

# Prevalence and correlates of fear of recurrence among oral and oropharyngeal cancer survivors

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## Abstract

**Purpose** Fear of recurrence (FoR) is a prevalent and difficult experience among cancer patients. Most research has focused on FoR among breast cancer patients, with less attention paid to characterizing levels and correlates of FoR among oral and oropharyngeal cancer survivors. The purpose was to characterize FoR with a measure assessing both global fears and the nature of specific worries as well as evaluate the role of sociodemographic and clinical factors, survivorship care transition practices, lifestyle factors, and depressive symptoms in FoR.

**Methods** Three hundred eighty-nine oral and oropharyngeal survivors recruited from two cancer registries completed a survey assessing demographics, cancer treatment, symptoms, alcohol and tobacco use, survivorship care practices, depression, and FoR.

**Results** Forty percent reported elevated global FoR, with similar percentages for death (46%) and health worries (40.3%). Younger, female survivors and survivors experiencing more physical and depressive symptoms reported more global fears and specific fears about the impact of recurrence on roles, health, and identity, and fears about death. Depression accounted for a large percent of the variance. Lower income was associated with more role and identity/sexuality worries, and financial hardship was associated with more role worries.

**Conclusions** FoR is a relatively common experience for oral and oropharyngeal cancer survivors. Many of its correlates are modifiable factors that could be addressed with multifocal, tailored survivorship care interventions.

**Implications for Cancer Survivors** Assessing and addressing depressive symptoms, financial concerns, expected physical symptoms in the first several years of survivorship may impact FoR among oral and oropharyngeal cancer survivors.

**Keywords** Fear of recurrence · Oral and oropharyngeal cancer · Survivorship care

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The American Cancer Society estimates that there will be 54,000 new oral and oropharyngeal cancers causing 11,580 deaths in the USA in 2023 [1, 2]. Although the incidence of these cancers has been increasing, mortality rates have stabilized. This is attributable to more efficacious treatments and a higher percentage of this population being diagnosed with HPV-associated cancers, which are commonly diagnosed in younger, more healthy patients and carry a more favorable prognosis [3, 4]. More favorable prognoses translate into a growing population of oral and oropharyngeal cancer survivors in the USA as well as increasing needs for ongoing survivorship care. Due to the location of the structures involved, the disease and the prevalence of late effects, this cancer can permanently reduce the ability to swallow, taste, speak, chew, and maintain comfortable movement of the head, neck, and shoulders. Physical effects include dry mouth,

difficulty with mastication, taste, speech, loss of hearing/tinnitus, and functional disorders and/or pain in the shoulder and neck areas [5–7]. In addition to the physical effects, this cancer can have a psychosocial impact on psychosocial distress and quality of life. Studies have documented clinical levels of anxiety around 32% during and immediately after treatment and 16–21% between one and 3 years after treatment [8]. Clinically relevant levels of depression among oral cancer survivors were highest just after finishing treatment (24%) and ranged from 9 to 19% between one- and 3 years post-treatment [8].

Fear of recurrence (FoR) has been defined as “fear, worry, or concern relating to the possibility that cancer will come back or progress” and is one of the most prevalent concerns among cancer patients [9]. Among oral and oropharyngeal cancer survivors, studies have illustrated a wide variability in levels of FoR, depending on the measurement and timing of the assessment, with figures ranging from 31% [10] to 52–53% [11–13]. Levels of fear change across disease phases, with the highest levels found to occur in the time period shortly after diagnosis [10]. However, some studies have reported that at least one in five oral cancer patients experience persistently high FoR post-treatment [10]. High levels of FoR are a significant psychosocial problem because they can interfere with daily and social functioning and are strongly associated with lower quality of life [10, 12].

To date, the vast majority of the literature has evaluated FoR among breast cancer patients. There has been much less attention paid to characterizing FoR among oral and oropharyngeal cancer survivors ( $N=18$ ) and even less focus on evaluating the contribution of potential sociodemographic, clinical, survivorship care transition practices, lifestyle, and psychosocial factors in FoR ( $N=12$ ). In terms of sociodemographic factors, the most consistent finding is that younger patients [10, 11, 14–17] and females [10, 16, 17] experience higher FoR. One study reported that patients receiving medical benefits, an indicator of lower SES, reported more FoR [17]. In terms of clinical factors, research *has shown that higher FoR is associated with being diagnosed with oral cancer (compared with oropharyngeal cancer)* [18], a longer period of time since treatment completion [17], a recurrence of the cancer or a second primary cancer [16], receipt of both radiation and chemotherapy [17], and more treatment-related physical symptoms [11, 13, 14, 19]. Health behaviors associated with higher FoR have included tobacco [13] and alcohol use [17]. Psychological distress is a strong and ubiquitous correlate of FoR [10, 12–15, 17].

This study had two aims. The first aim was to characterize FoR in a sample of oral and oropharyngeal cancer survivors. The second aim was to evaluate the role of sociodemographic factors, clinical factors, survivorship care transition practices, lifestyle factors, and depressive symptoms in FoR.

## Methods

### Eligibility

This cross-sectional study used data from an online baseline survey from a randomized controlled study, the Empowered Survivor trial, which is evaluating a self-management intervention for survivors of oral/oropharyngeal cancer [20]. The study protocol was reviewed and approved by the Rutgers University IRB and IRBs at the other participating sites in accordance with the US Federal Policy for the Protection of Human Subjects. The clinicaltrials.gov registration number is NCT04713449. Inclusion criteria were (1) 18 to 89 years of age at the time of contact; (2) diagnosed with a first primary oral or oropharyngeal cancer within the past 3 years; (3) had access to a device that connects to the internet; (4) reads and speaks English, and; (5) has sufficient vision to read a survey and complete an online intervention.

### Recruitment

Participants were recruited from two state registries: New Jersey and California. The New Jersey State Cancer Registry (NJSCR) confirmed patient eligibility, approached patients, and provided contact information to the main study site. The Cancer Registry of Greater California (CRGC) sent contact information to the main study site. For potential participants, staff sent a letter and pamphlet. Eligibility was ascertained during a call, and eligible persons were provided with an online consent and survey. Staff contacted participants biweekly, and survivors were considered passive refusers if they did not return a survey after repeated calls over a 1-month period.

### Measures

#### Socio-demographic variables

**Demographics** Participants reported age, biological sex, race, ethnicity, marital status, education, income, and employment status. For analyses, race and ethnicity were coded as 1 = White, not Hispanic and 0 = all other. Education was coded 1 = Bachelor’s degree or more, 0 = less than Bachelor’s degree. Employment status was coded 1 = employed, 0 = unemployed/disabled/retired = 0.

**Financial hardship** Participants reported if they had adequate financial resources to meet the daily needs of themselves and their family in the last month (1 = *yes*, 2 = *no*).

**Neighborhood socioeconomic disadvantage** The Area Deprivation Index (ADI) is based on a measure originally created by the Health Resources & Services Administration (HRSA) that has been adapted and validated to the Census Block Group neighborhood level [21, 22]. The ADI allows for rankings of neighborhoods by socioeconomic disadvantage in a region of interest [23]. It includes factors for the domains of income, education, employment, and housing quality. To calculate ADI, state census block group data were ranked in percentiles from 1 to 10 (1 = lowest disadvantage within state to 10 = highest level of disadvantage within state).

### Clinical factors

**Cancer medical history** Data collected from the cancer registries included: Date of diagnosis, tumor location, stage, and HPV status. Time since diagnosis was calculated in months from diagnosis.

**Cancer-related symptoms** Thirty-one items from the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire H&N-35 [24] assessed treatment effects including pain, problems swallowing, problems with teeth/chewing, difficulty opening mouth, dry mouth, sense of smell, speaking, eating, raising an arm, wound healing, and numbness. Items assessing appearance worries and fears about recurrence were excluded due to overlap with the FoR scale. Since we were evaluating total symptoms rather than specific symptoms, a mean was calculated rather than analyzing the separate subscales [25]  $\alpha = 0.94$ .

**Comorbidities** A checklist of 17 health conditions derived from the Health Information National Trends Survey was used (*yes/no*) [26, 27]. Frequency of affirmative responses were tallied (range = 0–17).

### Lifestyle factors

**Current alcohol use** One item from the Follow-up Care Use Health Outcomes Survey was used [28]: “Have you had any beer, wine, wine coolers, mixed drinks, liquor, or other alcoholic beverages during the past month?” Participants responding *prefer not to answer* were coded as a *no* for the analyses.

**Current tobacco use** Tobacco use was assessed using a single item to assess current smoking: “Have you smoked or used any type of tobacco product in the past month?” (1 = *yes*, 0 = *no*).

### Survivorship care practices

**Provision of a treatment summary** Participants reported receipt of a treatment summary (1 = *yes*, 2 = *no*).

**Survivorship preparedness** Preparedness is defined as the extent to which the person perceives they were prepared for what to expect physically, emotionally, and behaviorally after treatment [29–31]. Ten items assessed whether information received about survivorship care was sufficient, helpful, and covered self-care tasks [32–34]. Two items assessed satisfaction with the quantity of information and the way information was provided;  $\alpha = 0.94$ .

**Information needs** This 23-item scale, adapted from the FOCUS [28] and our work [35], assessed the desire for more information about oral cancer-specific topics (e.g., managing dry mouth, what a suspicious spot or lesion would look like). Response choices were *yes/no*. A total number of needs endorsed was calculated,  $\alpha = 0.93$ .

### Depressive symptoms

The Patient Health Questionnaire (PHQ-9) [36] assesses diagnostic criteria for depression. It is a widely used measure and has strong psychometrics [37]. Scores from 0–4 indicated no/mild depression, 5–9 indicate mild, 10–14 indicate moderate, 15–19 indicate moderately severe, and 20–27 indicate severe depression,  $\alpha = 0.91$ .

### Fear of recurrence

The Concerns about Recurrence Scale (CARS) [38] is a 29-item measure of the extent and nature of fear of breast cancer recurrence. We adapted the scale by asking about a recurrence of oral cancer. The scale has five scales. The global fears scale has four items assessing general fears (e.g., “How much time do you spend thinking about the possibility that your gynecologic cancer could recur?”). Ratings for the four global fears items ranged from 1 (*Don't think about it at all/not upset me at all/never worry about it/not at all afraid*) to 6 (*Think about it all the time/makes me extremely upset/worry about it all the time/very afraid*). The nature of fears was assessed with four scales: Health worries (10 items, “Interfere with my ability to plan the future”), identity and sexuality worries (7 items, “Make me feel badly about how my body looks or feels”), role worries (6 items, “Keep me from fulfilling important roles in my job or at home”), and death worries (2 items, “Threaten my life”). Ratings range from 0 (*not at all*) to 4 (*extremely*). For these scales, the stem for each item was, “I worry that a recurrence of oral cancer would...” Ratings for the subscales ranged from 0 (*not at all*) to 4 (*extremely*). Scores rounded to 3 or 4 indicate

moderate levels and scores rounded to 5 or 6 indicate high FoR [38, 39]. Internal consistency for all scales has been demonstrated focusing on breast cancer [38, 39], but there is no work with oral/oropharyngeal cancer survivors. Global,  $\alpha = 0.93$ , Health worries,  $\alpha = 0.96$ , Identity/sexuality worries,  $\alpha = 0.88$ , Role worries,  $\alpha = 0.91$ , and Death worries,  $\alpha = 0.90$ .

## Results

### Sample characteristics

Figure 1 illustrates the study flow. 1448 individuals were contacted. Of these individuals, 78 did not meet eligibility criteria, 132 could not be reached/incorrect contact information, 614 refused, and 389 completed the survey. Of the 152 individuals providing a reason for refusal, the most common reason was “not interested” (67%). The acceptance rate was 38.8%. Comparisons between the 389 participants and 814 refusers on available data (age, sex, stage, non-Hispanic white/not, cancer type, site) indicated that refusers were significantly older ( $t(1201) = 5.5$ ,  $p < 0.001$ ; Mean ( $M$ )<sub>refusers</sub> = 65.3 years, Standard Deviation (SD) = 10.4,  $M$ <sub>participants</sub> = 61.6 years, SD = 11.3) and more likely to be recruited from the CRGC (Chi-square = 238.4,  $p < 0.001$ ; Refusal rate<sub>CRGC</sub> = 85.9%, Refusal rate<sub>NJSCR</sub> = 39.4%). There were no differences for sex, minority status, stage, or cancer location.

Descriptive results are shown in Table 1. Participants were primarily male (72.7%), non-Hispanic (93.5%), and Caucasian (85.8%). About 28% had less than a college education, 28% reported an income less than or equal to \$60,000 a year, and about one quarter resided in an area with higher socioeconomic deprivation (rating 7–10). Financial hardship was relatively low, with only 8.6% reporting they did not have the means to provide for their family in the last month. Nearly half were retired or on disability (43.9%). More than half were diagnosed with oropharyngeal cancer. Average time since diagnosis was about 2 years, and half of the survivors underwent at least two of the three cancer treatments. Current smoking was low (8.6%) but alcohol use was relatively common (60.7%). In terms of post-treatment

care plan provision, approximately 70% of the sample reported receiving a written summary of the cancer treatments they received and details about recommended post-treatment cancer care. Average preparedness corresponded to *moderately agree* ( $M = 2.99$ ,  $SD = 0.81$ , 3 = *moderately*; 4-point scale). The lowest preparedness corresponded with “information has covered how to look for signs of oral cancer” ( $M = 2.61$ ,  $SD = 1.00$ , 3 = *moderately agree*), and the highest preparedness rating corresponded to “the way the information about head and neck cancer survivorship was presented.” ( $M = 3.39$ ,  $SD = 1.25$ , 3 = *moderately agree*). Information needs were relatively high, with a mean of 9.37 (maximum = 23). Over half (60.3%) fell into the “no to mild” depression range, 22.4% fell into the “mild” depression range, 9.9% fell into the “moderate” depression range, 3.9% fell into the “moderately severe” depression range, and 3.4% fell into the “severe” depression range.

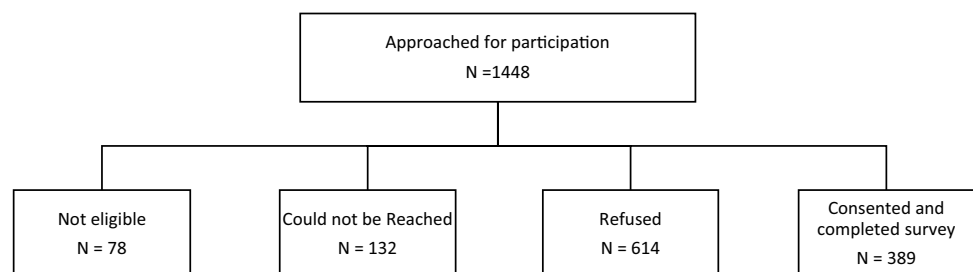
### Characterizing fear of recurrence

Average global FoR was mid-range (item  $M = 2.91$ ,  $SD = 1.45$ , range = 1–6) and average role worries (item  $M = 1.24$ ,  $SD = 1.09$ , range = 0–4) and identity/sexuality worries (Item  $M = 0.80$ ,  $SD = 0.96$ , range = 0–5) were relatively low. For global FoR, between 17.7% (“How much does the possibility that your head and neck cancer could recur upset you?”) and 20% (“How much time do you spend thinking about the possibility that your head and neck cancer could recur?”) rated the item *not at all*. Higher average scores were seen for health worries (item  $M = 1.74$ ,  $SD = 1.16$ , range = 0–4) and death worries (item  $M = 1.79$ ,  $SD = 1.35$ , range = 0–4). 40.3% had moderate to high scores (3–6) on the global FoR scale. Moderate to high scores for each scale were: Role worries, 27.2%, Health worries, 40.3%, Identity/sexuality worries, 14.9%, and Death worries, 46%.

### Regression analyses

Regression analyses proceeded in three stages. In the first stage, we estimated correlations for each FoR scale, with all potential predictors within each predictor domain (demographic, medical, survivorship care, health behaviors, and

Fig. 1 Study schema



**Table 1** Sample characteristics (*n* = 389)

Variable	N (%)	M (SD)
Age (years)		62.5 (10.5)
Sex		
Male	164 (70.7)	
Female	68 (29.3)	
Ethnicity		
Hispanic	13 (5.6)	
Non-Hispanic	217 (93.5)	
Missing data	2 (0.9)	
Race		
White	199 (85.8)	
Black	12 (5.2)	
Asian	4 (1.7)	
American Indian/Alaska native	1 (0.43)	
More than one race	14 (6.0)	
Missing data	2 (0.9)	
Education		
≤ High school	47 (20.2)	
Some college	59 (21.6)	
Trade/technical degree	21 (9.1)	
College degree	50 (20.6)	
Some graduate school	13 (5.6)	
Graduate school	49 (21.1)	
Income		
< \$20,000	18 (7.8)	
\$20,000-\$29,999	9 (3.9)	
\$30,000-\$39,999	9 (3.9)	
\$40,000-\$59,999	28 (12.1)	
\$60,000-\$74,999	21 (9.1)	
\$75,000-\$99,999	28 (12.1)	
\$100,000-\$119,999	26 (11.2)	
\$120,000-\$139,999	22 (9.5)	
\$140,000-\$159,999	17 (7.3)	
\$160,000 or more	50 (21.6)	
Missing data	4 (1.7)	
Marital status		
Married/cohabitating	163 (70.2)	
Single	20 (8.6)	
Divorced/separated	29 (12.5)	
Widowed	18 (7.8)	
Missing data	2 (0.8)	
Employment status		
Full-time	22 (9.5)	
Part-time	89 (38.2)	
On leave	2 (0.9)	
Retired	85 (36.6)	
Unemployed	15 (6.4)	
Disabled/on disability	17 (7.3)	
Missing data	2 (0.9)	
Area Deprivation Score		
1	38 (9.8)	

**Table 1** (continued)

Variable	N (%)	M (SD)
2	48 (12.3)	
3	39 (10.0)	
4	33 (8.5)	
5	44 (11.3)	
6	52 (13.4)	
7	34 (8.7)	
8	45 (11.6)	
9	25 (6.4)	
10	26 (6.7)	
Missing data	5 (2.3)	
Adequate finances to meet daily needs		
Yes	211 (90.9)	
No	20 (8.6)	
Missing data	1 (0.4)	
Cancer location		
Oral cavity	72 (31.0)	
Oropharyngeal	141 (60.8)	
Salivary gland	19 (8.2)	
Cancer stage		
0	1 (0.4)	
1	104 (44.8)	
2	50 (21.6)	
3	15 (6.5)	
4	47 (20.2)	
Unknown	3 (1.3)	
Missing data	12 (5.2)	
Recurrence (yes)	11 (4.7)	
Time since diagnosis (months)		26.45 (8.99)
Treatments		
Had surgery (yes)	148 (63.8%)	
Had radiation (yes)	183 (78.9%)	
Had chemotherapy (yes)	123 (53%)	
Total number		1.85 (0.68)
HPV status		
Negative	30 (7.7)	
Positive	213 (54.8)	
Not tested/Unknown	146 (37.5)	
Cancer symptoms and side effects		1.60 (0.50)
Comorbidities		0.73 (0.99)
Current alcohol use (yes)	235 (60.4)	
Current tobacco use (yes)	33 (8.5)	
Received treatment summary		
Yes	161 (69.4)	
No	57 (28.9)	
Missing data	4 (1.7)	
Preparedness		3.02 (0.77)
Information needs		9.37 (6.55)
Depressive symptoms		4.42 (5.39)
Fear of Recurrence – Global		2.91 (1.45)
Fear of Recurrence – Health		1.74 (1.16)

**Table 1** (continued)

Variable	N (%)	M (SD)
Fear of Recurrence – Identity/Sexuality		0.80 (0.96)
Fear of Recurrence – Role		1.24 (1.09)
Fear of Recurrence – Death		1.79 (1.35)

depressive symptoms). We retained all potential predictors that showed a significant correlation with at least one FoR scale at  $\alpha=0.05$ . In the second stage we conducted multiple regression analyses to identify the best predictors of each FoR scale within each predictor domain, using only those predictors retained from the first stage. In the third stage, all retained predictors were included in separate multiple regression analyses for each FoR scale.

First-stage correlations are reported in Table 2. Retained predictors included (1) Demographic: Age, biological sex, race (White vs. Other), ethnicity (Hispanic/Latinx vs. Other), marital status, income, and financial hardship; (2) Clinical: Stage, cancer symptoms and side effects, comorbidities; (3) Survivorship Care: Survivorship preparedness, information needs; (4) Lifestyle: Current alcohol use, and (5) Psychosocial: Depressive Symptoms.

The second stage involved conducting multiple regression analyses to identify the best predictors of each FoR scale within each predictor domain, using predictors retained from the first stage. Full regression results are supplied in Table 3. We observed similar patterns of significance and non-significance across the five FoR scales. Controlling for other demographic factors, older age, and more financial resources were significantly associated with lower FoR across scales. Females reported higher global FoR and more health and death worries. Higher income was significantly associated with fewer sexuality/identity and role worries. Controlling for other clinical factors, higher cancer symptoms and side effects were significantly associated with higher scores on all subscales. For survivorship care factors, greater preparedness was significantly associated with lower scores on all scales, and more information needs was significantly associated with higher scores on all scales. Controlling for other factors, current alcohol use was associated with lower global FoR, fewer identity/sexuality worries, and fewer role worries. Finally, depressive symptoms were associated with higher FoR for all scales. Predictors retained from the second stage included age, biological sex, income, financial hardship, cancer symptoms and side effects, survivorship preparedness, information needs, current alcohol use, and depressive symptoms. Variance accounted for across FoR outcomes in this stage of modeling ranged from none (Health behaviors) to 38% (Depressive symptoms).

The third stage of the analyses involved placing all retained predictors in separate multiple regressions for each

FoR scale. Full regression results are reported in Table 4. Controlling for other predictors, younger age, female sex, lower income, more cancer symptoms and side effects, and higher depressive symptoms were associated with higher global FoR. Higher identity and sexuality worries were associated with younger age, being female, having lower income, more cancer symptoms and side effects, more information needs, and higher depressive symptoms. More health worries were associated with younger age, more cancer symptoms and side effects, more information needs, and more depressive symptoms. More role worries were associated with younger age, more financial hardship, more cancer symptoms and side effects, more information needs, and more depression. Finally, the more death worries were associated with younger age, being female, lower income, more cancer symptoms and side effects, less survivorship preparedness, and more depressive symptoms. Current alcohol use did not predict any of the FoR scales when controlling for other predictors. Variance accounted for in outcomes ranged from 24.5% (Death worries) to nearly half of the variance (47.3%; Role worries).

## Discussion

Fear of cancer recurrence is a common and potentially traumatizing psychological symptom among cancer survivors, particularly in the population of oral and oropharyngeal cancer survivors, who can experience persistent disease and treatment physical effects. A greater understanding of survivors who are at increased risk for developing and experiencing this aversive psychological symptom would inform more efficacious clinical interventions to mitigate and potentially prevent FoR. We examined a comprehensive set of risk factors which included novel demographic and survivorship care transition practice factors. This study advances prior work in three ways. First, we assessed the role of two demographic factors, cancer-related financial hardships and neighborhood deprivation, which are known contributors to disparities in outcomes among cancer survivors [40]. Second, we evaluated the role of three survivorship care transition practices, the provision of a survivorship care plan, perceived preparation by the care team for survivorship, and information needs about survivorship self-care and surveillance, in FoR. Preparing survivors to manage their cancer-related symptoms and side effects and engage recommended follow up care may increase confidence in the ability to manage care and reduce worry. Third, we assessed not only the general level of worry but also the nature and dimensions of worries, including the worry about the impact of fear on the ability to fulfill family and work roles, adverse impact on future health, one's identity and sexuality, and the possibility of death. Understanding the multifaceted nature and unique

**Table 2** Correlations between variables included in regression models

Variable	1	2	3	4	5	6	7	8	9	10	
1. Age	1.00										
2. Sex	-.091	1.00									
3. Education	.089	.049	1.00								
4. Income	-.033	-.081	.372***	1.00							
5. ADI	-.021	-.041	-.261***	-.382***	1.00						
6. Fin. needs	.075	.005	.116*	.331***	.185***	1.00					
7. Stage	.012	.056	-.054	-.062	.082	-.119*	1.00				
8. Time since dx	.094	.021	.031	.060	.142**	.081	-.233***	1.00			
9. Symptoms	-.004	-.001	.131	.317***	.188**	-.250***	.128*	.001	1.00		
10. Comorbidities	.221**	.096	-.034	.228***	.105*	-.130*	-.085	.058	.175**	1.00	
11. Surv. care plan	-.143*	.069	-.012	.061	.006	.036	-.027	.059	-.033	-.057	
12. Alcohol use	-.020	-.116*	.057	.283***	-.104	.162**	-.037	.035	-.149*	-.090	
13. Tobacco	-.065	-.061	-.226***	.166**	.166**	-.101*	.019	.039	.129*	.073	
14. Info need	.056	.079	.020	.094	.094	-.170**	.111*	.011	.523***	.134	
15. Preparedness	-.098	-.107	-.017	.108**	-.077	.111*	.055	.019	-.215**	-.098	
16. Depression	-.186***	.022	-.169***	.138**	.138	-.282***	.008	.065	-.624***	.169***	
17. FoR Global	-.259***	.217***	-.046	.089	.030	-.174**	.101*	.089	.405***	.053	
18. FoR Role	-.328***	.200***	-.081	.196***	.086	-.282***	.062	.010	.504**	.108*	
19. FoR Health	-.264***	.093	-.072	.089	.047	-.171**	.046	.017	.447***	.069	
20. FoR Identity	.238***	.094	.023	.083	.083	-.250***	.045	.007	.484***	.105*	
21. FoR Death	-.194***	.167**	.026	.008	.008	-.120*	.023	.030	.347***	.037	
Variable	11	12	13	14	15	16	17	18	19	20	21
1. Age											
2. Sex											
3. Education											
4. Income											
5. ADI											
6. Fin. needs											
7. Stage											
8. Time since dx											
9. Symptoms											
10. Comorbidities											
11. Care plan	1.00										
12. Alcohol use	-.013	1.00									
13. Tobacco use	.001	.077	1.00								
14. Info need	-.011	-.187***	.060	1.00							
15. Preparedness	.296***	.104	-.047	.296***	1.00						
16. Depression	-.085	-.182***	.132**	.412***	-.275***	1.00					
17. FoR Global	.001	-.114*	.085	.320***	-.218***	.419***	1.00				
18. FoR Role	.032	-.100*	.027	.417***	-.244***	.620***	.664***	1.00			
19. FoR Health	.018	-.030	.005	.403***	-.218***	.522***	.747***	.874***	1.00		
20. FoR Identity	.020	-.104*	.044	.269***	-.250***	.597***	.556***	.825***	.729***	1.00	
21. FoR Death	-.007	-.032	.000	.320***	-.228***	.411***	.713***	.739***	.864***	.618***	1.00

ADI: Area Deprivation Index; Dx: diagnosis; Fin: Financial; FoR: Fear of Recurrence; Info: Information; Surv: Survivorship

correlates of oral cancer survivors' fears and its correlates can inform clinical interventions.

Our results suggest that about 40% reported elevated levels of global FoR, with similar percentages of death (46%)

and health worries (40.3%). Elevations in role (27.2%) and sexuality/identity worries (14.9%) were less common. It is difficult to make direct comparisons with other studies of oral and oropharyngeal cancer survivors due to differences

**Table 3** Results of the regression analyses including all factors

Fear of recurrence scales					
Predictors	Global	Health	Identity	Role	Death
Demographic factors					
Intercept	4.911(.940)*	3.535(.754)*	2.407(.627)*	4.222(.686)*	2.762 (.905)*
Age	-.031(.007)*	-.026(.006)*	-.019(.005)*	-.031(.005)*	-.024(.007)*
Sex	.617(.159)*	.479(.128)*	.145(.106)	.144(.116)	.482(.154)*
Race	.183(.223)	.099(.179)	.149(.148)	.161(.162)	-.077(.214)
Ethnicity	-.084(.330)	-.171(.265)	.014(.220)	-.189(.241)	.197(.318)
Marital status	-.150(.179)	.001(.143)	.058(.119)	-.025(.130)	.022(.172)
Income	.000(.030)	-.011(.024)	-.048(.020)*	-.044(.022)*	.020(.029)
Financial hardship	-.703(.262)*	-.548(.211)*	-.612(.175)*	-.784(.192)*	-.607(.253)*
Adjusted R <sup>2</sup>	.116	.115	.117	.180	.062
Clinical factors					
Intercept	.978(.233)*	.094(.183)	-.677(.148)*	-.522(.167)*	.323(.224)
Stage	.039(.034)	-.008(.027)	-.008(.022)	-.002(.024)	-.017(.033)
Cancer Symptoms	1.157(.138)*	1.049(.109)*	.928(.088)*	1.097(.099)*	.961(.133)*
Comorbidities	-.020(.069)	-.017(.055)	.014(.044)	.019(.050)	-.042(.067)
Adjusted R <sup>2</sup>	.161	.195	.229	.249	.115
Survivorship care transition practices					
Intercept	3.160(.338)*	1.818(.267)*	.888(.216)*	1.284(.245)*	2.302(.321)*
Preparedness	-.275(.095)*	-.204(.075)*	-.193(.061)*	-.208(.069)*	-.311(.090)*
Information needs	.060(.011)*	.056(.009)*	.052(.007)*	.061(.008)*	.044(.011)*
Adjusted R <sup>2</sup>	.117	.143	.180	.189	.096
Health behaviors					
Intercept	3.103(.116)*	1.771(.093)*	.903(.076)*	1.360(.087)*	1.831(.109)*
Alcohol use	-.336(.149)*	-.072(.120)	-.200(.097)*	-.221(.112)*	-.088(.141)
Adjusted R <sup>2</sup>	.010	.000	.008	.007	.000
Depressive symptoms					
Intercept	2.348(.085)*	1.230(.066)*	.315(.051)*	.669(.057)*	1.321(.082)*
Depressive symptoms	.127(.012)*	.115(.010)*	.109(.007)*	.129(.008)*	.106(.012)*
Adjusted R <sup>2</sup>	.209	.270	.354	.383	.167

\*  $p < .05$ **Table 4** Final regression analyses including only significant factors

Fear of recurrence scales					
Predictors	Global	Health	Identity	Role	Death
Intercept	2.371 (.630)*	.899 (.477)	.813 (.384)*	1.758 (.414)*	1.008 (.615)
Age	-.025 (.006)*	-.019 (.005)*	-.013 (.004)*	-.024 (.004)*	-.015 (.006)*
Sex	.617 (.142)*	.477 (.108)*	.123 (.087)	.128 (.093)	.464 (.139)*
Income	.059 (.024)*	.044 (.018)*	.008 (.015)	.011 (.016)	.084 (.024)*
Financial resources	-.273 (.234)	-.163 (.177)	-.277 (.143)	-.404 (.154)*	-.177 (.229)
Cancer symptoms	.623 (.172)*	.488 (.131)*	.296 (.105)*	.384 (.113)*	.482 (.168)*
Preparedness	-.083 (.086)	-.042 (.065)	-.057 (.053)	-.039 (.057)	-.171 (.084)*
Information needs	.014 (.011)	.018 (.009)*	.018 (.007)*	.021 (.007)*	.007 (.011)
Alcohol use	-.061 (.134)	.179 (.101)	.060 (.081)	.086 (.088)	.091 (.131)
Depressive symptoms	.072 (.016)*	.075 (.012)*	.070 (.010)*	.079 (.011)*	.073 (.016)*
Adjusted R <sup>2</sup>	.308	.379	.403	.473	.245

\*  $p < .05$



in measurement approaches across studies, the absence of “clinical” cut-offs for FoR, and the fact that the measure we used has not been included in prior studies and assesses the nature of fears which has not been assessed in prior work. Other studies of this survivor population have reported wide variations in general FoR, with figures ranging from 31% [10] to 52–53% [11–13]. In comparison with studies of patients with other cancers, we reported higher average global FoR than survivors of mixed cancers [38, 41] ( $M = 1.30$ ,  $SD = 1.1$ ), but a slightly lower global FoR than another study [42] ( $M = 12.55$ ,  $SD = 5.38$ ). A study of female breast cancer survivors [38] reported similar scores for Role ( $M = 1.11$ ,  $SD = 1.10$ ), Womanhood ( $M = 0.80$ ,  $SD = 0.98$ ), and Health worries ( $M = 1.91$ ,  $SD = 1.19$ ), and lower levels of Death worries ( $M = 2.16$ ,  $SD = 1.49$ ). The proportion of moderate to high global FoR in the current sample (40.3%) was higher than figures reported in a study of younger breast cancer survivors (28.8%) [43]. Our study adds to the existing literature by illustrating that survivors worry more about what a recurrence would mean for their future health as well as the possibility of dying more than how it impacts their social and personal identity.

Significant correlates of FoR identified illustrated consistency with the existing literature in that higher global FoR was associated with younger age [10, 11, 15–17], female sex [10, 16, 17], more cancer symptoms and side effects [11, 19], and higher depressive symptoms [10–13, 15]. Severity of physical symptoms has been a consistent correlate in this cancer survivor population, who experience multiple physical side effects that trigger worries that the cancer has recurred [19]. Our study extends prior work by also examining correlates of the nature of survivors’ fears. There was some consistency in correlates across the scales, with more FoR significantly associated with younger age, more cancer-related symptoms, and more depressive symptoms. However, there were some differences across subscales. First, health and global fears were higher among females. Reasons for the sex difference are not clear and should be examined in future research. Second, lower income was associated only with more role and identity/sexuality worries, and financial hardship was associated only with more role worries. The association between income and financial hardship with role worries was not surprising, as the scale assesses concerns about interference with important roles such as job and home responsibilities and relationships. The reason for the association between income and identity/sexuality worries is not clear and should be examined in future research.

Finally, two survivorship care transition practices, perceived preparedness for survivorship and information needs, were associated with some FoR scales, but not others. Less preparedness was only associated with more death worries. This is a surprising finding, as the scale assesses satisfaction with information about symptom management, identifying

signs of recurrence, and recommended follow-up care. Given that death worries can be particularly challenging, this finding suggests that comprehensive preparation during the transition to survivorship is key. More information needs were associated with more health, sexuality/identity, and role worries, but not predictive of death worries and global FoR. As the needs measure consists primarily of information about symptoms, symptom management, and recommended surveillance but did not assess how to manage fears, it is not surprising that it was not associated with death worries and global fears about recurrence.

Before concluding, it is important to note the factors that were not associated with FoR in the final regression analyses. Race, ethnicity, education, marital status, cancer stage, treatment received, tumor location, time since diagnosis, comorbid medical issues, receipt of a survivorship care plan, and preparedness were not associated with FoR. It is interesting to note that the role of race and ethnicity has not been examined in other studies evaluating FoR in this population. Our results are consistent with studies that have included education, marital status [11, 44], employment status [11], cancer location [10], stage [10, 11, 16, 17], treatments received [11, 16], comorbidities [11], and tobacco use [11], which have not illustrated an association. Finally, although alcohol use was not significantly associated with FoR in the final analyses, its use was associated with lower global FoR, fewer identity/sexuality worries, and fewer role worries in correlative and initial regression analyses.

Before concluding, it is important to point out strengths and limitations. Strengths include recruitment from two large state cancer registries which provides a representative, non-clinic-based sample, a multi-dimensional assessment of FoR, inclusion of both oral and oropharyngeal cancer survivors, assessment of sociodemographic factors such as area deprivation and financial hardship, and the assessment of survivorship care transition practices [11, 13, 19]. Limitations include the cross-sectional design and the primarily non-Hispanic white, male, and married sample. Although we included race and ethnicity in analyses, the proportion was small, results may have differed if more minority survivors had been enrolled. Due to missing data on medical records, HPV status was missing from some participants, and its impact could not be evaluated. We used the European Organization for Research and Treatment of Cancer Quality of life Questionnaire H&N-35 [24] as an indicator of symptoms rather than QOL, we excluded items assessing appearance worries and fears about recurrence, and analyzed an average for the scale rather than using subscales. We also adapted the Information Needs scale from the FOCUS to assess oral cancer-specific topics. Although a rationale was provided in both cases, this is a limitation. Participants who preferred not to answer the current alcohol use question were coded as not drinking. Including these participants in

the analysis could be the reason why this variable did not reach significance. Conclusions about the role of alcohol use in FoR would be premature. There was a significantly lower enrollment from one cancer registry, study refusers were older, and primarily men. We only included patients diagnosed in the last 3 years. Thus, our finding that time since diagnosis was not associated with FoR may not reflect the experiences of longer-term survivors. These limitations could have influenced our findings, and future studies should include more older and female survivors. Finally, we relied upon self-report measure of a survivorship care summary receipt, which may have resulted in a biased estimate of its association with FoR.

## Conclusions and clinical implications

The diagnosis and treatment of oral and oropharyngeal cancer is a challenging life experience that compromises health-related quality of life. Roughly 20% of these patients experience a recurrence of their cancer, with the vast majority occurring during the first 2 years after treatment completion [45, 46]. FoR is an adverse psychological effect of cancer but has received relatively little empirical attention. This study increases our understanding of FoR in this survivor population. About 40% reported elevated levels of global FoR, especially worries about death and health. Younger, female survivors as well as survivors experiencing more cancer-related physical and depressive symptoms are at risk for both general fears and specific fears about the impact of recurrence on their roles, health, and identity, and fears about death. Depression accounted for a lion's share of the variance in FoR. Financial hardships are associated with both general FoR and worries about the impact of recurrence on roles and responsibilities. Many of these are modifiable risk factors that could be addressed with multifocal, tailored survivorship care interventions that incorporate cognitive-behavioral or acceptance-based therapies [46]. This study suggests that survivorship interventions during the first several years of survivorship should assess and treat depressive symptoms, assess financial concerns and provide financial counseling, provide ongoing education about recommended survivorship care, and educate patient about expected physical symptoms and how to recognize symptoms which should prompt outreach to the treatment team.

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**Author contribution** SM and KP wrote the manuscript text and prepared the tables. SM and KP conducted data analyses; SF, MP, AS, and NS collected study data; SF and NS conducted data quality checks; SH, MI, and JVC participated in the study's design and conception.

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**Data availability** The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

## Declarations

**Ethics approval** This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of Rutgers University, ID#: Pro2020000768, Date: 7/14/2020.

**Consent to participate** Informed consent was obtained from all individual participants included in the study.

**Consent for publication** N/A No personal information of participants is published in this article.

**Competing interests** The authors declare no competing interests.

**Conflict of interests** The authors declare no conflict of interests.

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