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Relationships between fear of cancer recurrence, anxiety and worry, and health behaviors and health service use: a systematic review

Sarah C. Reed^{a,*}, Julie Berrett-Abebe^b, Robin L. Whitney^c, Sayantani Sarkar^d, Janice F. Bell^d

Abstract

Background: This systematic review was conducted to improve our understanding of the relationship between fear of cancer recurrence (FCR), anxiety and worry, and engagement in health behaviors and/or health service use. **Methods:** A systematic review following PRISMA methodology was performed to identify any publications that examined FCR, anxiety and worry, and health behaviors and/or health service use in the following databases: PubMed, CINAHL, and PsychINFO from January 1990 to April 2021. Quality was assessed using QualSyst, a standard quality assessment for evaluating primary research articles. **Results:** Seventy articles met the inclusion criteria, but the outcomes were too heterogeneous to combine in statistical meta-analysis. The measurement of FCR also varied widely and was inconsistent across studies. Among FCR specific measures, 36% used some version of the Fear of Cancer Recurrence Inventory. Prevention and detection of new and recurrent cancers accounted for 60% of all included studies, with the most frequently examined health behaviors being smoking status (17%) and physical activity (16%). Most associations indicated a significant relationship between FCR and current smoking, with those who are currently smoking experiencing higher levels of FCR. Relatively few studies explored the relationship between FCR and surveillance. Associations categorized under Interventions for Late Effects included a range of health services use with largely mixed results. Overall, studies had moderate to high quality. **Conclusions:** Given the measurement heterogeneity of FCR, future research would benefit from consistent operationalization and measurement. Some evidence suggests that FCR is associated with poor health behaviors. More studies are needed examining the relationship between FCR and surveillance. Research and clinical interventions may choose to focus on early post-treatment survivorship, given greater opportunities for support and intervention around FCR and other psychosocial concerns.

Keywords: Cancer survivorship, Fear of cancer recurrence, Health behaviors, Health service use

Introduction

Cancer survivors, a large and growing population, often experience a range of poor health outcomes, including late effects of cancer treatment, poor quality of life, and cancer recurrence.^[1,2] In 2018, there were almost 44 million cancer survivors worldwide who had been diagnosed in the past 5 years, with many more who were long term survivors.^[3] To support improved health and wellbeing, leading oncology organizations, including the American Cancer Society (ACS) and American Society of Clinical Oncology have developed survivorship care recommendations and guidelines, grounded in the Institute of

Medicine (IOM) report, From Cancer Patient to Cancer Survivor: Lost in Transition.^[4-6] The IOM report identified four components of survivorship care: prevention and detection of new and recurrent cancers; surveillance for recurrence or new primaries; interventions for late effects; coordination between specialists and primary care providers.^[6] Although different organizations approach the specific tasks of survivorship care and care planning in unique ways and some tailor recommendations to specific types of cancer, the recommendations are similar in prioritizing physical activity, healthy eating, reducing alcohol consumption, smoking cessation and other healthy behaviors as well as appropriate medical surveillance.^[4,5] In addition to routine screening for other primary cancers and surveillance for secondary cancers, guidelines generally recommend that survivors' health is managed by primary care providers, who then coordinate as needed with specialty care practices.^[7] And despite few cancer survivors meeting health behavior guidelines,^[8] research suggests that health behaviors such as physical activity, weight control, and healthy diet positively impact cancer survivors' overall health and wellbeing.^[9-11] A recent study reported that adherence to guidelines for nutrition and physical activity extends life in colon cancer survivors, highlighting the importance of modifiable health behaviors in improving health outcomes for cancer survivors.^[12]

Given our increasing understanding about the importance of adherence to survivorship care recommendations, including surveillance, appropriate medical visits, and healthy lifestyle behaviors, it is vital that we support cancer survivors in meeting

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recommendations. Often overlooked mechanisms for poor adherence to recommendations is fear of cancer recurrence (FCR), anxiety, and worry which play an important role in the lives of cancer survivors and may influence their health behaviors.^[13] Additionally, FCR, anxiety, and worry may have a role in the growing literature indicating that cancer survivors use more health services than their counterparts without a history of cancer.^[14–19] Fear of cancer recurrence has been defined as “fear, worry, or concern relating to the possibility that cancer will come back or progress.”^[20] FCR is pervasive among cancer survivors and rarely addressed in current models of cancer care.^[21,22] Although there is growing interest in the study and our understanding of FCR, the concept has not been consistently operationalized, with no “criterion standard” measure to identify FCR and its clinical significance.^[20,21] Although research suggests that FCR is distinct, conceptualization of FCR often overlaps with anxiety, worry, intrusive thoughts, and uncertainty.^[23] Theoretical models of FCR often include aspects of anxiety, worry, and uncertainty as important components but not individually predictive of FCR,^[24–26] with, for example, uncertainty acting as a moderator.^[24] Although there is agreement on the definition of FCR, the clinical aspects of FCR continue to be refined encompassing emotional and cognitive constructs, with recent work reflecting 4 key features: high levels of preoccupation; high levels of worry; that are persistent; and hypervigilance to bodily symptoms.^[20,27] Little is known about the extent to which FCR, anxiety, and worry may promote or inhibit health service use, or act as a barrier or facilitator to healthy behaviors recommended for cancer survivors. Although we are most interested in FCR, we chose to include FCR, anxiety, and worry because of the overlap and lack of consistency in how researchers have defined the construct over the past several decades. This systematic review was conducted to improve our understanding of the relationships between FCR, anxiety, and worry, and health behaviors and health service use, as well as to identify priority areas in which more research is needed.

Materials and methods

A systematic review following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines^[28] was performed in the following electronic databases: PubMed, PsychINFO, and CINAHL. In PubMed, the Medical Subject Heading (MeSH) terms included: fear, anxiety, or uncertainty; neoplasm, cancer, neoplasm recurrence, survivor, or survivorship; health service; health behaviors. PsychINFO and CINAHL included the following keywords: fear, anxiety, or uncertainty; cancer, survivor or survivorship; health service; health behaviors. (Complete search strategy is provided in Appendix 1, <http://links.lww.com/OR9/A27>.) Last, bibliographies in the identified articles were consulted to identify and include additional articles.

Inclusion and exclusion criteria

Eligible studies needed to be published in a peer-reviewed journal between January 1, 1990 to April 1, 2021, written in English; include an adult population, ≥ 18 years; identify participants as cancer patients or survivors with FCR, anxiety, and worry; and quantify survivors' health behavior and/or health service use. We excluded articles exclusively focused on childhood cancer survivors of any age and cancer survivors under active surveillance. Commentaries, editorials, poster abstracts, case

reports, qualitative studies, review articles, and theses/dissertations were not considered.

Screening process

Title, abstract, and/or full text were examined for inclusion and exclusion criteria. Excluded references identified by 1 author were independently examined by a second to validate their exclusion. If there was a disagreement, full text of the article was reviewed, with discrepancies discussed and resolved in consensus.

Data abstraction

Data were extracted from these studies by 3 authors (JBA, SCR, and SS) and included the following study characteristics: journal, authors, title, year, country, study design, population, inclusion criteria, sample size, time since diagnosis, FCR, anxiety and/or worry measure, health behavior and/or health service use measure, methods, and study outcomes. In longitudinal studies, estimates at baseline were used whenever possible; however, at times, follow-up estimates were included if measures of FCR, anxiety, or worry, and health behavior and/or health service use measure were not reported at baseline. Two authors independently extracted data, with discrepancies resolved by the lead authors (JBA and SCR).

Analysis

Papers were organized by the essential components of cancer survivorship care including: prevention and detection of new cancers and recurrent cancer; surveillance for cancer spread, recurrence or second cancers; intervention for consequences of cancer and its treatment.^[6] We categorized the components into the following domains: prevention and detection of new and recurrent cancers, which included health behaviors such as smoking, physical activity and screening related to national recommendations (eg, pap smear for cervical cancer screening); surveillance for recurrence or new primaries, which included studies focused on individuals being surveilled for cancers for which they had a history of (eg, mammography for a history of breast cancer); interventions for late effects, which focused on studies that included measure(s) of health service use; and other, which captured studies that did not otherwise fit into one of the described categories.

Quality

Quality was assessed by 4 authors (JBA, JFB, SCR, and RW) using QualSyst, a standard quality assessment for evaluating primary research articles from a variety of fields.^[29] We randomly selected 10% of the included studies and had 2 reviewers complete quality ratings on each. The dual reviews were substantively similar, so we proceeded with 1 reviewer for the remaining studies. Each article was reviewed using the 14-item checklist, with response options reflecting how fully each criterion was met (“yes,” “partial,” “no” or not applicable). “Yes” responses received 2 points; “partial” responses received 1 point and “no” responses received 0 points. All not applicable responses were excluded from the total score.

Results

After removing duplicate studies, 4540 references were reviewed from the combined searches in PubMed, PsychINFO, and

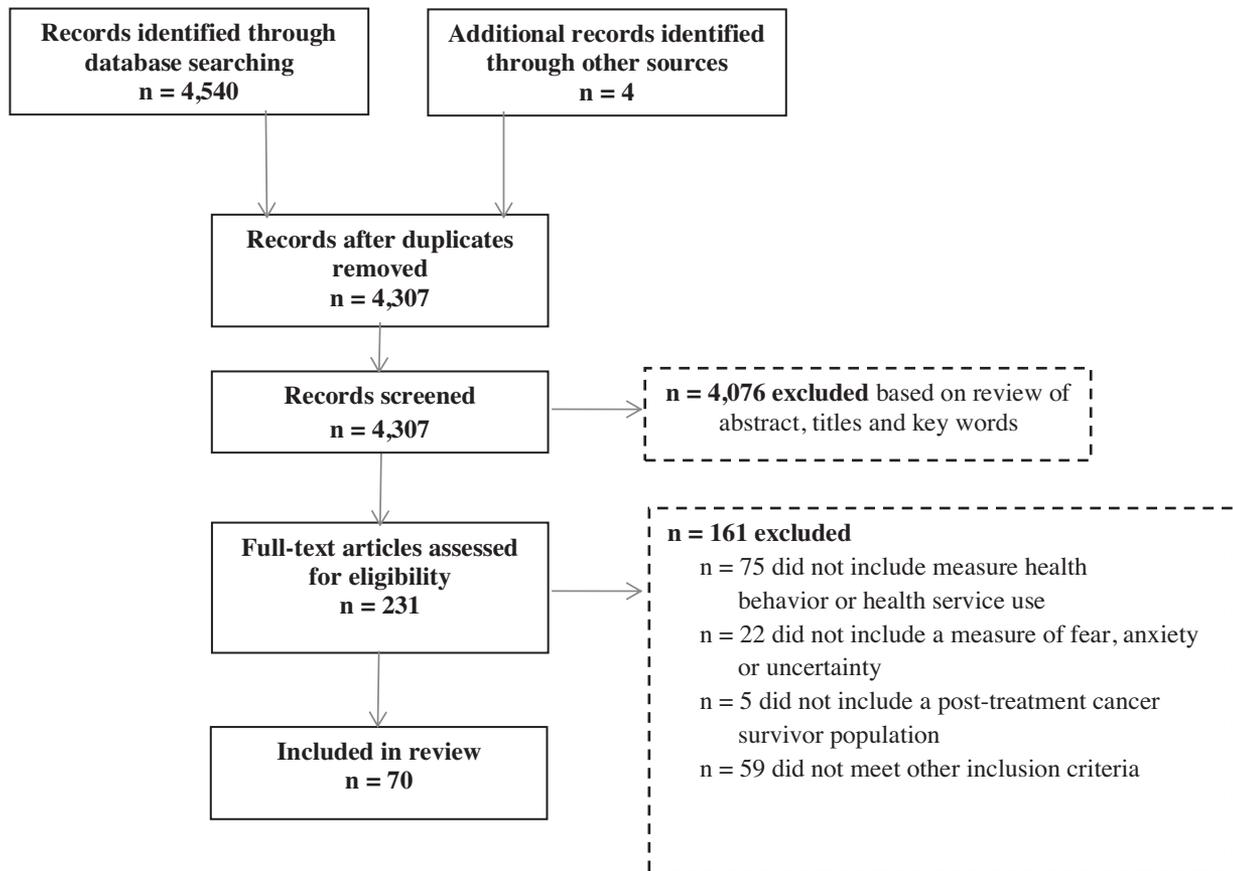


Figure 1. Study Selection.

CINAHL and articles identified outside of the search from bibliographies (Fig. 1). After a review of the title and abstract, 4076 articles were excluded. The full text of the remaining 231 articles was reviewed, and 161 were excluded. Seventy studies met the inclusion criteria.

Study characteristics

Study characteristics are described in Table 1.^[30–99] Dates of publication included 1990 to 1999 (4%); 2000 to 2009 (11%); 2010 to 2015 (34%); 2016–April 2021 (49%), with research being conducted internationally, most commonly the United States (47%), Canada (9%), Netherlands (10%), and Australia (9%). Most studies focused on mixed cancer diagnoses, which included ≥ 3 cancer types (39%) or breast cancer (26%). Fewer than half of the studies reported racial/ethnic characteristics of their participants (47%); of those, most participants were white, non-Hispanic. Although the majority of studies were cross-sectional in design (71%), sample sizes varied widely between studies, ranging from 49 to 10,969. The measurement of FCR, anxiety, and/or worry varied widely and was inconsistent across studies. Most studies used one construct (90%) and among all studies, anxiety was the most common (56%), followed by FCR (36%), worry (13%), and uncertainty (1%). Of the 39 studies that included anxiety, the Hospital Anxiety and Depression Scales^[100] (HADS) was the most commonly used standardized measure (51%). The most commonly used standardized measure for FCR was the Fear of Cancer Recurrence Inventory^[101] (short-form, long-form or

subscale) (40%). Also notable was the lack of consistency between how researchers conceptualized and operationalized FCR, anxiety, and/or worry. For example, Humphris et al^[59] conceptualized FCR and used the Worry of Cancer Scale and Alfano et al^[30] conceptualized FCR and used the modified Breast Cancer Anxiety and Screening Behavior Scale.

Fear of cancer recurrence and related constructs: relationships to survivorship care recommendations

Table 2 displays the associations between elements of cancer survivorship care recommendations, including health behaviors and health service use and FCR, anxiety, and/or worry. Associations are described as “+” (eg, presence of FCR and frequent primary care visits), “–” (eg, presence of FCR and less likely to meet guidelines for mammography) or “no relationship,” meaning there were no identified statistically significant associations reported. Additionally, the table is organized by survivorship care recommendation and within each recommendation each health behavior or health service use is ranked highest to lowest by the number of identified associations. For example, under Prevention and Detection of New and Recurrent Cancers, smoking (both present and former) includes 26 associations, followed by physical activity (both meeting guidelines and insufficiently active), with 24 associations. The term “association” is used rather than “study” because many studies in the review reported on >1 element of cancer survivorship recommendations.

Table 1**Study characteristics.**

#	Author, year	Country	Sample size	Diagnosis	Survivor definition	Study design	Construct (FCR, anxiety, uncertainty, worry): measure (FCRI, HADS, GAD-7)	Quality score
1	Alfano et al, 2009 ^[30]	USA	N=227	Breast	PD	C	FCR: modified Breast Cancer Anxiety and Screening Behavior Scale	15/22
2	Arrieta et al, 2012 ^[31]	Mexico	N=82	Non-small cell lung	PD	L	Anxiety: HADS, Mini International Neuropsychiatric Interview	21/22
3	Arts et al, 2018 ^[32]	Netherlands	N=1444	Lymphoma and chronic lymphocytic leukemia	PD	C	Anxiety: HADS	22/22
4	Beekers et al, 2015 ^[33]	Netherlands	N=3080	Mixed	PD	C	Anxiety: HADS	22/22
5	Benyamini et al, 2003 ^[34]	USA	N=49	Mixed	PT	C	Worry: cancer-specific worry (5 items), general health worry (3 items)	11/22
6	Blair et al, 2019 ^[35]	USA	N=283	Colorectal	PD	C	Worry: FACT-C; Anxiety: PROMIS-29	22/22
7	Boyes et al, 2011 ^[36]	Australia	N=1323	Mixed	PD	C	Anxiety: HADS, Mini Mental Adjustment to Cancer Scale	22/22
8	Boyes et al, 2013 ^[37]	Australia	N=1154	Mixed	PD	L	Anxiety: HADS	22/22
9	Brice et al, 2020 ^[38]	Australia	N=1475	Hematologic	PT	C	FCR: Fear of Recurrence Scale	22/22
10	Burstein et al, 1999 ^[39]	USA	N=480	Breast	PD	C	FCR: Fear of Recurrence Index	20/22
11	Cameron et al, 1998 ^[40]	USA	N=140	Breast	PT	L	Worry: (3 items)	13/28
12	Cannon et al, 2011 ^[41]	USA	N=551	Mixed	PT	L	Worry: (3 items)	22/22
13	Champagne et al, 2018 ^[42]	Canada	N=962	Mixed	PD	L	FCR: FCRI-SF	20/22
14	Charlier et al, 2012 ^[43]	Belgium	N=464	Breast	PT	C	Worry: (1 item)	15/22
15	Chipperfield et al, 2013 ^[44]	Australia	N=356	Prostate	PT	C	Anxiety: HADS	22/22
16	Choi et al, 2019 ^[45]	USA	N=52	Lung	PD	C	Anxiety: STAI; Worry: cancer-related worry questionnaire	14/22
17	Cillessen et al, 2020 ^[46]	Netherlands	N=125	Mixed	PD	RCT	FCR: FCRI	21/24
18	Cohen et al, 2018 ^[47]	Canada	N=84	Head and neck	PD	L	Anxiety: Structured Clinical Interview	21/22
19	Davies et al, 2018 ^[48]	UK	N=380	Melanoma	PT	C	Anxiety: HADS	21/22
20	DosSantos et al, 2019 ^[49]	France	N=129	Mixed	PD	L	Anxiety: STAI-Trait	22/22
21	Dunne et al, 2019 ^[50]	Ireland	N=395	Head and neck	PD	C	FCR: Fear of Relapse/Recurrence Scale	22/22
22	Fisher et al, 2016 ^[51]	UK	N=10,969	Colorectal	PT	C	FCR: (1 item)	18/22
23	Fujisawa et al, 2014 ^[52]	Japan	N=168	Mixed	PT	C	FCR: adapted from Quality of Life-Cancer Survivors Instrument	20/22
24	Gaskin et al, 2016 ^[53]	Australia	N=98	Prostate	PT	C	Anxiety: Memorial Anxiety Scale for Prostate Cancer	19/22
25	Guimond et al, 2017 ^[54]	Canada	N=110	Mixed	PD	L	Anxiety: HADS; FCR: FCRI subscale	21/22
26	Hall et al, 2019 ^[55]	USA	N=258	Mixed	PT	C	FCR: Assessment of Survivor Concerns	22/22
27	Harding, 2012 ^[56]	USA	N=1784	Mixed	PD	C	Anxiety: (single item)	15/22
28	Hawkins et al, 2010 ^[57]	USA	N=7903	Mixed	PT	C	FCR: Cancer Problems in Living Scale, Fear of Recurrence subscale	21/22
29	Henry et al, 2019 ^[58]	Canada	N=223	Head and neck	PD	L	Anxiety: Structured Clinical Interview	21/22
30	Humphris et al, 2004 ^[59]	UK	N=87	Head and neck	PT	L	FCR: Worry of Cancer Scale; Anxiety: HADS	16/22
31	Husson et al, 2017 ^[60]	Netherlands	N=2620	Colorectal	PD	C	Anxiety: HADS	21/22
32	Iyer et al, 2016 ^[61]	USA	N=204	Cervical	PT	L	Anxiety: PROMIS-SF	21/24
33	James et al, 2018 ^[62]	USA	N=56	Mixed	PD	L	Anxiety: HADS	16/22
34	Kasparian et al, 2012 ^[63]	Europe, Australia, USA	N=600	Melanoma	PD	C	Worry: modified Skin Cancer-Related Worry Scale (3 items)	22/22
35	Katz et al, 2009 ^[64]	USA	N=245	Breast	PT	C	Anxiety: modified Breast Cancer Anxiety and Screening Behaviors Scale	21/22
36	Kelly et al, 2020 ^[65]	USA	N=76	Breast	PD	L	Anxiety: HADS	21/22
37	Keyzer-Dekker et al, 2012 ^[66]	Netherlands	N=151	Breast	PD	C	Anxiety: STAI	22/22
38	Kowalkowski et al, 2014 ^[67]	USA	N=109	Bladder	PD	C	FCR: (5 items)	22/22

(continued)

Table 1
(continued).

#	Author, year	Country	Sample size	Diagnosis	Survivor definition	Study design	Construct (FCR, anxiety, worry): measure (FCRI, HADS, GAD-7)	Quality score
39	Lebel et al, 2013 ^[68]	Canada	N=231	Mixed	PD	C	FCR: FCRI	18/22
40	Leclair et al, 2019 ^[69]	USA	N=2337	Mixed	PD	L	FCR: Cancer Problems in Living Scale, Fear of Recurrence subscale; FCRI	22/22
41	Lee et al, 2021 ^[70]	USA	N=565	Mixed	PD	C	Anxiety: (1 item)	22/22
42	Li et al, 2020 ^[71]	Hong Kong	N=311	Mixed	PD	C	FCR: Fear of Progression Questionnaire Short Form	21/22
43	Lima et al, 2018 ^[72]	Brazil	N=220	Mixed	PD	C	Anxiety: HADS	20/22
44	Lindgren et al, 2020 ^[73]	Sweden	N=578	Mixed	PT	C	Anxiety: (1 item)	22/22
45	Matthews et al, 2007 ^[74]	USA	N=115	Breast	PT	C	Anxiety: Breast Cancer Anxiety Scale; STAI	18/22
46	Mosher et al, 2008 ^[75]	USA	N=678	Breast and prostate	PD	C	Worry: (12 items)	18/22
47	Mullens et al, 2004 ^[76]	USA	N=81	Colorectal	PT	C	Worry: cancer/medical related worry (6 items); Revised Impact of Event Scale subscale; Anxiety: Profile of Mood States, Tension–Anxiety subscale	19/22
48	Nicolajje et al, 2013 ^[77]	Netherlands	N=582	Endometrial	PT	C	Worry: Impact of Cancer, subscale	21/22
49	O'Malley et al, 2018 ^[78]	USA	N=325	Breast and prostate	PT	C	FCR: (1 item)	22/22
50	Otto et al, 2018 ^[79]	USA	N=300	Breast	PD	C	FCR: FCRI; Concerns About Recurrence Scale	21/22
51	Phillips et al, 2015 ^[80]	USA	N=1348	Breast	PD	C	Anxiety: HADS	20/22
52	Pradhan et al, 2015 ^[81]	USA	N=505	Breast	PT	C	Anxiety: STAI	19/22
53	Rakovitch et al, 2005 ^[82]	Canada	N=251	Breast	PD	C	Anxiety: HADS	20/22
54	Reed et al, 2019 ^[83]	USA	N=1,028	Mixed	PT	C	FCR: (1 item)	22/22
55	Riberiro et al, 2020 ^[84]	Brazil	N=128	Breast	PD	C	Anxiety: HADS	21/22
56	Sarkar et al, 2015 ^[85]	Germany	N=335	Mixed	PD	C	FCR: Fear of Progression Questionnaire; Anxiety: General Anxiety Disorder Scale	19/22
57	Shelby et al, 2012 ^[86]	USA	N=210	Breast	PT	L	Anxiety: Stanford Acute Stress Reaction Questionnaire	20/22
58	Simmons et al, 2013 ^[87]	USA	N=154	Thoracic, head and neck	PD	L	FCR: Fear of Relapse/Recurrence scale	22/22
59	Smith et al, 2019 ^[88]	USA	N=2,107	Mixed	PT	C	FCR: FCRI	22/22
60	Sohl et al, 2014 ^[89]	USA	N=1666	Mixed	PD	C	Anxiety: (1 item)	21/22
61	Thewes et al, 2012 ^[90]	Australia	N=218	Breast	PD	C	FCR: FCRI	20/22
62	Thomas et al, 1997 ^[91]	UK	N=65	Mixed	PD	L	Anxiety: HADS	11/22
63	Trask et al, 2008 ^[92]	US	N=345	Breast	PD	C	Anxiety: Beck Anxiety Inventory; Worry: Impact of Events Scale	20/22
64	Van Liew et al, 2014 ^[93]	USA	N=138	Head and neck	PD	C	FCR: FCRI subscale	20/22
65	van Putten et al, 2016 ^[94]	Netherlands	N=2451	Colorectal	PD	L	Anxiety: HADS	20/22
66	Wang et al, 2018 ^[95]	Taiwan	N=10,537	Esophageal	PD	C	Anxiety: diagnosed by psychiatrist	22/22
67	Weis et al, 2018 ^[96]	Germany	N=1,398	Mixed	PD	C	Anxiety: Generalized Anxiety Disorder-7; HADS	22/22
68	Welch et al, 2019 ^[97]	USA	N=753	Breast	PT	C	Anxiety: HADS	22/22
69	Westmass et al, 2019 ^[98]	USA	N=2,241	Mixed	PT	L	FCR: Cancer Problems in Living Scale, Fear of Recurrence subscale; FCRI	22/22
70	Zhang et al, 2015 ^[99]	China	N=97	Breast	PD	C	Uncertainty: Mishel Uncertainty in Illness Scale for Adults	16/22

C = cross-sectional, HADS = Hospital Anxiety and Depression Scales, L = longitudinal, PD = post-diagnosis, PROMIS = Patient-Reported Outcomes Measurement Information System, PT = post-treatment, SF = short form, STAI = State Trait Anxiety Index.

Generally, the greatest number of studies looked at the relationships between FCR, anxiety, and/or worry, and prevention and detection of new and recurrent cancers (90 associations, 60%), while the fewest number of studies

looked at surveillance (8 associations, 5%). Thirty percent of associations were contained within interventions for late effects (45/150) and 5% of associations were in the other category.

Table 2

Relationships between fear of cancer recurrence, anxiety and worry, and elements of survivorship care recommendations.

	Fear of cancer recurrence			Anxiety			Worry			Row total
	+	-	No relationship	+	-	No relationship	+	-	No relationship	
Prevention and detection of new and recurrent cancers										
Smoking (present)	22, 38, 54, 58, 64, 69	25	9, 21, 23	7*, 8*, 27, 30	25	16, 31, 32, 41	16			20
Smoking (former; ex-smoker; quitter)	22	30, 69		8*		2, 7*				6
Physical activity (meeting guidelines, increased, participating)			1, 9, 54		51, 65	15, 24, 27, 36, 44, 52, 55, 68			14, 46	15
Physical activity (insufficiently active, sedentary, decreased activity, not meeting guidelines)	22, 26, 40		1	7*, 15, 31, 32		24				9
Behavior change (positive, improve e.g., vitamins, exercise, avoiding alcohol)	28		21	47		47	47		47	6
Behavior change (negative)			28							1
Alcohol use (level considered "risky", "intensive" drinker)	26		9, 21		31	27, 32				6
Self-management (self-care, stress management, patient activation, self-monitoring)	21, 25				36	33	70†	5		6
Nutrition (healthy eating or diet, meeting recommendations)			1, 9, 26			36			46	5
Nutrition (unhealthy eating or diet, not meeting recommendations)	40		1							2
Healthy lifestyle factors						36				1
Unhealthy lifestyle factors composite (physical activity, fruit and veg intake, cigarette smoking)				6					6	2
Primary Care (refused recommendation to return to primary care)				62						1
Screening (self and clinical skin exam)			9						34	2
Screening (pelvic exam, pap smear, guidelines)	9				35					2
Screening (bowel)			9							1
Screening (mammography)			9							1
Screening (prostate check)			9							1
Sunscreen Use	26		9							2
Tamoxifen							12			1
Surveillance for recurrence or new primaries										
Surveillance, breast (guidelines, mammography)		61			57	35			11	4
Surveillance, breast (breast self-exam)	61					63			11, 63	4
Interventions for late effects										
Psychosocial and/or psychiatric care (frequent visits and consultations)	9, 13, 61		9, 42, 50, 56	3*, 18, 37, 67		56				12
CAM (eg, acupuncture, massage, foot reflexology, mindfulness, mind-body therapies)	10, 61	17	9, 13, 56	45, 60		53, 56				10
Specialist visits (includes frequent ≥4)	50, 59		39, 56	3*		37, 56	48			8
Primary care (unscheduled visits, ≥3 times)	39, 50, 61			3*		37				5

(continued)

Table 2
(continued).

	Fear of cancer recurrence			Anxiety			Worry			Row total
	+	-	No relationship	+	-	No relationship	+	-	No relationship	
High resource use (frequent phone calls, visits and consultations)	13, 50			19			12			4
Spiritual/religious support services			56			56				2
Antidepressant, anxiolytics/hypnotics use	9, 13		50							3
ER visits	39									1
Other										
Treatment adherence (poor)				43		2, 20				3
Treatment adherence				66						1
Information seeking (disease-related internet use)			42			4				2
Opioid use				29						1
Column total	33	5	32	24	7	33	5	1	10	

* Comorbid anxiety and depression.

† Uncertainty.

Prevention and detection of new and recurrent cancers

Most studies examined relationships between FCR and smoking (17%) or physical activity (16%), with far fewer studies reviewing associations with other health behaviors and service use. Although the table displays mixed results in this category, there are patterns within each specific health behavior. Among studies examining smoking, 10 studies used a measure of anxiety; 11 studies used a measure of FCR, and 1 study used a measure of worry. Additionally, slightly more than 50% of the studies were conducted in the United States. Most associations indicate a relationship between FCR and current smoking, with those who are presently smoking experiencing higher levels of FCR. The associations between anxiety and present smoking are mixed.

More studies explored physical activity and anxiety (62%) versus physical activity and FCR (29%), and physical activity and worry (9%). Between physical activity and anxiety, no significant association was observed; however, there was an association between physical *inactivity* and anxiety (4/5 associations). Overall, of the 13 studies examining physical activity and anxiety 8 used the HADS (62%). Very few studies looked at the relationships between FCR, anxiety ,and/or worry, and alcohol use, nutrition, or sunscreen use. The 6 studies that examined alcohol use varied in results (4 associations with no relationship, 1 significant relationship between FCR and risky alcohol use, and 1 significant relationship between anxiety and less alcohol use).

Surveillance for recurrence or new primary cancers

Although surveillance for recurrence or new primary cancers is an important survivorship health recommendation, relatively few studies (8 associations from 5 studies) explored the relationship between FCR, anxiety and/or worry and surveillance. One study identified an association between FCR and regular breast self-exams, as well as an association between FCR and not following mammography recommendations. Most associations of anxiety or worry, and surveillance (5/6) found no significant relationship.

Interventions for late effects

Associations categorized under Interventions for Late Effects included a range of health service use with largely mixed results.

Selected constructs for the 20 included studies included: 10 FCR; 8 anxiety; and 2 worry. Among the 10 FCR studies examining relationships with late effects, 6 used a version of the FCRI. Additionally, 30% were conducted in the United States. Most associations between accessing psychosocial care, and higher FCR or anxiety were significant (7/12). Likewise with primary care visits (4/5 reported an association). The few associations (5 total) between high resource use or ER visits, and high FCR, anxiety, or worry were significant. No associations were found between spiritual/religious support service use, and FCR or anxiety in the single study that examined these relationships. Eight studies examined Complementary and Alternative Medicine (CAM), with varied conceptualized and operationalized terms. Specialist visits were also varied with mixed results (4/8 associations indicated significant relationships with FCR, anxiety, or worry).

Other

Several health behaviors were not included into the above survivorship recommendation categories: treatment adherence, information seeking, and opioid use. We identified 4 associations between treatment adherence and anxiety. Of the 3 associations between poor treatment adherence and anxiety, 1 included a significant association, whereas the other 2 indicated no significant relationship. The single association between increased opioid use and anxiety indicated a significant relationship.

Quality

Quality scores ranged from 11/22 to 22/22, with 2 studies including additional criterion due to their study design (13/28, 21/24). Overall, studies had moderate to high quality with a mean score of 20/22.

Discussion

A systematic review of the associations between FCR, anxiety and/or worry and cancer survivorship recommendations, including health behaviors and health service use, captured a

robust number of studies. Close to half of studies were conducted in the past 4 years, likely indicating increased interest in both FCR and health behaviors in cancer survivorship. Surveillance and intervention for late effects have received far less attention than prevention and detection of new and recurrent cancers. This represents an opportunity for increased research focus. We suggest that studies of health behaviors and health service use should include FCR as well as health behaviors or service use that have received less attention (eg, alcohol use, sunscreen use, surveillance). Further, studies that include health behaviors of alcohol use and sunscreen use should be prioritized because alcohol use is a risk factor for multiple cancers^[102] and lack of sunscreen use is a risk factor for skin cancer, a common form of cancer in the United States and around the world.^[103]

Another notable finding was the great variability in how FCR, anxiety, and worry were operationalized and measured in the included studies. There was no single “criterion standard” measurement for FCR, anxiety, or worry; researchers used various measures, some of which were standardized scales and some of which were 1 item measures. The lack of consistency makes it more difficult to compare findings between studies. There was also variability in how FCR was conceptualized. For example, in Humphris et al,^[59] FCR was measured by Worry of Cancer Scale whereas in Alfano et al,^[30] FCR was measured by modified Breast Cancer Anxiety and Screening Behavior Scale. One plausible explanation for these 2 examples, especially given that the almost 50% of studies that included FCR were published in the last 4 years, were the limited tools available to measure FCR at the time the respective studies took place.^[104,105] In many other studies, FCR was measured using FCR-specific scales. Despite the clinical cut-off for FCR continuing to be debated and with the understanding that all measurement tools have some shortcomings,^[105,106] we recommend that the Fear of Cancer Recurrence Inventory (FCRI) and FCRI-Short Form (FCRI-SF) be used as high-quality measurement tools for FCR. FCRI has excellent internal consistency ($\alpha = .96$) and good test–retest reliability ($r = 0.88$).^[20] The FCRI-SF, a subscale of FCRI, is used to screen for clinical levels of FCR. A cutoff score of 13 was associated with good sensitivity (88%) and specificity (75%).^[107]

Consistent with other work,^[108] the findings from our systematic review suggest that that while closely related to anxiety and worry, FCR may be a unique construct. For example, the mixed findings among studies examining the relationship with smoking demonstrated more consistency among studies focused on FCR versus anxiety. Although there are methodological issues due to lack of consistency in measurement of FCR, anxiety, and/or worry, when looking at the category of Prevention and Detection of New and Recurrent Cancer overall, associations between FCR and health behaviors were more likely to have significant relationships, whereas associations between anxiety and worry were more likely to show no significant relationship. Although more research is needed to fully understand the pathways between health behaviors and FCR, it seems likely that in many circumstances, fear that cancer will return is higher when people are engaged in risky behaviors (eg, smoking), while in some circumstances people who are more fearful that cancer will return are also more vigilant about engaging with survivorship care recommendations (eg, self-management). Similar patterns may hold for health service use, with those who experience FCR potentially utilizing more health care services. Mediators may help to further explain the relationship between FCR and health behaviors and/or health service use. Recent models have explored potential pathways

leading to FCR.^[24] For example, physical symptoms (eg, pain) and/or cognitions or beliefs (eg, importance of body vigilance) may act as “triggers” leading survivors on the one hand, to seek out reassurance from a care provider or on the other, cognitive avoidance.^[24] Although small in number, this appeared to hold true for associations between ER visits and high resource use and FCR. More unclear is the relationship between surveillance and FCR. One potential pathway is that those with FCR may avoid surveillance because of their fear. This review had only a small number of studies looking at this association and results were mixed. Overall, we recommend more research to better understand the contextual features of different behavioral responses in the context of FCR.

Survivorship recommendations and guidelines vary by diagnosis, treatment regimen, and the organization making the recommendation.^[4–6] To better understand whether and how FCR activates, supports, or limits adherence to these recommendations more consistency across these recommendations would greatly benefit both clinical care and research and are necessary to move our understanding of the relationships between FCR and health behaviors forward. Given that FCR is a prevalent and often unaddressed psychosocial concern in cancer survivorship and there is some evidence to suggest that FCR is related to risky health behaviors or preventable health care service use, it is important to consider ways to identify and address FCR in survivorship populations. Effective, evidence-based mind-body and psychological interventions are available to address FCR and should be considered for implementation.^[109,110] Furthermore, behavioral health providers (such as social workers, psychologists, and mental health counselors) have the skills and expertise to address FCR but have not always been part of routine survivorship care. We believe this should be a priority for policy and practice. In addition to including behavioral providers on survivorship care teams, we recommend that survivorship care clinics be made more widely available to all cancer survivors as a strategy to improve medical and psychosocial care for this vulnerable population.

Study limitations

As the first comprehensive review of the associations between health behaviors, health service use, and FCR, anxiety, and/or worry this article has several strengths including a large number of studies and a reproducible search strategy. At the same time, several limitations must be considered. First, manuscripts included in the review were from a range of countries and world regions, but researchers often did not include data on race or ethnicity, limiting our ability to draw conclusions about social determinants of health and equity. Second, although included studies had fairly high-quality scores, the majority were of cross-sectional design; therefore, it was not possible to explore causal relationships between variables. Third, there were several measurement inconsistencies across studies: researchers named constructs differently, but used the same measurement tools (eg, anxiety and distress in different studies were both measured by HADS); the same construct (eg, FCR) was measured by a wide variety of tools, including some which were not validated measures, limiting our ability to make comparisons across studies; and the definition of CAM was particularly heterogeneous across studies, with some researchers including psychological services, while others included spiritual services. Finally, in our review we assume that health service use beyond cancer survivorship recommendations is not desirable, but this may not

be the case in some circumstances. For example, some cancer survivors might be vulnerable to secondary infections or late side-effects from treatment, making more frequent visits to PCPs necessary.

Conclusions

Opportunities exist to extend future research to better understand the relationships between FCR, health behaviors, and health service use. We recommend that FCR be included in cancer research examining health behaviors and health service use, particularly in longitudinal study designs and with racially and ethnically diverse populations. Given the measurement heterogeneity of FCR and related constructs, future research would also benefit from consistent operationalization and measurement. As evidence suggests that FCR is related to poor health behaviors, research and clinical interventions should focus on early post-treatment survivorship, given greater opportunities for support and intervention around FCR and other psychosocial concerns. Additionally, there may be opportunities to focus on health behaviors and/or health service use that are most responsive to intervention (eg, guidance around health service use through cancer survivorship plans).

Conflicts of interest

The authors report no conflicts of interest.

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