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REVIEW ARTICLE

Systematic review of interventions by non-mental health specialists for managing fear of cancer recurrence in adult cancer survivors

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Abstract

Purpose Fear of cancer recurrence (FCR) affects 50–70% of cancer survivors. Evidence-based psychological interventions for FCR are effective but resource-/time-consuming. This systematic review identified interventions by non-mental health specialists addressing FCR, evidence of a relationship between specialist communication and FCR and stakeholder perspectives on how specialist communication can address FCR.

Methods A systematic literature review was conducted using nine databases (Medline Ovid, EMBASE, Cochrane, CINAHL, Scopus, PsychINFO, Informit, Web of Science and Google Scholar). Included studies were English, published 1997–2018, on adult cancer patients examining 'fear'/'worry' and 'cancer recurrence'/'progression' and 'health communication'/'medical encounter'/'interventions'. Data was extracted, summarised and rated for quality by two authors.

Results Of 6248 articles screened, 16 were included. No phase III randomised controlled trials were found. Five studies piloted an intervention, three were correlational studies, five were cross-sectional patient surveys and three were specialist surveys. Four out of five interventional studies were nurse-led: one trained patients in discussing FCR with their specialist while three delivered supportive counselling and/or taught strategies to manage FCR. The last intervention trained mixed health professionals to manage FCR through normalisation, education and lifestyle strategies. Three intervention studies measured FCR objectively, and two demonstrated a reduction in FCR in the short term. Consultation duration, empathy and clear information delivery were associated with FCR. Patients indicated desire to discuss FCR; however, specialists indicated discomfort with managing FCR.

Conclusions Research on non-mental health practitioner-led interventions to address FCR is lacking. Further studies on whether specialist interventions delivered during follow-up consultations are useful in managing FCR are required.

Keywords Cancer · Fear of recurrence · Survivorship · Intervention · Patient education · Review

Background

Improvements in cancer screening, diagnosis and management have resulted in substantial improvements in survival rates in recent decades. Research on cancer survivorship has identified that fear of cancer recurrence (FCR) remains one of the most prevalent unmet needs of cancer survivors in follow-up clinics [1]. FCR is defined as 'fear, worry or concern relating to the possibility that cancer will come back or progress' [2]. FCR is a significant problem affecting 50–70% of cancer survivors across all cancer subtypes, which persists over time [3, 4]. A systematic review of FCR in adult cancer survivors found inconsistent relationships between the stage of cancer or objective markers of recurrence risk and patients' reported level of FCR [3]. High levels of FCR affect patients' quality of life and productivity and also increase resource expenditure and health system utilisation [5]. Importantly, 30% of patients surveyed report significant unmet need for help with managing FCR [1].

A number of evidence-based psychological interventions have been evaluated in randomised controlled trials,

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including one conducted by this research team of ConquerFear, a psychological intervention based on meta-cognitive therapy compared with relaxation training, which demonstrated sustained efficacy in reducing FCR in patients with high baseline FCR levels [6]. However, these programmes are resource-intensive and time-consuming. Also, uptake of psychosocial referral is relatively low, primarily because patients prefer to receive informal support from their treatment team, family and friends [7]. Furthermore, many small or private cancer services lack psychosocial staff to which to refer. Finally, the majority of patients have mild to moderate FCR [3] and existing FCR interventions have not been tailored for treating these patients. Furthermore, it is possible that interventions to address mild to moderate FCR may have value in preventing the development of severe FCR, by giving patients the skills to address FCR early, before entrenched patterns of thinking and emotionally responding develop.

For these reasons, interventions delivered by non-mental health specialists including doctors, nurses and radiographers for FCR within the context of routine medical oncology follow-up clinics may be a very useful adjunct to psychological interventions. In these clinics, significant time is spent assessing for symptoms and signs of cancer recurrence and discussing biochemical and radiological test results to provide early evidence of recurrence. Brief oncologist-/nurse-delivered FCR interventions have the potential to reduce suffering, improve communication and rapport and prevent the development of severe FCR.

Additionally, communication strategies and aspects of the clinical consultation such as consultation length and emotional cues delivered during the consultation may also affect patients' FCR. For example, a correlational study between consultation content and FCR in breast cancer patients receiving radiotherapy revealed that consultations for patients with FCR-decreasing trajectories were longer and expressed more emotional cues and concerns than FCR-increasing trajectories [8]. Furthermore, a large US survey of 1295 breast cancer patients which examined the impact of doctor-patient communication on patients' perception of recurrence showed that over 60% of doctors did not ask about patients' FCR, and patients who did not have a conversation with their doctor about recurrence risk were more likely to over or under-estimate their recurrence risk [9].

The aim of this systematic review was to provide a comprehensive review of existing studies of (a) non-mental health specialist-led educational, communication and/or psychological interventions addressing FCR; (b) evidence of a relationship between FCR and specialist communication; and (c) patients' and specialists' views on how interventions can address FCR.

Methods

Inclusion and exclusion criteria

Publications were included if they were in English, published between 1997 and 2018 inclusive and addressed FCR in cancer patients aged 18 years or above. Papers needed to report on (a) non-mental health specialist-delivered interventions targeting FCR or a related concept such as dealing with uncertainty, (b) the relationship between specialist communication and FCR or (c) specialist/patient perspectives on specialist communication regarding FCR. Intervention studies and cross-sectional surveys or qualitative studies of any sample size were included. Papers had to include an intervention, aim or outcome related to FCR.

Review articles, conference abstract–only publications, editorials, letters and protocols were excluded. Additionally, studies reporting on psychological interventions delivered by psychologists/psycho-oncologists were excluded, as these were not the focus of the current review and have been reviewed elsewhere [10–12].

Search protocol

A systematic search of the following nine electronic databases was conducted: Ovid MEDLINE, EMBASE, Cochrane Database of Systematic reviews, CINAHL, Scopus, PsychINFO, Informit, Web of Science and Google Scholar. The search strategy included the keywords cancer [neoplasm* or cancer or malignan* or tum??r or onco*] and fear [fear or worry or anxiety] combined with recurrence [recur* or relapse or progress* or coming back] and consultation/follow-up [communication or prognos* or physician-patient relation or aftercare* or follow-up or survivorship]. An example of the search strategy used for Ovid MEDLINE is shown in Appendix Table 1 in the supplementary material. The references in identified papers were also reviewed.

All references were imported into Endnote Version X8.2. After removal of duplicates, publication titles and abstracts were initially screened for eligibility. Of those included after initial screening, full-text articles were reviewed by two independent coauthors (50% JL and PB, 50% JL and JB) for final inclusion, with an inter-author concordance rate of 80%. Discrepancies were decided by consensus.

Data extraction

For each publication, data was extracted using a standardised coding sheet adapted from the PRISMA statement [13]. Data extracted included (a) cancer type, (b) sample size and (c) socio-demographic information of subjects and country/countries; the study was conducted in (d) study aims and design (e) survey/intervention measures and (f) outcomes (qualitative

and quantitative). Quantitative data were summarised with means and ranges. Qualitative findings were synthesised using thematic synthesis as described by Thomas and Harden [14]. For each study, participant quotations and text under the 'results/findings' and 'conclusion/discussion' section, which were related to communication about FCR, were identified. JL conducted line-by-line coding of the text into concepts inductively derived from the data. Concepts were compared and transferred across studies by adding coded text into existing concepts or creating additional codes for new concepts. Similar codes were grouped into themes. Preliminary themes were discussed by the authors, to ensure the analysis reflected the full range of data reported across all studies.

Quality assessment

Studies were rated for quality using QualSyst, a standard quality assessment criteria for evaluating research from a variety of study designs [15]. This process was undertaken by JL, and a subset (4 studies) also rated by PB. There was agreement in the quality score in one article, and discrepancy of only 5% in the other studies, resolved through discussion.

Results

Characteristics of studies

The search strategy identified 6248 bibliographic records after removal of duplicates, which were reduced to 314 after title/abstract screening. After full-text review, this was further reduced to 48 articles (Fig. 1). After close reading by two authors, a further 32 articles were excluded due to non-eligibility; thus, 16 articles were included in the systematic review.

Characteristics of included studies are summarised in Table 1. Only five intervention studies were identified with two being phase I/II randomised controlled trials of nurse-delivered communication or counselling interventions versus standard care. There were three correlational studies investigating relationships between communication variables coded from audiotaped consultations and FCR, and eight cross-sectional surveys or qualitative studies investigating stakeholder perspectives, of which three included health care professional and five included patient participants. Of the 16 included studies, breast cancer was the most commonly studied cancer subtype (6/16), followed by head and neck (2/16) and colorectal (2/16). The remaining studies examined oesophageal, prostate or ovarian cancers (1/16 each), or mixed cancer types (3/16). Most of the FCR intervention literature was published by researchers in the USA (6/16), followed by the UK (5/16) and Australia (2/16).

Evaluation of quality of studies

Overall, the quality of the studies as assessed by QualSyst was satisfactory (range of 64 to 100%). The mean Qualsyst quantitative score for four out of the five intervention studies was 80.8% (± 3.1%), with the qualitative intervention assessing patient satisfaction to a telephone intervention scoring 75% [18]. The mean Qualsyst for the eight quantitative non-interventional studies was 85.1% (± 12.7%) with the three qualitative studies scoring 86.7% (± 5.8%).

Intervention studies

Of the five intervention studies, one was a phase I randomised controlled trial (RCT) and one was a phase II RCT. Both were small RCTs that examined the impact of a nurse-delivered psychological or communication intervention compared with standard care on FCR, anxiety and depression, with sample sizes of 44 and 90. Table 2 summaries the range of interventions used. Key components included provision of reassurance, encouragement of expression of fears, relaxation strategies, coping strategies, information and supportive counselling. Interventions ranged from a single session to six weekly contacts, with both being delivered face-to-face.

Humphris and colleagues examined the effect of a nurse-delivered psychological AFTER (Adjustment to the Fear, Expectation or Treat of Recurrence) intervention on depression, anxiety and cancer worry in the context of a phase II RCT of 90 patients previously treated for oral/oropharyngeal cancer [16]. The intervention comprised six 60-min weekly face-to-face sessions with a trained nurse, incorporating patient-centred assessment and expression of FCR, behavioural modification when excessive self-checking behaviour was identified, relaxation strategies and coping strategy education [30]. The study was powered on the depression subscale of the Hospital Anxiety and Depression Score (HADS) and not FCR. Change score differences at 11 months after the intervention compared with 7 months after the intervention showed reduction in FCR on the Worry of Cancer (WoC) Scale (change score 2.5, $p = 0.03$) and anxious preoccupation with cancer (change score 2.0, $p = 0.04$) but not general anxiety ($p = 0.28$) and depression ($p = 0.44$). However, the reduction in FCR and anxious preoccupation with cancer was not sustained at 15 months after the intervention. The secondary analysis showed that the effect of the intervention indirectly influenced FCR on the WoC scale at 11 months ($p < 0.05$) but directly influenced FCR at the 7-month follow-up ($p = 0.01$). This intervention was not targeted to patients with high FCR, and 15% of patients in the intervention group reported minimal levels of fear at 7 months after the intervention [16].

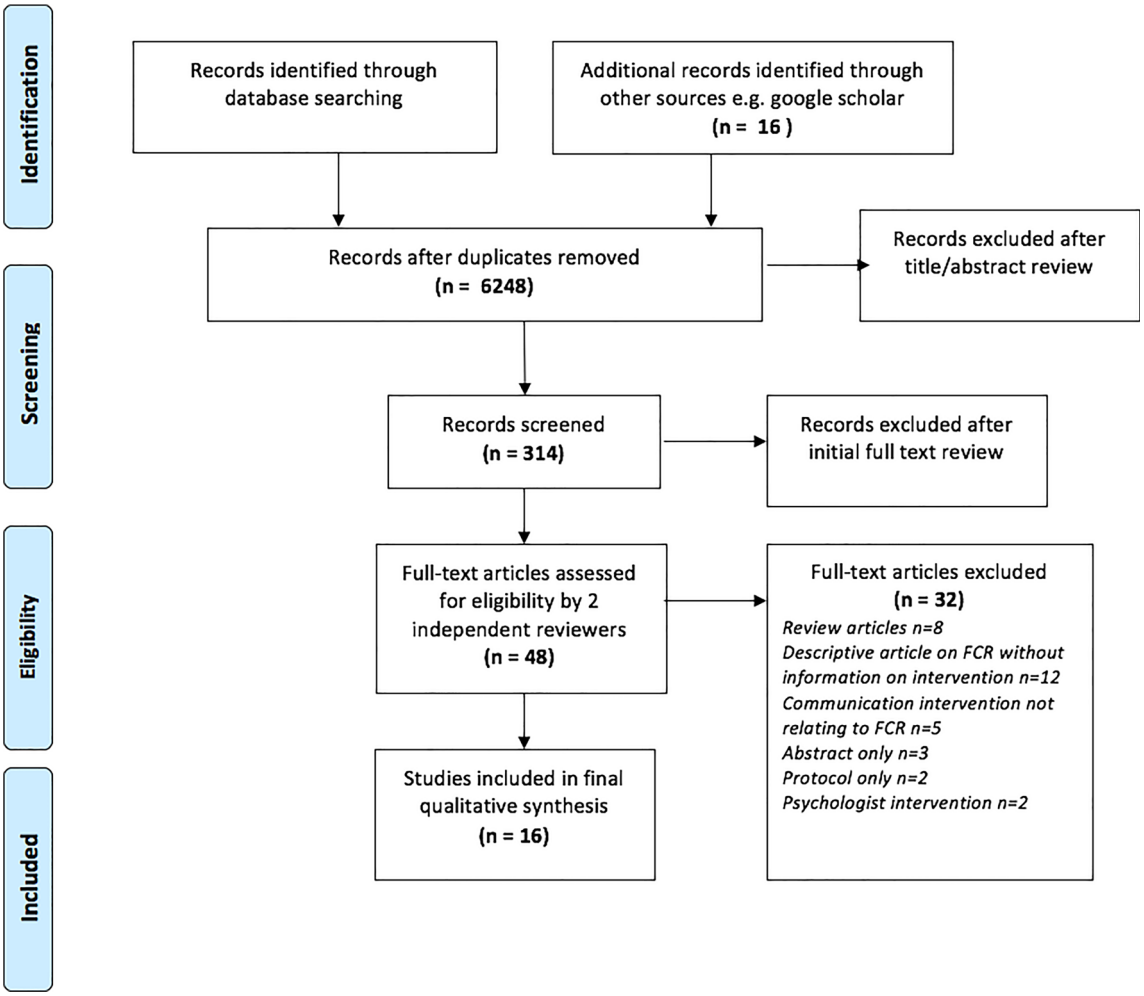

Fig. 1 PRISMA flowchart of study selection process. FCR fear of cancer recurrence

The second RCT was a small pilot phase I trial of a nurse-delivered single-session coaching intervention versus standard care delivered 1 week prior to oncologist follow-up to encourage breast cancer patients to express FCR and raise this at their follow-up appointment [17]. There was no selection for high baseline FCR as part of the inclusion criteria for the study; however, all participants were young women (aged 18–45). While the intervention was found to be useful by 80% of participants, no difference in FCR as measured on the Concerns about Recurrence Scale was found [31]. Only self-efficacy was significantly greater for the intervention arm compared with the control arm (effect size 3.17, $p = 0.04$). The applicability of the findings from this study to other cancer patients is limited given the recruited patients were mostly Caucasian, young and well educated.

The other three interventions were single-arm phase I pilot interventions. Cox and colleagues assessed the feasibility of a nurse-delivered 3-monthly 20-min telephone intervention with patients to discuss recurrence symptoms and FCR and relay CA125 results to 52 ovarian cancer patients. While FCR was discussed with a third of participants, FCR was not measured pre- and post-intervention [18]. Berrett-Abibi et al piloted a 30-min training programme with some resources for mixed health professionals in the primary care setting, including doctors and nurses, focused on normalisation of FCR, education and lifestyle suggestions, and referral to psychosocial health professionals for patients with high FCR [19]. Participants self-reported an increase in knowledge and self-efficacy in dealing with FCR and supported the training, albeit with some concerns about barriers to implementation.

Davidson and colleagues assessed the feasibility of a nurse-delivered abbreviated version of the AFTER intervention, called mini-AFTERc. This single-session 30-min telephone intervention delivered by three experienced breast care nurses was piloted in 16 breast cancer survivors who had moderate baseline FCR (scored > 13 on FCR inventory (range 0–36)). The study demonstrated good intervention fidelity (85%) assessed objectively using audiotaped recordings of the conversations, and nurses and patients reported the intervention as acceptable and feasible. While the follow-up was short

Table 1 Summary of the five intervention studies, three correlational studies and eight cross-sectional survey studies included in the final systematic review

Study; country	Study design	Sample size	Cancer type	Response rate	Methods/measures	Outcomes	Quality QualSyst Score
Intervention studies							
Humphris 2012; UK [16]	Phase II RCT nurse-delivered psychological intervention versus standard care	90	Head and neck	NS. 90 registered. 31/34 controls completed 46/53 interventions completed	Nurse-delivered AFTER (adjustment to the fear, expectation or threat of recurrence) intervention comprising CBT, relaxation, patient-centred expression of FCR, caregiver incorporation at 7-month mark. Measures: 14-item Hospital Depression and Anxiety Scale, 3-tem Worry of Cancer Scale, EORTC Quality of Life Questionnaire V2, Mental adjustment to Cancer Scale	Primary outcome: change in anxiety subscale of HAD between 7th and 11th month assessments not significant ($p = 0.28$). AFTER intervention reduced FCR as assessed by Worry of Cancer Scale ($p = 0.039$) and the anxious preoccupation subscale of MAC ($p = 0.042$), but not general anxiety ($p = 0.28$) nor depression ($p = 0.44$). Both these effects were not sustained at final follow-up at 15 months (8 months after intervention).	QUANT 83%
Shields 2010; USA [17]	Phase I RCT of nurse-delivered communication coaching intervention versus standard care	44	Breast	44/67 (66%)	Coaching intervention by oncology nurse practitioner 1 week prior to clinic appointment, with mailed prompt sheet addressing patients' 3 biggest worries/concerns for them to raise with oncologist at consultation. Measures: 14-item Likert scale of breast cancer self-efficacy, 20-item Spielberger State-Trait Anxiety Inventory subscale, Centre for Epidemiological Studies Depression Scale, 33-item Concerns about Recurrence Scale.	Prompt sheet was used by 90% of participants prior to oncology clinic. 80% found prompt sheet helpful. Questions about recurrence were the third most common question identified by the intervention. The intervention improved breast cancer self-efficacy (ES 3.17, $p = 0.04$); there were no measured differences in FCR.	QUANT 83%
Cox 2008; Australia [18]	Single-arm nurse-lead telephone follow-up intervention	52	Ovarian	52/77 (68%)	3-monthly 20-min telephone intervention to discuss symptoms of recurrence, psychological concerns including FCR and discuss pathology (CA125) results. Measured satisfaction and experience with follow-up with questionnaire	Mean patient satisfaction 8.24/10. 33% of patients discussed FCR However, little information provided in paper about strategies used to manage FCR Nurse-lead intervention feasible to address FCR, however degree of FCR change pre- to post-intervention not assessed.	QUAL 75%
Berrett- Abebe (2) 2018, USA [19]	Single-arm, pre-post-training evaluation	46	Heterogeneous	Not stated	Primary care workers: doctors (28), doctor assistants (5), nurse practitioners (3), social workers (2), nurses (8) completed questionnaires before and immediately after a 30-min training. The intervention comprised didactic information on FCR, screening questions for FCR, brief interventions for FCR (normalisation, psycho-education and lifestyle, and referral for higher FCR). Measures: Likert scales	The training increased knowledge and self-efficacy and was acceptable, although participants raised barriers. Suggested the training was feasible.	QUANT 77%
Davidson 2018; UK [20]	Single-arm nurse-lead telephone intervention	16	Breast	66/102 (65%) baseline questionnaire response rate. 16/18 (89%) intervention response rate.	Nurse-delivered 30-min single telephone session Mini-AFTERc (abbreviated version of AFTER intervention) which targets recurrence fears, inappropriate/excessive checking behaviours and general cancer beliefs. Measures: Feasibility, 9-item FCRI measured at baseline and 1 week post-intervention, fidelity using audio recordings	Baseline FCR in all participants was 17.66/36. FCR scores of 12/16 patients decreased from baseline to 1-week follow-up (coefficient − 4.2, effect size 0.8 $p = 0.03$). Adherence to intervention was 85%. Mean duration of intervention was 25 min. Nursing staff deemed intervention to be useful and easy to follow.	QUANT 79%

Table 1 (continued)

Study; country	Study design	Sample size	Cancer type	Response rate	Methods/measures	Outcomes	Quality QualSyst Score
Correlational studies examining associations between doctor/nurse communication and FCR							
Barracliffe 2018; UK [8]	Correlations between FCR trajectories and consultation length and emotional cues and concerns.	12	Breast cancer patients receiving adjuvant radiotherapy	Not reported	Patients completed FCR measure pre-radiotherapy and daily through 2–3-week treatment (15–25 days). Six patients with largest decreases in FCR and 6 with largest increases in FCR were selected. Consultations with 2 radiotherapists (maximum 3) and participation patients were audiotaped and coded for time and emotional cues and concerns.	FCR-decreasing trajectory consultations were longer (on average 4.5 min, $p < 0.02$), expressed twice as many cues and concerns as the increasing trajectory group ($p < 0.001$) and were more likely to refer to cancer directly ($p < 0.05$).	QUANT 77%
Gros 2015; Germany [21]	Pre-postconsultation	169	Colorectal cancer	NS. Questionnaire completion rate of recruited participants 90%	12-item Likert scale Fear of Progression Questionnaire (FOP-Q-SF). Interruptions during consultation and duration of consultation and comprehensibility of information were each assessed on single item 5-point scale Degree of empathy assessed on 10-item CARE instrument. Items assessed before first consultation and within 3 days after consultation	FOP decreased in 59% of consultations, increased in 36% and was stable in 5%. Interruptions during consultation predicted lack of FOP decline ($p = 0.008$). Unexpectedly, a high perceived empathy was negatively associated with FOP reduction ($p = 0.013$). Fully comprehensible information associated with FOP reduction ($p = 0.001$). No effect on duration of medical encounter (< 30 min versus 30-60 min) on FOP.	QUANT 77%
Ozakinci 2017; UK [22]	Analysis of clinical encounter and patient survey	11	Head and neck	NS	57-item PCI, recorded consultation for thematic analysis, follow-up telephone interview of patients assessing ongoing concerns, frequency of FCR, how FCR was addressed during consultation and ongoing support	Consultant raised FCR in 10/11 consultations. Strategies included normalisation, reassurance and referral to counsellor. Patients identified external triggers (media) and internal triggers (new symptoms) for elevated FCR. Patients felt uncomfortable with raising FCR with clinician due to fear of appearing ungrateful or damaging the relationship.	QUAL 80%
Cross-sectional surveys/qualitative studies: patients							
Franssen 2009; Netherlands [23]	Patient survey	176	Oesophageal	176/204 (86%)	15-item Likert scale questionnaire of prognostic information preferences 14-item Hospital Anxiety and Depression (HADS) scale FCR measured by 3-item Likert scale questionnaire. 5-item Wake Forest Physician Scale to assess patient trust of physicians 8-item quality-quantity questionnaire	93% of patients desire detailed prognostic information; 82% want 5-year recurrence risk information Those wanting more prognostic information had the highest FCR ($p = 0.013$) and were most actively involved during the consultation ($p < 0.001$) Although anxiety and depression were related to FCR, neither attribute influenced patients information preferences	QUANT 86%
Janz 2017; USA [9]	Patient survey	1295	Breast	2502/3930 (68%) responded 1295/3930 (33%) completion rate	3-item Likert scale on doctor-patient communication regarding recurrence risk. Patients perceived risk of recurrence questioned and compared with objective risk. General worry and worry about recurrence assessed with 1 item each	60% patients reported their doctor did not ask about FCR 14% patients reported their doctor did not discuss risk recurrence at all Patients who over-/under-estimated recurrence risk less likely to report having a	QUANT 100%

Table 1 (continued)

Study; country	Study design	Sample size	Cancer type	Response rate	Methods/measures	Outcomes	Quality QualSyst Score
						discussion with doctors about risk (OR 0.5 and 0.46 respectively).	
Kelly 2013; USA [24]	Patient survey	113	Breast	113/141 (80%)	Cancer recurrence risk communication questionnaire, Profile of Mood States (POMS), Cancer Worry Scale, self-rated perceived lifetime risk of breast cancer recurrence (8-items)	40% of patients perceived their HCP did not discuss recurrence risk, while only one patient did not want to discuss recurrence risk Patients with higher FCR have an exaggerated perceived recurrence risk	QUAL 90%
Maguire 2016; Ireland [25]	Patient survey	817	Prostate	817/1229 (66.5%)	5-item FCR scale, Global Health Score subscale of EORTC Quality of Life Questionnaire, Decisional Regret Scale, patient self-rated satisfaction with treatment information.	FCR scores were low on average. Low satisfaction with information received ($p = 0.003$) and treatment regret ($p < 0.001$) were associated with FCR on multivariate analyses. The lower the satisfaction with information, the higher the FCR.	QUANT 100%
Papagrigoridis 2003; UK [26]	Patient survey	95	Colorectal	95/156 (60%)	39-item mailed questionnaire exploring self-rated anxiety before clinic visit, experience at clinic, experience of investigations, attitude towards information about risk of recurrence.	35% reported anxiety prior to clinic follow-up. 77% (66) would like to know about the occurrence of recurrence even if there was no treatment/survival benefit. Only 21% (19) patients could name symptoms associated with cancer reappearing while 64% (61) would like to learn more about what these symptoms are.	QUANT 64%
Cross-sectional surveys/qualitative studies: health care professionals							
Janz 2015; USA [27]	HCP survey	766	Breast	766/1500 (60.5%)	Mailed custom Likert scale questionnaire asking about clinician's confidence in presenting risk information, identifying and managing FCR, and likelihood of using 9 strategies to manage worry	74% of oncologists were confident with managing FCR versus 64% surgeons ($p = 0.0002$). 60% of doctors routinely initiate discussions regarding FCR. Medical oncologists and female doctors were more confident with presenting risk information than surgeons and male doctors. Strategies used to address FCR include doctor discussion (> 90%), cancer support groups (> 80%), provision of reading or online material (> 60%), peer counselling (50%), psychologist referral and medications.	QUANT 95%
Thewes 2014; Australia [28]	HCP survey	141 (77 clinical HCPs, 64 psychosocial profes-sionals)	Heterogeneous	141/271 (52%)	HCPs perception on the prevalence of FCR, experience with managing FCR and proportion of cancer survivors in their practice with FCR. HCPs current approaches to managing FCR, perceived level of challenge in managing FCR. Level of interest in FCR training.	> 99% surveyed HCPs interested in further FCR training. FCR is common and takes > 25% of time in consultations. Information giving (92%) and referral to psychosocial support (88%) were top strategies used by HCPs. 74/77 reported some challenge in managing FCR and all HCPs interested in training for FCR. Psychosocial professionals used acceptance and commitment therapy, CBT, mindfulness and psycho-education.	QUANT 82%
		42	Heterogeneous	Not stated			QUAL 90%

Table 1 (continued)

Study; country	Study design	Sample size	Cancer type	Response rate	Methods/measures	Outcomes	Quality QualSyst Score
Berrett-Abebe (1) 2018, USA [29]	Qualitative interview study				Primary care workers: doctors (13), nurses (8), social workers (8), psychologists (7), public health (2) and chaplain (1) participated in telephone interviews eliciting perspectives on content for inter-professional training on FCR, and the feasibility of delivering FCR interventions in the primary care setting. Interviews were audiotaped, transcribed and thematically analysed.	Intervention suggested for patients with some FCR (most) included normalisation, psycho-education, reassurance, empathy and lifestyle interventions. Referral to psychosocial specialist care was recommended for high FCR. Regarding content for training, participants suggested basic training on cancer, communication skills training in empathy.	

NS not specified, *FCR* fear of cancer recurrence, *RCT* randomised controlled trial, *HCP* health care professional

(1 week after the intervention only), there was a significant decrease in recurrence fears at follow-up (effect size 0.8, $p = 0.03$) [20].

Observational studies

From the 11 observational studies, two broad themes were identified as (1) factors in the clinical encounter that were reported to influence FCR and (2) strategies to manage FCR. Eight studies explored theme 1. Three studies were correlative studies with sample sizes of 11 to 169 which examined associations between doctor communication coded from audiotaped consultations and patient-reported FCR [8, 21, 22]. Five studies with sample sizes ranging from 95 to 1295 surveyed cancer patients to identify factors in the clinical consultation which influenced their degree of FCR [9, 23–26]. In particular, there was a relationship between patients' information needs and provision of information and FCR levels. Aspects of patient-provider communication including consultation length, degree of empathy and emotional cues expressed influenced FCR. Three studies, with sample sizes ranging from 42 to 766, surveyed health care professionals on attitudes, confidence and strategies with managing FCR [27–29] and addressed theme 2. These themes are elaborated further below.

Factors that influence FCR in the clinical encounter

Information needs/provision In surveys of breast cancer patients in the USA, 40–60% reported that their doctor did not ask them about FCR while 14–40% reported that the risk of recurrence was not discussed at all [24]. Importantly, high FCR was found to be associated with over-estimates of risk of recurrence by patients [24]. Patients who over- or under-estimated their recurrence risk were less likely to report having a discussion with their doctor about their recurrence risk (over-estimating risk: OR 0.48 95% CI 0.3–0.77; under-estimating risk: OR 0.46 95% CI 0.28–0.69) [9]. Information giving, in the form of likelihood of a patient remaining disease free, was the most commonly used strategy (by 92% of HCPs) to manage FCR associated with recurrence of symptoms [28].

Focus group interviews with patients who completed a patient concerns inventory to assist with identification of FCR revealed that some patients felt uncomfortable with raising FCR with their health practitioner, due to fear of appearing ungrateful or damaging the patient-physician relationship by suggesting that their treatment may not have been fully successful [22].

In 4/5 (80%) of the patient survey studies, a common theme that patients desire detailed prognostic information was identified. Moreover, those with the highest FCR wanted the most prognostic information ($p = 0.013$) and were the most actively

Table 2 Summary of intervention components

Study; phase (*n*)	Breathing, relaxation or imagery training	Patient-centred assessment of fears	Encourage expression of fears	Supportive counselling/ empathy	Reassurance/ normalisation	Teaching coping strategies, e.g. distraction, calming self-talk	Education re-recurrence symptoms	Referral to psychosocial HP for high FCR
Humphris 2012 [16]; RCT phase II ($n = 90$)	✓	✓	✓	✓				
Shields 2010 [17]; RCT phase I ($n = 44$)			✓		✓			
Cox 2008 [18]; single-arm phase I ($n = 52$)			✓		✓			
Berrett-Abebe (2) [19] 2018; pre-post-pilot ($n = 46$)		✓			✓		✓	✓
Davidson [20] 2018; single-arm phase I ($n = 16$)		✓	✓	✓	✓			

involved during the consultation ($p < 0.001$). Of the surveyed patients, 93% desired detailed prognostic information [23]. Moreover, cancer patients indicated a desire to be better informed on the symptoms of cancer recurrence. Only 21% of colorectal cancer patients could name symptoms associated with cancer reappearing while 64% would like to learn more about what these symptoms are [26].

Provider-patient communication and relationship with FCR

Existing studies report inconsistent findings with regard to consultation duration and degree of empathy expressed during the consultation, and their impact on FCR. Gros and colleagues examined how the nature and duration of clinical consultations affected fear of cancer progression (FOP) change before and after the consultation in newly diagnosed colorectal cancer patients [21]. Patients unsatisfied with information provided during the consultation ($p = 0.001$) and who experienced more interruptions during the consultation ($p = 0.008$) had a lower decline in FOP. Unexpectedly, a higher degree of perceived empathy conveyed by the doctor to the patient was also associated with less FOP reduction ($p = 0.013$), perhaps because patients with the highest FOP triggered greater empathy but were also harder to shift in terms of FOP [21]. There was no effect of consultation length on FOP levels. In contrast, Barracliffe and colleagues found that longer consultations and greater expressions of emotional cues by patients during the consultation with their radiotherapist were associated with greater decline in the trajectory of FCR in breast cancer patients during the course of their adjuvant radiotherapy [8].

Patients identified external triggers (an upcoming appointment or scan, mention of cancer in media, diagnosis of cancer in friends/family) as triggers for increased FCR, but more importantly for health professional communication, they also mentioned internal triggers (specifically, worry about new, unexplained symptoms) [22]. Physical symptoms were the most common emotional cue and concern raised by breast cancer patients during adjuvant radiotherapy and often indicated worry about cancer recurrence, although the issue of FCR was only indirectly alluded to in these contexts [8]. Reassuringly, across the studies, discussion of FCR by health professionals did not trigger increased FCR in patients.

Strategies used to manage FCR

Across the health practitioner studies, strategies reported to be used currently to manage FCR included provision of risk information by the oncologist, reassurance/normalisation, referral to cancer support groups and online resources, peer counselling and psychologist referral. Both patients and non-mental health specialists in several studies identified that reassurance and normalisation of feelings of FCR, without dismissing these fears, were important strategies to manage FCR during the consultation. Information giving, in the form of likelihood of a patient remaining disease free, was the most commonly used strategy (by 92% of specialists) to manage FCR associated with recurrence of symptoms [28].

In the primary care context, a tiered approach to manage FCR was suggested in which all survivors receive basic interventions and those with higher FCR received more intense, targeted interventions such as counselling [29]. Surveyed non-mental health specialists in the three studies included in this systematic review expressed significant interest in further

FCR training, with over 99% of surveyed Australian oncologists indicating interest in FCR training [28].

While all surveys of non-mental health specialists identified FCR as a common issue which takes significant time to address in follow-up consultations, the proportion of specialists reporting confidence in managing FCR differed across studies. Of the surveyed Australian specialists, 53% reported that FCR management was somewhat challenging with 32% rating it as moderately challenging and 11% as very challenging [28]. Meanwhile, 74% of surveyed medical oncologists and 64% of breast surgeons reported confidence in managing FCR, with oncologists consistently reporting higher confidence than surgeons in presenting risk information, identifying worry and managing worry [27]. No studies have examined the relationship between health professionals' confidence in managing FCR and changes in FCR in their patients' post-consultation.

Discussion

Recognition of FCR as a prevalent, unmet need for cancer survivors has led to the development of numerous psychological interventions incorporating strategies such as psycho-education, cognitive behavioural therapy and meta-cognitive therapy in both individual and group settings for addressing FCR [6, 10, 32, 33]. As not all cancer survivors have high FCR, resource-intensive face-to-face psychological interventions are not likely to be cost-effective for the whole patient population. Rather, there is a need for the development of a stepped-care model for managing FCR based upon its severity. For example, patients with mild-moderate FCR could be adequately managed using brief interventions delivered by other practitioners (including nurses, general practitioners and oncologists) or via online self-help tools. Davidson and colleagues found that a brief telephone nurse-led intervention was feasible to incorporate into clinical practice and reduced short-term FCR in breast cancer patients with moderate baseline FCR levels [20]. A number of evaluations of online CBT-based FCR interventions are currently underway. Examples include the CAREST-trial, a randomised controlled trial of the cost-effectiveness of CBT-based online self-help training for breast cancer survivors [34] and the e-TC electronic (web-based) intervention for testicular cancer survivors to reduce anxiety and depression [35]. The use of brief targeted interventions for patients with mild-moderate FCR may prevent the development of severe, disabling FCR in cancer survivors, an area which warrants further research.

There have been two recent systematic reviews published in the last year on psychosocial interventions for FCR including cognitive behavioural therapy and mindfulness and relaxation training [11, 12]. However, this systematic review is the first to examine non-psychologist-delivered interventions for FCR and reveals novel insights on patient-provider perspectives on how the clinical consultation affects FCR. This systematic review shows that doctor-led interventions are currently lacking. While five intervention studies were found, four were nurse-led communication interventions. One was a feasibility study of a training intervention for primary care workers on FCR, which included 28 doctors, but did not assess the impact of the intervention on patients' levels of FCR. Of the two randomised controlled trials, both had small sample sizes [16, 17].

Components of existing FCR interventions included provision of reassurance, encouragement of expression of fears, relaxation strategies, coping strategies, cognitive restructuring and supportive counselling. Although perceived to be useful by patients, only the AFTER intervention was found to reduce short-term FCR but this effect was not sustained at follow-up. Only one of the three interventions that measured FCR included clinically significant FCR as an eligibility criterion [20]. The nurse-delivered telephone counselling intervention for breast cancer patients included only young women with breast cancer, a population known to have higher baseline FCR [3]. This might explain the lack of change in FCR despite improvements in self-efficacy, as more resource-intensive interventions might be necessary to reduce FCR in this population. Further studies examining brief interventions for patients with mild-moderate FCR levels at baseline and more intensive interventions for patients with high FCR at baseline are warranted.

Additionally, few studies have reported on FCR trajectories in cancer patients over time. Barracliffe and colleagues identified that greater emotional cues and concerns expressed by patients during review appointments were associated with decreased FCR over time [8]. Soriano and colleagues examined the association between daily FCR levels and FCR triggering events and self-checking behaviour in breast cancer patients 5 months after completing surgery over 3 weeks and found that fluctuations in FCR affected same-day checking behaviour, but patients' trajectories of FCR differed greatly between patients [36]. There is a need for more longitudinal studies to examine the impact of repeated brief FCR interventions delivered by non-mental health specialists, and its influence on FCR trajectory over time.

Possible reasons for the lack of doctor-/physician-delivered interventions for FCR include the issue that addressing FCR may take considerable time [28] and this may not be feasible in a time-pressured follow-up clinic schedule. However, it may be possible to deliver such interventions quite rapidly. The feasibility of abbreviated, less intensive versions of existing psychological interventions have been piloted and found to be promising (e.g. mini-AFTER, a telephone based psycho-oncology intervention delivered by breast care nurses, based upon the AFTER psychologist-delivered intervention) [20]. Further studies incorporating novel delivery methods

such as video-conferencing, mobile app–based interventions and web-based interventions are required.

Although FCR has been described in the literature for nearly 45 years [37], interest in its management has only increased in the last decade in the psycho-oncology research community but not necessarily the wider oncology community. As such, doctors are not currently routinely trained in managing FCR. In fact, 40–60% of surveyed breast cancer survivors reported that their doctor did not ask about FCR [9]. Although doctors' self-reported confidence with managing FCR varied across studies and specialty disciplines, 99% of Australian health professionals (of whom 77/141 were doctor/nurses) expressed a desire for further training in managing FCR in their patient [28], suggesting that this is an area of high need in health professional education.

This systematic review did provide novel insights into patients' information needs and the impact of the content and communication style of follow-up clinics on their FCR levels. The majority (80%) of the cross-sectional surveys of cancer patients indicated that provision of honest factual information about prognosis and recurrence risk information was helpful to address FCR. In agreement with a recent review, the studies included in this review consistently support the provision of information on recurrence rates, information on recurrence symptoms and tools to help patients understand their recurrence risk [38]. The degree of empathy conveyed by the doctor was found to be associated with high FCR in colorectal cancer patients in one study [21]; however, the expression of emotional cues by breast cancer patients correlated with greater FCR decline in another [8]. The discrepancies found between these two studies may relate to the fact that different populations were included (experiencing FOP versus FCR) and differences in the way emotional content was recorded (patient perceived empathy ratings versus an objective coding system for identifying emotional sequences during the consultation). Additionally, the Barracliffe study analysed FCR trends over weekly clinic reviews for 2 to 3 weeks [8] whereas the Gros study examined FOP before and after the first clinical consultation only [21]. Further studies on the characteristics of provider-patient communication and its impact on patients' FCR are required.

Limitations of the current review include the small number of interventions identified and heterogenous nature of the findings which limited the ability to provide information on the effectiveness of non-mental health practitioner–lead brief interventions on FCR. Additionally, this systematic review was not prospectively registered on PROSPERO. However, the procedures and processes were defined up-front.

In summary, this systematic review identified only five nurse-delivered interventions to address FCR in cancer survivors. No doctor-led interventions in the context of oncology follow-up clinics were found. However, correlational and cross-sectional surveys of patients and doctor/nurses revealed a desire for better FCR discussions at follow-up clinics and the provision of prognostic and recurrence information by doctors. The findings of this systematic review will be used to guide the development of a pilot doctor-led intervention (registered at the Australia and New Zealand Clinical Trials Registry (ACTRN12618001615279p)) to address FCR in breast cancer survivors during follow-up clinics.

Author's contributions JB conceived the original concept for the systematic review. JL performed the systematic review. All authors reviewed short-listed articles and discussed the findings from the systematic review. JL and PB independently assessed article quality. JL took the lead with manuscript preparation. All authors critically reviewed the manuscript.

Compliance with ethical standards

Conflict of interest All authors have no disclosures relevant to the project. JB serves on advisory boards for Roche, Novartis, Pfizer and Lilly. JL received grants from AVANT Mutual and Astra Zeneca for work unrelated to the current submission.

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