ORIGINAL RESEARCH

Pan-cancer analysis of fear of cancer recurrence among cancer survivors

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Background: Fear of cancer recurrence (FCR) is a phenomenon estimated to affect a large portion of cancer survivors. This study sought to determine whether patients from a National Cancer Institute-designated institution had their clinical needs met relating to FCR.
Patients and methods: Patients referred to the survivorship clinic completed The Clinical Needs Assessment Tool for Cancer Survivors (CNAT-CS). Correlations between responses were calculated and univariable and multivariable logistic regression was used to identify predictors of met or unmet needs related to FCR.
Results: Of 647 patients, 241 (37.2%) reported they did not have clinical needs related to FCR and 386 (59.7%) reported they had clinical needs related to FCR but that the needs had been met. Only 20 (3.09%) reported that clinical needs relating to FCR were unmet. According to univariate logistic regression, sex had no impact on FCR ($P = 0.8427$), nor did years since diagnosis ($P = 0.1014$). Results of multivariable regression indicate that the odds ratio of reported FCR as an unmet need (versus not a need) is 0.939; the odds decreased by 6% ($P = 0.0023$) for every year increase in age. For each unit increase in distress score, the odds of reporting FCR as an unmet need increased by 32% ($P = 0.0007$).
Conclusions: This study is unique in not only examining the presence of FCR but also whether patients reported that their needs were met for FCR. The study found that most patients had clinical needs for FCR, but the needs were met at the time of the survey. Patients who report higher distress scores are more likely to report FCR as an unmet need. Therefore, cancer survivors reporting high distress scores in clinic visits should be evaluated for FCR.
Key words: survivorship, fear of cancer recurrence, cancer anxiety

INTRODUCTION

Fear of cancer recurrence (FCR) in cancer survivors is an understudied phenomenon estimated to occur in one-third to more than one-half of all cancer survivors.[1] Traditionally, FCR has been defined as 'the fear, worry, or concern relating to the possibility that cancer will come back or progress'.[2] FCR continues to be a need that remains unmet for many cancer survivors.[3,4] FCR is often highly correlated with increased anxiety and depression as well as decreases in overall quality of life.[1,5,6] The overall prevalence for FCR is unknown and groups have estimated wide ranges from 39%

to 97%.[7] Meta-analyses have found that FCR was found most in women and younger patients, but that FCR occurs in all continents and at all time points since diagnosis.[7]

With the improvement in many cancer therapies and subsequently improved patient survival, research into FCR has also grown. The modern definition of FCR has evolved and additions include hypervigilance and sensitivity to bodily symptoms that some cancer survivors can develop.[8] Risk factors identified to contribute to FCR include age <50 years, female sex, treatment type and length, and lower socioeconomic status.[9,10] Identifying patients at risk for FCR is important to elicit intervention development, as the number of cancer survivors will continue to increase due to advancements in screening, early detection, and novel treatment modalities (Figure 1). The survivorship clinic at the National Cancer Institute (NCI)-designated center where the study took place offered a unique opportunity to examine cancer survivors for their ongoing needs. The study's primary aim was to shed light on the prevalence of FCR and its components as patients transition from post-treatment care from their primary oncology team to a general survivorship clinic. The secondary aim of the study was to identify

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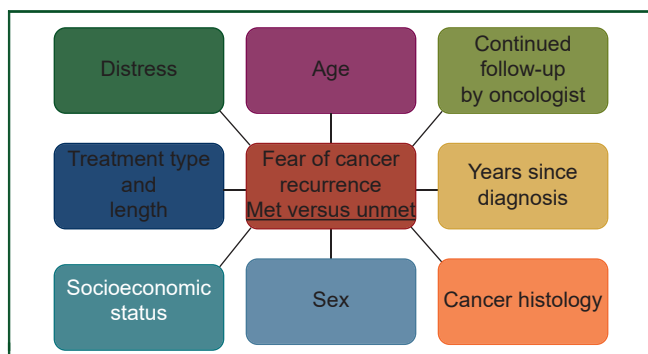E-mail: smitha.pabbathi@moffitt.org (S. Pabbathi).

Figure 1. Factors influencing fear of cancer recurrence being a met versus unmet need. Risk factors identified to contribute to fear of cancer recurrence include age <50 years, female sex, treatment type and length, and lower socioeconomic status.[9,10] Distress score, cancer histology, continued follow-up with oncologist, and years since diagnosis were derived from our study.

Table 1. Demographic characteristics of study population

All patients (N = 657)	
Race, n (%)	
Asian	7 (1.07)
Black	64 (9.74)
White	555 (84.5)
Other/missing	31 (4.72)
Sex, n (%)	
Female	442 (67.3)
Male	215 (32.7)
Diagnosis, n (%)	
Breast cancer	390 (60.0)
Colorectal cancer	12 (1.85)
Esophageal cancer	30 (4.62)
Ewing sarcoma	8 (1.23)
Lung cancer	7 (1.08)
Lymphoma	32 (4.92)
Prostate cancer	134 (20.6)
Renal cell carcinoma	21 (3.23)
Uterine/ovarian cancer	5 (0.77)
Other	11 (1.69)
Timeline	
Age at diagnosis (years)	55 (range, 4-86)
Years since diagnosis	10 (range, 1-34)
Distress score category, n (%)	
Distress score 0	214 (34.9)
Distress score 1-4	255 (41.6)
Distress score 5-7	106 (17.3)
Distress score 8-10	38 (6.20)

whether needs associated with FCR were met in the survivorship clinic and whether demographic factors or psychological distress related to FCR unmet needs.

To meet the study objectives, we examined patient responses to The Clinical Needs Assessment Tool for Cancer Survivors (CNAT-CS), a questionnaire completed by new patients when they are referred to the survivorship clinic. The CNAT-CS includes an assessment of FCR within the domains of physical, psychological, and emotional states. This study is unique in that it is a large-scale investigation of whether clinical needs are met relating to FCR in an NCI-designated institution.

MATERIALS AND METHODS

Sample

Patients were 657 cancer survivors between the ages of 25 and 92 years (mean age, 67 years) who completed the CNAT-CS between 2010 and 2016, and who were referred to the survivorship clinic at a comprehensive NCI-designated cancer center (Table 1).

Measures

The CNAT-CS screening tool included 37 items, each having three possible responses ('not a concern,' 'is a concern, I am handling okay,' and 'I need help'). A numerical value of 0 was assigned for 'not a concern' (not a need); 1 for 'is a concern, I am handling okay,' (met need); and 2 for 'I need help' (unmet need). The CNAT-CS was available in both English and Spanish.[11] This was conducted in the form of a survey questionnaire provided to each patient when they transitioned to the survivorship clinic.

Procedures

We received approval for this retrospective chart review by the Moffitt Cancer Center Scientific Review Committee Institutional Review Board (IRB), IRB number MCC18873. We conducted a retrospective chart review of 657 patients who completed the CNAT-CS between 2010 and 2016. The chart review was conducted in the general survivorship clinic using electronic health records. The data were abstracted from the medical records and analyzed using R (v4.1.1).

As part of a patient's initial visit, a needs assessment tool was administered to cancer survivors of solid tumors such as breast, genitourinary, and gastrointestinal malignancies, when they transitioned into the survivorship clinic. This clinic provides focused survivorship care to patients who have completed cancer treatments with curative intent and wish to remain at the cancer center. The focus of this clinic is to ensure that cancer survivors are receiving guideline-directed surveillance and screening tests focused on their diagnosis and treatment and second cancer risk assessment. The data were then analyzed for correlations between responses. Univariate logistic regression was used to predict an unmet need. Multivariable logistic regression was only run if the question had >30 persons reporting it as an unmet need; covariates included age, sex, distress score, and years since diagnosis. Odds ratios (ORs) and P values were calculated and presented.

RESULTS

A total of 657 patients were included within the study where 442 (67.3%) were female and 215 (32.7%) were male. The majority of patients (84.5%) were white (n = 555), followed by 9.74% black (n = 64); the remaining patients identified as 'other' or Asian. The patients median age was 67 years, median age of diagnosis 55 years, and median years since diagnosis 10 years. Eleven cancer types were represented in this sample, with the most common being breast (59.4%) and prostate (20.4%). 'Fear of cancer coming back' was

reported most frequently (59.7%) but was reported as 'I am handling OK.' Some 241 (37.2%) reported FCR was not a need and 20 (3.09%) reported FCR as an unmet need. A total of 613 patients had recorded distress scores of 0 ($n = 214$), 1-4 ($n = 255$), 5-7 ($n = 106$), or 8-10 ($n = 38$).

According to univariate logistic regression, sex had no impact on FCR ($P = 0.8427$) nor did years since diagnosis ($P = 0.1014$). The analysis of multivariable regression included only age and distress score (no sex or years since diagnosis) because of the small number of unmet needs $n = 20$. The OR of reporting FCR as an unmet need (versus not a need) was 0.939; the odds decreased by 6% [OR 0.939; 95% confidence interval (CI), 0.90-0.98; $P = 0.0023$] for every year increase in age. For each unit increase in distress score, the odds of reporting FCR as an unmet need increased by 32% (OR 1.323; 95% CI, 1.13-1.56; $P = 0.0007$).

DISCUSSION

'Fear of cancer coming back,' i.e. FCR, was the highest need reported from the 647 patients, but the majority responded with 'handling OK.' Only 3.1% identified this need as an unmet need. Previous studies on breast cancer survivors have reported that as many as 22% (2 years post-treatment) and 18% (2-5 years post-treatment) of survivors identify as having FCR.[12] The studies, however, did not assess whether FCR was a met versus unmet need. Our study included patients with a wide variety of solid tumor diagnoses not exclusive to breast cancer, which can influence the results, making our findings more generalizable to a broader population of cancer survivors, whereas other studies have identified FCR as a significant issue in cancer survivorship.[1]

Our study used the CNAT-CS, which contains 37 questions that address psychological, physical, and emotional states. Other studies used similar clinical tools such as a Fear of Progression Questionnaire, Generalized Anxiety Disorder Questionnaire, and Patient Health Questionnaire. Additionally, some used the Memorial Symptom Assessment Scale, Supportive Care Needs Survey, and Medical Outcomes Study. Thus, diverse assessment tools may account for outcome differences in FCR.[1,12]

The current study was based on patients in a survivorship clinic, which continues to support survivors who have completed cancer treatment for curative intent. The survivors receive a comprehensive assessment, and a personalized survivorship plan is created with the patient focused on prevention, screening, and early detection of second cancers, evaluation of long-term and late effects of treatment, and assists in coordination of care with providers outside the cancer center. The survivorship clinic assumes their surveillance care for their cancer diagnosis providing patients with the reassurance of being connected to the cancer center, so in the event of a recurrence they have continuity in care.[13]

Our analyses show that as patients age, the likelihood of reporting FCR as an unmet need diminishes. This is consistent with other studies which have found a correlation between age and FCR.[9,12] Our study further supports this by finding that for every year of increase in age, the OR of reporting FCR as an unmet need decreases by 6%. This age differential may be due to younger survivors having greater worries for the future than older survivors.[14] In addition, the present study also found no correlation between years since cancer diagnosis and FCR being an unmet need ($P = 0.1014$), whereas other studies have found relationships of those <2 years after treatment had a significant amount of unmet needs compared with those >2 years after treatment.[12] These differences in findings may be due to variations in patient survivorship clinics.

Although the current study that included patients with a mixture of cancer types did not find a relationship between sex and FCR needs being met, such relationships have been mixed through different studies. One study found that when controlling for cancer type, there was no difference in sex and FCR rates.[4] Another study, however, with a greater percentage of women than our study, found sex to correlate with FCR.[12]

There have been several studies that show a relationship between FCR and higher distress scores.[1,10,12] Our study extends these findings, and highlights that higher distress scores corresponded with greater FCR as an unmet need versus a met need. Patients who had higher distress scores frequently have more symptoms of anxiety and depression which corresponds with FCR.[10] Psychological distress can in turn lead to noncompliance, which may increase FCR as patients may delay surveillance screening and other resources available to them. Identifying those at highest risk for distress, however, is likely an important marker to identifying FCR as an unmet need. Providing interventions to decrease distress may lead to FCR becoming a met versus unmet need.

Limitations of this study include that there are a small number of participants ($n = 20$) who reported FCR as an unmet need. The overall small number of patients reporting FCR as an unmet need limits the number of predictors able to be used in the multivariable model. An additional limitation is that FCR was measured in a trichotomous way as 'met,' 'unmet,' or 'not a need'. Also, there was no stratification or scale, which made it not possible to determine the severity of the FCR. A further limitation is that there was only one question asking whether FCR was met or unmet among 36 other survey questions.

This study examined potential associations for FCR as an unmet need in relation to distress scores and age. Again, also interesting is that we did not find sex differences in FCR needs being met, despite previous reported impacts of sex on FCR.[15] The role of sex in FCR has been mixed through different studies. A study found that when controlling for cancer type, there was no difference in FCR rates between sexes.[4] Although our study did not control for sex, the amount of females was 67%, whereas in studies where sex was found to correlate with FCR the percentage of females was greater.[10] One study examined FCR in couples where one had cancer; this study found that FCR was higher in women as patients than as caregivers. Conversely for males, those who had wives with breast cancer had higher FCR than those

males who had prostate or lung cancer themselves.[16] Our study only examined patients themselves and not their spouses or caregivers. This could further extrapolate the difference in sex between couples and rates of FCR.

Providers may need to be aware that this may be more of an issue for younger survivors and thus develop clinics to address this need. Also, it might be important to conduct a study asking those patients who are managing their FCR—how do they do it, what are they doing that helps them handle it, and use that information to develop clinics that highlight things that work/are working, and what other studies are doing. The data obtained here provide an important opportunity to focus on met versus unmet needs. Future studies should explore specifically how patients came to identify these needs as met, so care providers can better support survivors and their needs.

DISCLOSURE

The authors have declared no conflicts of interest.

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