young women's vulnerability to FCR. Most studies which explore this issue have focussed on motherhood [18, 19]; however, two studies found no association between FCR and motherhood [3, 20]. There is some evidence that the relationship between age and FCR may also be, in part, mediated by the perceived physical, social or economic consequences of having a recurrence [18], anxiety [3, 18] and self-efficacy [21]. Differences in the coping strategies employed may further explain the relationship between FCR and age. Whilst specific coping strategies such as reassurance seeking from health professionals, frequent bodily



Department of Medical Psychology, Radboud University Medical Centre, Postbus 9101, 6500 HB Nijmegen (840), The Netherlands

School of Psychology, The University of Sydney, Sydney, Australia

School of Psychology, University of Ottawa, Ottawa, ON, Canada

Montfort Hospital Research Institute, Ottawa, ON, Canada

checking and avoidance have been postulated to increase FCR [2], relatively few studies have examined the relationship between FCR and coping. A recent literature review [22] concluded that there is only weak to moderate evidence for the relationship between coping strategies and FCR due to the small number of studies and heterogeneity of the scales used.

Another area which has also received little attention is the specific content of FCR. Studies of health anxiety have suggested that images of dying, suffering, abandonment and abandoning others are salient amongst health anxious patients [23, 24] and that future-oriented intrusive images maintain health anxiety by increasing estimation of the likelihood of feared events [23, 24]. It is possible that specific fears are associated with greater FCR; however, very few studies have explored the content of recurrence fears. One quantitative study which compared the nature of FCR amongst younger versus older breast cancer survivors using The Concerns About Recurrence Scale [25] found that compared to their older peers, young women endorse greater FCR across all questionnaire domains (concerns about health, role, womanhood and death) [18, 21, 25]. No study has investigated if and how the specific content of women's worst fear might influence their FCR.

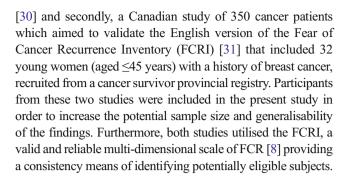
Recently, there have been a growing number of studies investigating psychological interventions for FCR. Some of these treatments use verbal and/or written exposure to the worst fear as part of the treatment plan [26, 27]. A better understanding of the content of worst fears could help refine current intervention protocols and guide future research in this area.

The aims of the present study were to qualitatively explore how young women with breast cancer cope with FCR and to identify if young women with low, medium and high levels of FCR use different coping strategies. Additionally, this study aimed to understand the content of worst fears about potential cancer recurrence. As there is currently little data available on coping strategies and FCR or about the content of specific fears, a qualitative approach as described by Miles and Hubermann [28] was chosen. This approach was selected because it is one of the most comprehensive and explicit frameworks with regards to data analysis and techniques to protect against threats to validity [29].

Methods

Participants

Participants in this study were recruited as part of two existing studies of recurrence-free women previously diagnosed with early breast cancer: firstly, a cross-sectional study of FCR in Australian women aged 45 years or less who were consecutively seen at one of seven metropolitan cancer centres or were members of two breast cancer consumer groups (n = 218)



Eligibility criteria

The participants were (a) diagnosed with stages 0-II breast cancer at least 1 year prior, (b) ≤45 years at the time of diagnosis and (c) fluent in English. In order to identify a stratified sample, the following process was used. Scores on the FCRI from the parent studies were examined, and percentile ranges corresponding to low, moderate and high FCRI scores based on sample distribution were identified. Due to the smaller number of potentially eligible women in the Canadian sample, different percentile ranges were created; however, FCRI scores in each category were similar. In the Australian sample, women who scored below the 5th percentile were classified as 'low FCR' (FCRI possible score range = 10–28), between the 48th and 52nd percentile 'moderate FCR' (FCRI score range = 67–68) and above 95th percentile 'high FCR' (FCRI score range = 112-142). In the Canadian sample, women who scored <33rd percentile were classified 'low FCR' (FCRI score range = 15-55), between the 33rd and 66th percentile 'moderate FCR' (FCRI score range = 56–77) and >66th percentile 'high FCR' (FCRI score range = 78–139).

Procedure

Ethical approvals were obtained from the appropriate institutional and university ethics committees. Eligible women were sent invitation letters and telephoned 7–14 days later to obtain informed consent. Telephone interviews were audio recorded and conducted by one of three psychologists or psychology graduate students. Interviews were conducted according to a semi-structured interview schedule which explored circumstances of diagnosis, follow-up care, frequency and intensity of FCR, impact of FCR, perceived benefits of worrying about recurrence, worst fears and coping techniques. This manuscript reports specifically on the results of analyses concerning worst fears and coping techniques. The recruitment continued until saturation of data was achieved.

Data analysis

The audio-tapes of interviews were transcribed verbatim. The transcripts were analysed for emergent themes using a



'transcendental realism' qualitative methodology described by Miles and Huberman [28]. NVivo 10 was used to assist with the organisational aspects of data analysis. Coding of transcripts was conducted by two authors (BT, CSL). Four interviews (13 %) were double-coded, and a percentage of agreement between coders was calculated for each node (mean = 98 %, range = 87–100 %). Initial coding was conducted in two phases: a deductive phase in which pre-specified open codes derived from the study questions were applied, followed by an inductive phase where new codes emerged from transcripts without a priori specification. Following initial coding, all members of the research team met to clarify the meaning of and further refine the coding system. Axial coding was then carried out to explore the relationships between the initial codes, reorganise coding into related concepts and sub-themes and develop final meta-level themes. Discrepancies in coding were resolved through consensus discussion. In order to explore the influence of attitudes on level of FCR, the content of most feared aspects of potential recurrence and coping strategies data matrices were then created to visually explore the data according to level of FCR and develop initial hypotheses which were explored in the final stages of the analysis. In accordance with the methods proposed by Miles and Huberman [28], the following strategies were applied to field notes and initial conclusions in order to reduce threats to the validity of our findings: checking for rival explanations, triangulation of data, use of if-then statements, looking for negative evidence, following-up surprises and ruling out spurious relationships. Finally, representative quotes were selected to illustrate emergent themes.

Results

Participants and response rate

Twenty-eight Australian women and 10 Canadian women meeting all study criteria received study invitations. Twenty Australian and 10 Canadian women consented respectively (response rate = 71 % Australian sample, 100 % for the Canadian sample). Participants ranged in age from 32 to 45 years at diagnosis and were between 2 and 11 years post-diagnosis (mean = 5.5 years). More than half of the samples were partnered (25 women) and had university level education (17 women), and the majority were mothers (22 women). Participants' FCRI scores ranged from 14 to 139 (mean = 72.3 SD = 38.6). The mean score reported by younger breast cancer patients (n = 218) in the Australian parent study was 60.8 (SD = 25.7) [30]. In the initial Canadian sample, the mean FCRI score reported by young women (n = 27) was 69.6 (SD = 29.4). According to the criteria described above, 10 women were classified as having a low level of FCR, 9 as having moderate FCR and 11 women had high FCR. See Table 1 for details of FCR and demographic characteristics of the sample.

Coping

Participants in the present sample identified a range of coping strategies for managing FCR including behavioural distraction; spirituality or religion; cognitive strategies such as 'positive thinking', cognitive avoidance (e.g. pushing thoughts away, thinking about something else), or challenging negative thoughts; and using health behaviours and lifestyle changes (e.g. healthy diet, exercise, use of complementary therapies). Avoidance-based strategies such as distraction and cognitive avoidance were reported as helpful by many women in our sample.

"That's why it's hard to sleep because you're just lying there. I try and tell myself to think about something else, even if it's just a song or something, it just keeps wandering back, it's like you can't get rid of it. During the day you can think 'oh can't think about that now, I've got to go to the shops' or 'I've got to do this', 'I've got to pick up someone." (Tamara, 1 moderate FCR)

Other helpful strategies identified by participants included surrounding oneself with positive people, stress reduction techniques (e.g. relaxation, breathing, meditation) or using downward comparisons (i.e. comparing oneself favourably with people in worse circumstances). Two participants spoke about using alcohol or other drugs as helpful coping strategies.

Participants in this study also identified unhelpful coping strategies. These included speaking to unsupportive or negative people about FCR, being self-critical and focusing on or ruminating about FCR.

Opinions were varied about the helpfulness of support groups and disclosure about FCR to friends and family. Some participants from all levels of FCR reported disclosure to friends and family and support groups provided opportunities for emotional ventilation and mutual support. However, others found it anxiety producing because of the perceived impact of those discussions on others, or in the case of support groups, being exposed to negative feelings, recurrence or death amongst group members.

Reassurance seeking via unplanned medical tests or researching symptoms on the Internet or in textbooks was generally reported as helpful despite some theories of FCR [2, 32] identifying these behaviours as maintaining factors.

"I never get the doctors [GP] to check I just go straight to the specialist because that avoids a lot of anxiety for me because the doctors don't really know, and usually if I can get an appointment then I will see the specialist and then my fears have been allayed." (Tamara, moderate FCR)

¹ Participant names have been altered to protect privacy.

Table 1 Participant FCRI scores and demographic characteristics

Participant ^a	FCRI total score	FCRI score percentile ^b	FCR level	Country	Age at diagnosis	Partnered (yes/no)	Education	Children	Time since diagnosis (years)
Anna	28	7	Low	Canada	45	Yes	University	Yes	7
Brenda	67	56	Moderate	Canada	43	Yes	High school	No	8
Carolynne	67	56	Moderate	Canada	39	Yes	University	Yes	7
Diana	88	78	High	Canada	37	Yes	University	Yes	9
Evelyn	138	100	High	Canada	43	Yes	High school	Yes	7
Faye	68	59	Moderate	Canada	44	Yes	University	Yes	11
Geraldine	122	96	High	Canada	42	No	University	Yes	6
Helene	91	82	High	Canada	45	Yes	University	Yes	6
Isla	68	59	Moderate	Canada	43	Yes	University	Yes	5
Jennifer	55	33	Low	Canada	43	Yes	University	Yes	3
Kate	27	4	Low	Australia	32	Yes	University	Yes	11
Louise	24	3	Low	Australia	32	Yes	University	No	5
Melanie	26	4	Low	Australia	44	Yes	High school	Yes	4
Natalie	14	1	Low	Australia	43	Yes	High school	Yes	6
Olivia	19	2	Low	Australia	41	Yes	University	Yes	5
Petra	18	2	Low	Australia	45	Yes	Diploma/trade	Yes	2
Rebecca	20	3	Low	Australia	42	Yes	University	Yes	4
Sylvia	67	49	Moderate	Australia	45	Yes	High School	Yes	4
Tamara	68	52	Moderate	Australia	32	Yes	University	Yes	9
Ursula	67	49	Moderate	Australia	34	Yes	University	Yes	4
Wendy	68	52	Moderate	Australia	45	Yes	High school	Yes	3
Xanthe	68	52	Moderate	Australia	45	Yes	High school	Yes	4
Zoe	68	52	Moderate	Australia	45	Yes	Diploma/trade	Yes	4
Annalise	112	95	High	Australia	34	No	Diploma/trade	No	4
Barbara	114	97	High	Australia	39	No	High school	No	9
Christine	116	98	High	Australia	44	No	Diploma/trade	No	3
Donna	114	97	High	Australia	39	Yes	University	Yes	4
Elizabeth	113	96	High	Australia	31	Yes	University	No	3
Francis	116	98	High	Australia	43	Yes	University	No	4
Georgia	139	100	High	Australia	40	No	High school	No	4

^a Patient names have been altered to protect privacy

Some women had awareness that excessive use of these strategies was, at times, not helpful. When talking about her tendency to "Google relentlessly", one participant said:

"Pt: With Google everything is tangential, you read something then it goes on to something else and then you are constantly clicking to the next thing and you can work yourself up a lather about it...... I guess it's meant to lessen my anxiety so that I can sleep and not worry so much. Interviewer: How does it affect you?

Pt: Well it takes time I guess, it takes time out of my day to obsess about it." (Geraldine, high FCR)

Contrary to expectations based on the FCR literature, breast self-examination or other forms reassurance seeking by bodily checking were not explicitly identified as a coping technique by women in this sample.

Differences in coping between women with low versus moderate to high FCR

Women with low levels of FCR reported a greater repertoire of coping skills and were more likely to feel that their chosen coping skills were effective. Some women with low levels of FCR expressed a sense of mastery over FCR and described personality factors or traits that helped them to cope with FCR.

"I mean you could worry and make yourself sick about something that is never going to happen....I think I



^b Based on percentile raking of FCRI score from parent study Australian sample (n = 218) Canadian sample (n = 350)

^c Rounded to nearest whole year

naturally by instinct challenge negative thoughts. I reckon it is just part of the way I'm made." (Kate, low FCR)

By contrast, many of those with moderate to high levels of FCR described their coping strategies as effortful, ineffective, or time-consuming. Amongst some women with high levels of FCR, coping strategies and healthy lifestyle behaviours took on an obsessional quality, were burdensome, or a source of anxiety if they were unable to be completed.

"I came home with a list, that if I do this the cancer won't come back. And so my whole mission then became you know organic food, to be juicing, to be exercising, to do this, to do that which, you know, ... I had to do too many things all at once otherwise the cancer was going to come back. And it all, you know, it seems very illogical now but back then it was just, you know, put me a tailspin that I just couldn't get out of." (Donna, high FCR)

Compared with women with low levels of FCR, those with moderate to high FCR reported greater use of distraction and cognitive avoidance. Qualitative differences were not observed between women with moderate and high scores.

Worst fears

Unsurprisingly, fear of death and the process of dying were amongst the most feared aspects of potential cancer recurrence. Although fear of death was reported by women with all levels of FCR, when speaking about worst fears, those with lower levels of FCR commonly described more practical concerns about having to go through cancer treatment again and impact on family finances and disruption to family routines.

"Chemotherapy was worse than cancer itself, I remember thinking at the end of the treatment if it ever came back I'd just take a tablet and go to heaven. I wouldn't do the chemo again, I wouldn't do it again." (Olivia, low FCR)

Whereas those with moderate to high FCR reported more elaborate thoughts of death and the pain and suffering associated with death. Some women with moderate to high levels of FCR spoke about having known others who had died from cancer and graphic accounts of witnessing their suffering, and this appeared to influence their beliefs about death from cancer.

"It is not that I'm going to have to go through that experience again, oh my God, I've got secondary cancer, I'm going to die, it's not that I'm going to die, it's that I'm going to have a really horrible life. I've seen people die of cancer, it's them dying bits, it's not the end

of my life bit that's the fear, it's having no quality of life, I think that's really scary." (Annalise, high FCR)

"You tend to think of whether it might lead to a long unpleasant illness that my whole family would have to view and I would have to manage, and leading on to death which is not the sort of ideal way anyone chooses to go, those thoughts go through my mind." (Tamara, moderate FCR)

Whilst we did not specifically ask about the experience of imagery, the graphic description of dying by some women with moderate to high levels of FCR suggests that for some worst fears may be experienced as images. Interestingly, many of those who reported fear of dying also reported use of distraction (e.g. keeping busy) or cognitive avoidance to manage those fears.

Loss of control and independence or being a burden to others were other common worst fears.

"I really don't want to be dependent on anyone and I don't want to linger on and on and on and become more and more incapacitated, that's what I worry about and also I always want to have enough money, like I know I've got a husband ...but I also want to have enough money on my own to support myself while I'm sick." (Xanthe, moderate FCR)

Missed opportunities and the impact of potential recurrence on others including family, friends and colleagues and abandoning others were other common worst fears themes across levels of FCR. For those with young children, the impact of potential recurrence was particularly salient.

"I think of death, suffering and think of not being there for my kids, not seeing them get married and all of these milestones, and I think about my husband having another wife after...I think about not being able to enjoy my retirement if I go to soon." (Isla, moderate FCR)

When speaking about the possibility of cancer recurrence, one woman with high levels of FCR said:

"You don't want to wreck the lives of those around you... you wouldn't be able to do your job you'd be letting other people down" (Annelise, high FCR)

Although it was not the focus of this study, we did not find any qualitative evidence of cultural differences between coping strategies or worst fears of Australian and Canadian participants.



Discussion

This is the first study to explore the coping strategies used by young women with breast cancer to manage FCR and provide a qualitative account of the most-feared aspects of potential recurrence. Findings demonstrate that a diverse range of coping strategies are used by young breast cancer survivors to manage FCR and that some strategies (e.g. avoidance-based coping) are seen as helpful by patients despite health professionals and theories of FCR identifying avoidance them as unhelpful and maintaining factors [2, 32]. Cross-cultural differences between Australian and Canadian participants were not observed, suggesting that these themes are common across these two relatively similar Western cultures. Further research is needed to confirm this finding and explore whether cultural differences exist between other cultural groups.

A somewhat surprising finding was the fact that bodily checking was not explicitly described as a coping strategy by any participants in this study; however, reassurance seeking via unplanned medical tests or researching symptoms on the Internet or in textbooks was generally reported as helpful despite some theories of FCR [2, 32] identifying these behaviours as maintaining factors. This suggests bodily checking might be less central to the maintenance of FCR than previously thought or that young women do not recognise bodily checking as a coping response to FCR.

This study found that women with high FCR might engage in time-consuming health behaviours (e.g. dietary changes, complementary therapies). Somewhat counterintuitively, these behaviours, which are intended to reduce FCR, may become burdonsome and a source of anxiety themselves if they are unable to be completed as planned. Previous literature suggests that cancer-related anxiety may motivate health behaviours [33], but this has not yet been systematically explored. Further research on the association between FCR and health behaviours is needed.

Whilst the types of coping strategies used by women with lower levels of FCR in this study were qualitatively similar to those with moderate to high levels of FCR, women with lower FCR describe a greater repertoire of strategies and a greater sense of mastery over FCR. By contrast, women with moderate to high levels of FCR reported using fewer coping strategies and described their coping efforts in a manner which suggests they may be time-consuming, repetitive or even obsessive and consequently worrisome if not successfully completed. This is inline with previous research which has shown that the intrusive thoughts associated with high FCR are more characteristic of obsessions [34]. These findings highlight a need for more research into the ways in which chronic pathological FCR differs from more normative or transitory FCR [34]. Furthermore, this study provides some support for the use of interventions which address an obsessive or ruminative thinking style rather than just the verbal content of fears. The Conquer Fear Study, underway in Australia, is a randomised controlled FCR intervention study which includes components of metacognitive therapy [35] which deals specifically with correcting a maladaptive cognitive processing style and rumination [36].

Fear of death is common amongst many young women with breast cancer due to feelings of unfinished life or missed opportunities [37]. Results from the present study suggest that whilst women from all levels of FCR identify fear of death as their worst fear, those with moderate to high levels of FCR described more elaborate fears of suffering, abandonment of others, disability and lack of independence associated with death and dying. This is in accordance with previous research involving health-anxious patients who report similar themes [24]. By contrast, those with lower levels of FCR tended to describe more practical concerns such as having to go through treatment again, disruption to family life and finances. This study generates a number of new hypotheses about potential differences in the content of fears in FCR between women with higher and lower levels of FCR. More research, using a quantitative method and larger samples, is needed to test these hypotheses and replicate these findings.

Whilst the present study did not specifically focus on exploring imagery, the graphic account of death fears by some women suggests that some worst fears may be experienced as images. There is currently limited work on imagery associated with FCR, but this is in accordance with previous research which shows that FCR is a mix of thoughts and images and that the proportion of images to thoughts increases with increasing FCR severity [34]. Further research on the role of imagery in FCR may help to refine the exposure exercises in existing FCR treatment protocols and determine which patients benefit most from exposure exercises.

Young age may limit the effectiveness of coping due to fewer life experiences dealing with illness [38]. Another clinical implication of our findings for FCR treatment is that young women with higher levels of FCR may benefit from learning a greater repertoire of coping skills. The present findings also highlight the need for more patient education regarding factors that contribute to the development and maintenance of FCR (e.g. excessive reassurance seeking and avoidance).

The strength of this study was that it included a large sample and participants from two countries. However, some limitations should be acknowledged in considering the findings. Firstly, this study focussed specifically on young women with breast cancer, a patient sub-group particularly vulnerable to FCR. Further research on the specific nature of FCR and coping strategies employed by older women to deal with FCR is warranted. Other possible limitations include the use of telephone interviews, a wide variation in time since diagnosis amongst participants and the smaller number of young Canadian women relative to Australian women.

This study is the first to describe the coping techniques used by younger breast cancer survivors to deal with FCR



and provides insight into the specific content of recurrent fear amongst a vulnerable patient sub-group. Qualitative differences in coping strategies used by young women with low, moderate and high levels of FCR emerged. Further studies including quantitative studies of coping and content and nature of recurrence fears are recommended.

Acknowledgments B. Thewes was supported by a National Breast Cancer Foundation Post-Doctoral Research Fellowship. P. Butow was supported by a NH&MRC Research Fellowship Award. S. Lebel was supported by Research Development Funds from the University of Ottawa. The authors wish to thank the women who participated and acknowledge the assistance of Breast Cancer Network Australia (BCNA) and the Young Breast Cancer Action Group of NSW who assisted with this recruitment of participants for this study.

Compliance with ethical standards

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Conflict of interest The authors have no conflict of interest to declare.

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