


ORIGINAL ARTICLE

Self-efficacy in managing post-treatment care among oral and oropharyngeal cancer survivors

Sharon L. Manne¹  | Shawna V. Hudson² | Deborah A. Kashy³ |
Matin Imanguli^{1,4} | Morgan Pesanelli¹ | Sara Frederick¹ | Janet Van Cleave⁵

¹Rutgers Cancer Institute of New Jersey, New Brunswick, New Jersey, USA

²Institute for Health, Health Care Policy and Aging Research, Robert Wood Johnson Medical School, New Brunswick, New Jersey, USA

³Department of Psychology, Michigan State University, East Lansing, Michigan, USA

⁴Department of Otolaryngology-Head and Neck Surgery, Robert Wood Johnson Medical School, New Brunswick, New Jersey, USA

⁵NYU Rory Meyers College of Nursing, New York, New York, USA

Correspondence

Sharon L. Manne, Rutgers Cancer Institute of New Jersey, 120 Albany Street, Tower A, Eighth Floor, New Brunswick, NJ 08901, USA.
Email: sharon.manne@rutgers.edu

Funding information

This project was supported by the National Cancer Institute under R01 CA240344-01A1, awarded to Sharon Manne. Services, results and/or products in support of the research project were generated by Rutgers Cancer Institute of New Jersey Population Science Research Support Shared Resource.

Abstract

Objective: Physical and psychosocial effects of oral cancer result in long-term self-management needs. Little attention has been paid to survivors' self-efficacy in managing their care. Study goals were to characterise self-care self-efficacy and evaluate socio-demographics, disease, attitudinal factors and psychological correlates of self-efficacy and engagement in head and neck self-exams.

Methods: Two hundred thirty-two oral cancer survivors completed measures of socio-demographics, self-care self-efficacy, head and neck self-exams and attitudinal and psychological measures. Descriptive statistics characterised self-efficacy. Hierarchical regressions evaluated predictors of self-efficacy.

Results: Survivors felt moderately confident in the ability to manage self-care ($M = 4.04$, $SD = 0.75$). Survivors with more comorbidities ($\beta = -0.125$), less preparedness ($\beta = 0.241$), greater information ($\beta = -0.191$), greater support needs ($\beta = -0.224$) and higher depression ($\beta = -0.291$) reported significantly lower self-efficacy. Head and neck self-exam engagement (44% past month) was relatively low. Higher preparedness ($OR = 2.075$) and self-exam self-efficacy ($OR = 2.606$) were associated with more engagement in self-exams.

Conclusion: Many survivors report low confidence in their ability to engage in important self-care practices. Addressing unmet information and support needs, reducing depressive symptoms and providing skill training and support may boost confidence in managing self-care and optimise regular self-exams.

KEYWORDS

oral cancer, self-efficacy, survivorship care

1 | INTRODUCTION

The American Cancer Society estimates that there will be 54,000 new oral and oropharyngeal cancers causing 11,230 deaths in 2022 in the United States (Cancer Stats And Figures, 2022). Key risk factors are tobacco and alcohol consumption and the human papillomavirus

(HPV). Although the incidence of these cancers has been increasing, mortality rates have stabilised. This stabilisation is likely 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 favourable prognosis (Ang et al., 2010; Chaturvedi et al., 2011). As the

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial](https://creativecommons.org/licenses/by-nc/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2022 The Authors. *European Journal of Cancer Care* published by John Wiley & Sons Ltd.

population of oral and oropharyngeal cancer survivors grows, attending to their care needs becomes increasingly important. Demographic characteristics and prognosis of the population of oropharyngeal cancers depend upon whether the patient has an HPV-related oropharyngeal cancer. Persons with HPV-related oropharyngeal cancers are more likely to be White men under the age of 50, non-smokers and have a less significant use of alcohol than persons with non-HPV-related cancers (Smith et al., 2004). Risk factors also differ, in that persons with HPV-related cancers have an increased number of oral and vaginal sex partners at a younger age (Gillison et al., 2008).

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 can include dry mouth, difficulty with mastication, taste, speech, loss of hearing/tinnitus and functional disorders and/or pain in the shoulder and neck areas (Badr et al., 2017; Cardoso et al., 2021; Epstein et al., 2012). Long-term self-care needs can be complex and involve non-oncology care providers including rehabilitation and pain management experts to restore and/or prevent further deterioration of function (Cohen et al., 2016; Dingman et al., 2008; Head and Neck Cancers, 2022; Tippett & Webster, 2012). Other key self-management practices include dietary changes, regular mouth and dental care to reduce dental caries, jaw, neck and, in the first year or so after treatment, engagement in head, neck and shoulder exercises to maintain muscle flexibility and strength, cessation of tobacco and alcohol use, managing financial and employment concerns and coping with emotional distress and fear of recurrence (Cardoso et al., 2018; Chen et al., 2013; Massa et al., 2018; O'Brien et al., 2017; Papadakos, McQuestion, et al., 2018). Engagement in regular survivorship-specific self-care can reduce further loss of function and severe late effects (Logemann, 2006; Silverman & Society, 2003). Because between 20% to 50% develop a recurrence or metastatic disease within the first 2 years (Kissun et al., 2006), the recommended surveillance regimen includes regular self-exams of the head and neck (Cohen et al., 2016; Denlinger et al., 2016; Pfister et al., 2020), as self-exam may lead to earlier detection of recurrence or second primary (Mathew et al., 1995). Unfortunately, adherence with post-treatment regimen is less than optimal: Up to 80% do not engage in regular mouth care (Shinn et al., 2013; Thariat et al., 2012) and over half continue to drink alcohol (Mayne et al., 2009). There is little available data on levels of engagement in head and neck self-exams (Mayne et al., 2009; Shinn et al., 2013; Toljanic et al., 2002).

There are numerous studies documenting quality of life (QOL) and symptom burden among oral cancer survivors (Murphy & Gilbert, 2009), but there has been less attention paid to characterising survivor's confidence in their ability to manage their self-care. The economic and time constraints affecting oncology care provision place the primary responsibility of day-to-day management of post-treatment symptoms and care on survivors. Recent studies indicate that oral cancer survivors struggle with self-management (Dunne et al., 2019). There are a number of barriers to optimal cancer self-management, including low health literacy (Papadakos, Hasan, et al., 2018), greater patient activation (Mazanec et al., 2016), elevated

distress and avoidant coping (Wu et al., 2020) and lower engagement in effective self-management strategies (e.g., taking breaks when doing daily chores, seeking support and seeking information) (Saeidzadeh, Gilbertson-White, Babaieasl, et al., 2021; van Dongen et al., 2020). In our work, we focus on self-efficacy (Durosier Mertilus et al., 2022; Papadakos et al., 2018b; Saeidzadeh, Gilbertson-White, Cherwin, et al., 2021; van Dongen et al., 2020). According to self-efficacy theory, self-management is associated with self-efficacy, which is defined as a belief in one's ability to execute actions to deal with a situation successfully. Self-efficacy (Bandura, 1986, 1997) is comprised of three domains: knowledge and skills to accomplish the task, confidence in one's ability to motivate oneself and the resources available to accomplish the task and confidence in one's ability to execute the task (Bandura, 1986, 1997). Efficacy is a task-specific expectation; people estimate their confidence in their ability to manage a task by evaluating the steps involved to successfully complete a task (Bandura, 1986, 1997). Confidence in the ability to execute a task is the most widely-studied dimension of self-efficacy and is considered a key resource in assisting with disease management (Lorig et al., 1999). Self-efficacy is linked to the initiation and maintenance of health behaviours (Baldwin et al., 2006; Jung & Brawley, 2011; Linde et al., 2006; Schwarzer & Renner, 2000), and greater efficacy is associated with better cancer surveillance behaviours (Bunkam & Kusol, 2021; Coroiu et al., 2020; Luszczynska & Schwarzer, 2003). Self-efficacy predicts psychosocial and functional outcomes among cancer survivors (Greene & Hibbard, 2012; Liang et al., 2008; van Osch et al., 2008; Wu et al., 2020).

To date, there has been little attention paid to characterizing levels of self-efficacy to manage survivorship care among oral cancer survivors, correlates of self-care self-efficacy, and characterizing the association between self-efficacy and performance of head and neck self-exams. A greater understanding of self-efficacy along with the demographic, disease-related and psychological factors associated with self-efficacy and correspondence between efficacy and head and neck self-exams will inform future interventions seeking to bolster survivor's self-care. When considering sociodemographic correlates of self-efficacy, it is important to consider age, sex, marital status, education, income, race/ethnicity, insurance status and financial hardships. Potential disease-related correlates of self-efficacy include type of cancer, time since diagnosis, cancer stage and receipt of a treatment summary at the end of treatment. We selected three attitudinal constructs. First, we focused on preparedness for survivorship. Preparedness is a key construct in health care decision-making (O'Connor & Jacobsen, 2007) and associated with self-efficacy in prior studies of cancer survivors (Manne et al., 2014). Second, we assessed information needs. Knowledge about tasks improves self-efficacy, and information needs are associated with self-efficacy (Keinki et al., 2016). Third, we assessed unmet support needs, which have been linked with lower self-efficacy (Lou et al., 2021). Finally, we assessed two psychological factors: fear of cancer recurrence and depressive symptoms. Prior work has found that distress and self-efficacy are negatively correlated (Melchior et al., 2013). In terms of self-management practices, we focused on head and neck self-exams. As noted previously, engagement in self-exams is important, but most survivors do not engage in regular exams.

Thus, we examined the association between engagement in self-exam and self-efficacy in conducting oral self-exams.

The study goal was to examine self-care self-efficacy and engagement in head and neck self-exam. Our specific aims were to (1) characterise self-efficacy in managing survivorship care, (2) evaluate the degree to which sociodemographic, disease, attitudinal and psychological factors predict self-efficacy and (3) examine the role of demographic, disease, attitudinal and psychological factors and self-efficacy in engagement in oral self-exams.

2 | METHODS

2.1 | Eligibility

This cross-sectional study used data from an online baseline survey from a randomised controlled trial, the Empowered Survivor trial, which is evaluating a self-management intervention for survivors of oral/oropharyngeal cancer (NCT047134). The study protocol (Pro2019000158) was reviewed and approved by the Rutgers Cancer Institute of New Jersey's IRB and IRBs at the other participating site in accordance with the US Federal Policy for the Protection of Human Subjects. The clinicaltrials.gov registration number is NCT047113449. Inclusion criteria were (1) 18 to 89 years of age at the time of contact, (2) diagnosed with a first primary invasive oral or oropharyngeal cancer within the past 3 years, (3) had internet access, (4) can read English and (5) had sufficient vision to read a survey and complete an online intervention.

2.2 | Recruitment

Participants were recruited from two state registries. New Jersey's registry confirmed patient eligibility, approached patients and provided contact information to the main study site. California's registry sent contact information to the main study site. For potential participants, staff sent a letter and study pamphlet. Eligibility was ascertained during a call, and eligible persons were provided with an online consent and survey. Staff contacted participants weekly, and survivors were considered passive refusers if they did not return a survey after repeated calls over a 1-month period. Participants were enrolled between January 2021 and November 2021.

Seven hundred sixty-nine individuals were contacted. Of these, 65 did not meet eligibility criteria, 99 could not be reached/contact information was incorrect, 384 refused and 232 completed the survey. Of the 152 persons providing a reason, the most common reason was 'not interested' (41%). Of those eligible, acceptance was 37.6% (232/616). Comparisons between 232 participants and 384 refusers on available data (age, time since diagnosis, sex, stage, minority/not and cancer type) indicated that refusers were significantly older, $t(614) = 3.04$, $p < 0.001$; $M_{\text{refusers}} = 64.72$ years, $SD = 11.83$, $M_{\text{participants}} = 61.93$ years, $SD = 10.57$, and diagnosed for a longer time, $t(614) = 3.91$, $p < 0.001$; $M_{\text{refusers}} = 35.36$, $SD = 4.88$;

$M_{\text{participants}} = 26.45$, $SD = 8.99$. There were no differences for sex, minority status, stage of disease or cancer location.

2.3 | Measures

2.3.1 | Socio-demographic measures

Participants reported sex, age, education level, marital status, insurance status, race/ethnicity, income and financial hardships in the last month ('Did you have adequate financial resources to meet the daily needs of you and your family?').

2.3.2 | Medical/clinical measures

Time since diagnosis, whether the survivor had been diagnosed with a second cancer, recurrence status, treatments received (0–3) and comorbidities (Charlson index; Charlson et al., 1987) were self-reported. Tumour location and cancer stage were extracted from registry data. Tumour types were characterised as oral, oropharyngeal or salivary cancers. Participants reported receipt of a treatment summary and other details about their care.

2.3.3 | Attitudes about survivorship care

Preparedness

Preparedness is defined as the extent to which the person perceives they were prepared for what to expect physically, emotionally and behaviourally when treatment was completed (Jones et al., 2013; Leach et al., 2017; Stanton et al., 2005). This 10-item scale assesses whether information received about survivorship care was sufficient, helpful, comprehensive and covered self-care tasks (1 = *strongly disagree*, 5 = *strongly agree*) (Manne et al., 2014; Manne et al., 2020; Stacey et al., 2003). Two items assessed satisfaction with the quantity of information and the way information was provided (1 = *not at all satisfied*, 4 = *very satisfied*). The 5-point scale was converted to a 4-point scale for analyses; $\alpha = 0.94$.

Information needs

Information needs is defined as desired information about disease, treatment and key cancer-related self-management tasks. This 23-item scale, adapted from the Health-Related Topics section of the FOCUS ('Follow-up Care Use Among Survivors (FOCUS) Survey', 2020) and prior work (Manne et al.,), assesses the desire for more information about oral cancer topics (1 = yes, 0 = no). A total number of needs endorsed was calculated; $\alpha = 0.93$.

Support needs

Support needs are defined as assistance needed to accomplish tasks. The Supportive Care Needs Survey (Boyes et al., 2009) is a 34-item scale assessing physical, psychological and health care system needs

(1 = N/A, 5 = high need). An average number of needs rated as a 'moderate' or 'high' need was calculated; $\alpha = 0.93$.

2.3.4 | Psychological factors

Concerns about recurrence

Five items assess worry about a recurrence of oral cancer (e.g., 'How much does the possibility that your head and neck cancer could recur upset you?') (1 = *It does not upset me at all*, 7 = *It makes me extremely upset*) (Vickberg, 2003). A mean score was calculated. $\alpha = 0.93$.

Depressive symptoms

The Patient Health Questionnaire (PHQ-9) (Kroenke et al., 2001) assesses diagnostic criteria for depression. It is a widely used measure and has strong psychometrics (Hinz et al., 2016). Scores from 0 to 4 indicate no/mild depression, 5–9 indicate mild, 10–14 indicate moderate, 15–19 indicate moderately severe and 20–27 indicate severe depression. $\alpha = 0.91$.

2.3.5 | Outcomes

Oral cancer self-management self-efficacy

This scale was developed for this study by the study team. The measure consisted of 22 items assessing confidence in managing common physical (e.g., dry mouth, difficulty swallowing and speaking and jaw and neck muscle stiffness) and emotional effects, managing follow-up surveillance and appointments and reduction of risky behaviours (e.g., smoking and drinking). These self-management tasks were selected as they are the most common challenges, side effects and surveillance needs associated with these cancers (Carneiro-Neto et al., 2017; McDowell et al., 2021; Penner, 2009; Rieger et al., 2006; Windon et al., 2019). There were 11 areas assessed: dry mouth symptoms, dental care, proper nutrition, swallowing/speaking difficulties, neck and shoulder muscle flexibility/strength, follow-up care appointments, communication with providers, detecting lesions through self-exam, emotional responses, smoking and alcohol use. One item assessed overall confidence in managing head and neck survivorship care.

Ratings ranged from 1 = *not at all confident* to 5 = *very confident*. For descriptive analyses, we present the 11 areas separately and overall scores. For the correlates analyses, we used the item average for the scale. Tobacco and alcohol items were not included in the combined reliability calculation as sample sizes for these two scales were smaller. Scale reliabilities were excellent: combined efficacy scale, $\alpha = 0.93$; dry mouth, $\alpha = 0.78$; good nutrition, $\alpha = 0.81$; managing swallowing and speaking, $\alpha = 0.76$; maintaining neck and shoulder flexibility, $\alpha = 0.89$; follow-up care and communication with providers, $\alpha = 0.87$; detecting lesions, $\alpha = 0.84$; and managing emotions, $\alpha = 0.78$.

Head and neck self-examination

Participants were asked whether they conducted a comprehensive examination of the inside of the mouth, face and neck to look for

signs of oral cancer in the last month. Those conducting an exam were asked whether they checked 11 areas and asked the degree to which they know what to look for (1 = *not at all*, 5 = *completely*).

2.4 | Statistical methods

For Aim 1, we used descriptive statistics to characterise self-efficacy. For Aim 2, we used a hierarchical regression approach to predict overall self-efficacy. Demographic predictors included age, sex, race/ethnicity, education, income, employment status and whether the survivor had sufficient financial resources in the past month. There were too few unmarried ($n = 8$) and uninsured ($n = 4$) participants to include these variables in analyses. Medical variables included stage, time since diagnosis, number of treatments, comorbidities, treatment summary receipt and cancer location, which was coded in two dummy variables: oropharynx (1) versus oral cavity (0) and salivary (1) versus oral cavity (0). The third step in the regression included attitudinal predictors: preparedness, information and support needs and the final step included fear of recurrence and depressive symptoms. For the third aim, we used binary logistic regression to predict whether the survivor reported having conducted a thorough oral exam in the past month (yes = 1, no = 0). The same four sets of predictors were included, with the exception that we also included self-efficacy to conduct an oral exam as an additional attitudinal factor.

3 | RESULTS

3.1 | Descriptive statistics

Descriptive data are shown in Table 1. Participants were primarily male (70.7%), non-Hispanic (93.5%) and Caucasian (85.8%). Approximately half had a college level or higher education. Nearly half were either retired or on disability (43.9%). More than half were diagnosed with oropharyngeal cancer. Average time since diagnosis was approximately 2 years, and half underwent two of the three types of cancer treatments. Approximately 70% reported receiving a cancer treatment summary.

Table 2 (bottom row) presents the overall descriptive statistics for the attitudinal and psychological variables. In terms of levels of depressive symptoms, 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. In terms of post-treatment care plan receipt, approximately 30% 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 ratings corresponded with '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

TABLE 1 Sample characteristics (*n* = 232)

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)	

(Continues)

TABLE 1 (Continued)

Variable	N (%)	M (SD)
Disabled/on disability	17 (7.3)	
Missing data	2 (0.9)	
Insurance status		
Yes	226 (97.4)	
No	4 (1.7)	
Missing data	2 (0.9)	
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)	
Second cancer (yes)	22 (9.5)	
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)
Received treatment summary		
Yes	161 (69.4)	
No	57 (28.9)	
Missing data	4 (1.7)	

information about head and neck cancer survivorship was presented' ($M = 3.39$, $SD = 1.25$, $3 = moderately agree$). The most commonly reported information needs were as follows: how to do self-exam (70.6%), symptoms that prompt contacting a doctor (65.9%), foods that are helpful in managing dry mouth (65.1%), late/long-term side effects (61.3%) and managing oral health (61.2%). Support needs that were rated 'moderate' or 'high' need for help were in the fatigue and emotional domain: lack of energy (22.4%), feeling down or depressed (20.3%) and uncertainty about the future (19.4%). In contrast, very low support needs were reported in the medical care domain (e.g., staff attends to needs).

Fear about recurrence was relatively low (item $M = 2.85$, $SD = 1.46$, highest rating = 6). Comparisons with studies of other cancer survivor populations using the same measure indicate the current sample reported higher general fear than survivors of mixed types of cancer (Simard & Savard, 2009; $M = 1.30$, $SD = 1.0$). Comparisons with studies of oral/oropharyngeal survivors are compromised because these studies use different measures of FOR (Casswell et al., 2021; Hodges & Humphris, 2009; Mirosevic et al., 2019). However, they have reported higher levels of FOR, with two studies reporting over half of the sample higher level of fear in their study (Casswell et al., 2021; Mirosevic et al., 2019).

TABLE 2 Means, SDs and correlations among the outcomes, attitudinal factors and psychological factors

	1.	2.	4.	5.	6.	7.	8.	9.
1. Overall self-efficacy	1.00							
2. Conduct self-exam	0.21**	1.00						
3. Survivor preparedness	0.46**	0.25**	1.00					
4. Informational needs	-0.48**	-0.10	-0.34**	1.00				
5. Moderate to high support needs	-0.55**	-0.04	-0.26**	0.47**	1.00			
6. Fear of recurrence	-0.37**	0.05	-0.24**	0.39**	0.51**	1.00		
7. Depressive symptoms	-0.53**	0.01	-0.32**	0.46**	0.74**	0.50**	1.00	
8. Self-exam self-efficacy	0.65**	0.46**	0.26**	-0.27**	-0.24**	-0.12	-0.18**	1.00
M	4.04	0.48	2.99	0.43	3.66	2.95	4.91	3.47
SD	0.75	0.50	0.80	0.29	6.40	1.46	5.65	1.27

* $p < 0.05$. ** $p < 0.01$.

TABLE 3 Descriptive information for oral cancer self-efficacy

Measure	M (SD)
Overall self-efficacy	4.04 (0.75)
Managing dry mouth	3.90 (0.99)
Managing dental care	3.89 (1.28)
Maintaining nutrition	4.02 (1.09)
Difficulty swallowing and speaking	4.00 (1.01)
Jaw, neck and shoulder flexibility and strength	3.82 (1.13)
Managing follow-up appointments and communication with providers	4.49 (0.74)
Detecting lesions through self-exam	3.47 (1.27)
Managing emotional reactions	4.02 (1.02)
Stopping alcohol use (if drinks) ($n = 152$)	4.39 (1.04)
Tobacco cessation (if smokes) ($n = 29$)	3.41 (1.48)

In terms of survivorship care practices, 44% reported engaging in a self-exam in the past month, with the roof of the mouth (37.9%), under the tongue (40.1%) and floor of the mouth (40.5%) being the least commonly checked areas among participants conducting an exam.

3.2 | Aim 1: Self-efficacy in managing oral cancer survivorship care

Table 3 presents descriptive information for the overall self-efficacy and 10 task-specific scales. Overall scores indicated that self-efficacy was relatively high, with a mean score corresponding to *moderately* (4 on a 5-point scale). Self-efficacy was highest for managing post-treatment appointments/communication with the health care providers and stopping the use of alcohol among the subgroup who reported consuming alcohol. The lowest ratings were in the 'somewhat confident' range and included confidence detecting lesions ($M = 3.47$), managing neck and shoulder flexibility and pain ($M = 3.82$), dental care ($M = 3.89$) and dry mouth ($M = 3.90$). We also

tested whether self-efficacy differed by cancer location and found two significant mean differences. Self-efficacy to manage dry mouth, $F(2, 229) = 5.36$, $p = 0.005$, was higher among oropharyngeal cancer survivors ($M = 4.07$, $SD = 0.88$) compared with oral cavity cancer survivors ($M = 3.61$, $SD = 1.05$) and salivary gland cancer survivors ($M = 3.77$, $SD = 1.30$). Self-efficacy to manage emotions, $F(2, 228) = 5.16$, $p = 0.006$, was higher in among oropharyngeal ($M = 4.17$, $SD = 0.88$) and salivary gland cancer survivors ($M = 4.16$, $SD = 0.87$) compared with oral cavity survivors ($M = 3.71$, $SD = 1.23$).

3.3 | Aim 2: Predictors of oral cancer self-management self-efficacy

Table 4 presents the results for the hierarchical regression predicting overall self-efficacy. Demographic variables did not predict self-efficacy. Medical factors accounted for 8% of the variance, but only comorbidities were a significant predictor. Participants with more comorbidities reported lower self-efficacy.

Attitudinal factors accounted for 39% of the variance. Higher preparedness was associated with higher self-efficacy, and greater informational and support needs were associated with lower self-efficacy. Of the two psychological factors, only depression predicted self-efficacy such that survivors higher in symptoms reported lower self-efficacy.

3.4 | Aim 3: Predictors of engaging in self-exams and flexibility/strengthening exercises

Results for whether the survivor reported conducting a thorough oral exam in the past month are presented in Table 5. As sets, demographic factors, medical factors and psychological factors did not predict conducting an oral exam, although there was a significant difference as a function of cancer location. Participants with oropharyngeal cancer were less likely than those with oral cavity cancer to conduct a self-exam. In addition, preparedness and oral exam self-

TABLE 4 Hierarchical regression results predicting overall self-efficacy for oral cancer self-management

	<i>b</i>	<i>se</i>	β	<i>p</i>	ΔR^2	<i>p</i> for ΔR^2
Demographic variables						
Age	−0.005	0.005	−0.065	0.315		
Sex	−0.112	0.104	−0.067	0.283		
Race/ethnicity	−0.158	0.109	−0.078	0.150		
Education	−0.071	0.088	−0.048	0.420		
Income	−0.014	0.018	−0.053	0.430		
Employment status	−0.074	0.093	−0.050	0.425		
Access to financial resources	−0.194	0.153	−0.071	0.207		
					0.039	0.359
Medical factors						
Cancer stage	0.059	0.038	0.092	0.123		
Time since diagnosis	−0.050	0.056	−0.048	0.374		
Total number of treatments	0.060	0.063	0.056	0.340		
Treatment summary received	−0.039	0.095	−0.023	0.686		
Number of comorbidities	−0.089	0.040	−0.125	0.028		
Salivary versus oral cavity	−0.262	0.165	−0.090	0.113		
Oropharynx versus oral cavity	0.093	0.105	0.061	0.380		
					0.077	0.028
Attitudinal factors						
Preparedness	0.226	0.056	0.241	0.000		
Informational needs	−0.482	0.159	−0.191	0.003		
Moderate to high support needs	−0.026	0.009	−0.224	0.007		
					0.387	0.000
Psychological factors						
Fear of recurrence	−0.024	0.034	−0.047	0.483		
Depressive symptoms	−0.037	0.011	−0.291	0.002		
					0.030	0.003

Notes: Sex is coded male = 1, female = 0; race/ethnicity is coded White, not Hispanic = 1, other = 0; education is coded BA/BS or more = 1, some college or less = 0; income is coded over 100 K = 1, under 100 K = 0; employment status is coded 1 = full or part time employed = 1, other = 0; Access to financial resources is coded 1 = yes, 0 = no. Two dummy variables, salivary versus oral cavity and oropharynx versus oral cavity, are used to code cancer location.

efficacy were both positive predictors of conducting an oral self-exam. The set of attitudinal factors together accounted for approximately 22% of the variance in oral exam completion. For each one unit increase in preparedness, the likelihood of conducting an exam doubled ($OR = 2.08$). For each one unit increase in oral exam self-efficacy, the likelihood of an exam is more than doubled ($OR = 2.61$).

4 | DISCUSSION

Survivors of oral and oropharyngeal cancers typically manage significant adverse medical and psychosocial effects which require ongoing management. There has been a great deal of attention paid to the impact of these cancers on QOL, but less attention has been given to characterising survivors' confidence in managing their care and what predicts confidence levels. As bolstering self-efficacy is associated

with engagement in cancer-related self-care (Luszczynska & Schwarzer, 2003), this is an important survivorship goal. Overall, our results suggest that survivors felt moderately confident in their ability to manage their care. Among the self-care tasks assessed, the highest confidence was associated with managing medical appointments and communication with health care providers. Survivors felt less confident in their ability to manage other important aspects of post-treatment care, such as conducting regular oral self-exams, maintaining dental care and managing dry mouth. These findings suggest that survivors may benefit from further education and training in how to manage these oral cancer side effects and self-exams.

A second goal was to evaluate correlates of self-efficacy. It is interesting to note that sociodemographic factors such as income, education, financial hardships and marital status did not predict self-efficacy. Since there are no prior observational studies of self-efficacy among oral cancer survivors, comparisons with prior work cannot be

TABLE 5 Hierarchical logistic regression results predicting whether the survivor has conducted a thorough oral exam in the past month

	<i>b</i>	<i>se</i>	<i>Exp (b)</i>	<i>p</i>	Cox and Snell ΔR^2	<i>p</i> for Block
Demographic variables						
Age	0.015	0.021	1.015	0.486		
Sex	0.337	0.495	1.400	0.496		
Race/ethnicity	-0.573	0.499	0.564	0.251		
Education	-0.524	0.410	0.592	0.201		
Income	0.001	0.085	1.001	0.995		
Employment status	-0.152	0.442	0.859	0.731		
Access to financial resources	0.417	0.671	1.518	0.534		
					0.039	0.332
Medical factors						
Cancer stage	-0.111	0.176	0.895	0.528		
Time since diagnosis	-0.108	0.258	0.898	0.675		
Total number treatments	0.025	0.297	1.025	0.934		
Treatment summary received	0.056	0.449	1.057	0.901		
Number of comorbidities	0.130	0.198	1.139	0.511		
Salivary versus oral cavity	-0.971	0.654	0.379	0.138		
Oropharynx versus oral cavity	-0.981	0.423	0.375	0.020		
					0.083	0.234
Attitudinal factors						
Preparedness	0.730	0.270	2.075	0.007		
Informational needs	-0.395	0.763	0.673	0.604		
Moderate to high support needs	0.014	0.043	1.015	0.735		
Oral exam self-efficacy	0.958	0.173	2.606	0.000		
					0.218	0.000
Psychological factors						
Fear of recurrence	0.162	0.166	1.176	0.329		
Depressive symptoms	0.035	0.053	1.036	0.505		
					0.006	0.419

Notes: Sex is coded male = 1, female = 0; race/ethnicity is coded White, not Hispanic = 1, other = 0; education is coded BA/BS or more = 1, some college or less = 0; income is coded over 100 K = 1, under 100 K = 0; employment status is coded 1 = full or part time employed = 1, other = 0; Access to financial resources is coded 1 = yes, 0 = no. Two dummy variables, salivary versus oral cavity and oropharynx versus oral cavity, are used to code cancer location.

made. However, prior studies of survivors with other cancers have suggested that higher educational background and income (Akin et al., 2008; Ali et al., 2020; Grimmer et al., 2017; Liang et al., 2008; Yuan et al., 2014) and being married (Grimmett et al., 2017) are associated with higher self-efficacy. The evidence for age is less consistent, with some studies finding that older age is associated with higher efficacy (Philip et al., 2013), but other studies not showing an association (Akin et al., 2008; Ali et al., 2020; Ziner et al., 2012). Sex has not been associated with self-efficacy in the limited work evaluating sex differences (Al-Harithy & Wazqar, 2021; Yuan et al., 2014). A possible explanation for the lack of association between socioeconomic factors and self-efficacy noted in the current sample is that, although education level was well distributed, the majority reported a relatively high income, were insured and did not experience financial hardship. Future studies evaluating self-efficacy among oral cancer

survivors with lower sociodemographic status may provide a better evaluation of this factor.

The only medical factor associated with lower self-efficacy was comorbidities. Studies focusing on other survivor populations have reported the association between comorbidities and lower self-efficacy (Al-Harithy & Wazqar, 2021) but other studies have not (Perkins et al., 2009). Given the fact that other medical concerns come with their own self-care demands, it is not surprising that confidence in managing cancer self-care was more of a challenge among those with other medical conditions. There were no other medical factors associated with efficacy. Stage of disease (Al-Harithy & Wazqar, 2021) and time since diagnosis (Akin et al., 2008) have not been associated with self-efficacy in the limited research in other cancers. Our finding that receipt of a treatment summary was not associated with self-efficacy is interesting but not surprising. Summaries

that do not include information about self-management tasks and how to perform them may not facilitate skill-building. As has been pointed out in recent reviews (Hill et al., 2020), merely providing a plan does not predict better survivorship care outcomes. Oral cancer survivors reported lower self-efficacy than oropharyngeal cancer survivors but only in the univariate tests that did not include other variables. Post-hoc examination suggests that oral cancer survivors report more health-related QOL concerns (e.g., pain, dental issues and body image concerns), suggesting that these survivors struggle with more post-treatment challenges. Future research should evaluate the unique self-care self-efficacy concerns in this population.

The most important correlates of low self-efficacy were attitudinal. More preparedness by the treatment team, fewer information needs and fewer support needs were associated with higher self-efficacy and accounted for nearly 40% of the variance. These findings are consistent with self-efficacy theory, which proposes that efficacy is built by task-specific mastery which can be bolstered by training and practice (Bandura, 1986, 1997). Prior studies have not evaluated these variables, and thus this study adds to the general literature on modifiable knowledge and skills that could be increased to foster self-efficacy in managing post-treatment care among oral cancer survivors. Finally, depression was associated with lower self-efficacy, even after accounting for all other variables. Depression is a known barrier to self-care. In fact, low self-care is typically a way to diagnose depression and a focus of psychological treatment. The prior studies that have illustrated an association between efficacy and depression have defined it differently. Efficacy has been defined as confidence in the ability to execute coping behaviours in the face of stressors and focused more on emotional regulation (Heitzmann et al., 2011; Kohno et al., 2010; Philip et al., 2013; Yuan et al., 2014) rather than managing cancer-specific self-care tasks. Our findings extend this literature by illustrating that depression may impact confidence in managing cancer- and treatment-related self-care tasks. Taken together, these findings indicate that assessing and providing survivorship care information and skill training in recommended self-management tasks may foster greater confidence and that assessing and addressing depressive symptoms may also foster self-efficacy.

The final aim was to evaluate engagement in and correlates of self-exam. Less than half of survivors reported engaging in a self-exam in the past month, and among those conducting an exam, 44% were not comprehensive. Survivors provided with information about survivorship care by their care team and reported more self-exam self-efficacy and were more likely to engage in self-exams. Both information provision and building efficacy are modifiable factors that can be addressed with comprehensive education and training.

One strength is the characterisation of self-efficacy in managing aspects of oral cancer survivorship care, which is an understudied issue in a growing population. Limitations include the cross-sectional design and a primarily non-Hispanic White, male, married, higher income, insured and early-stage cancer sample. Levels of fear of cancer recurrence were lower than those reported among oral and

oropharyngeal cancer survivors in prior work (Casswell et al., 2021; Mirosevic et al., 2019), which may have limited the role of this variable in self-efficacy and oral self-exams. We did not assess general anxiety, which has been shown to be associated with lower self-efficacy in prior work with cancer survivors (Mystakidou et al., 2010; Papadopoulou et al., 2017; Porter et al., 2008). Finally, we relied upon self-report measures of self-exams and treatment summary receipt. The measure of oral cancer self-exam asked about performance in the last month, but guidelines do not specify frequency. This time frame may have underestimated performance.

5 | CONCLUSIONS

Many oral and oropharyngeal cancer survivors report less than ideal levels of confidence in the ability to engage in important self-management practices. Engagement in self-exams was quite low. In terms of clinical implications, it will be important for oncology care providers to assess survivors' self-efficacy for managing post-treatment care and provide evidence-based interventions to optimise self-management. Although there is limited support for specific evidence-based interventions for cancer survivors, such interventions could include skill-based education and training, symptom self-monitoring, goal setting, action planning and provision of regular feedback from the oncology care team (Hanlon et al., 2017; Howell et al., 2017). Survivors reporting low confidence in their ability to stop smoking could be referred to a tobacco cessation program or Quit Centre, survivors reporting low confidence in performing oral self-exams could be provided training in how to conduct a comprehensive exam, and survivors reporting low confidence managing dry mouth could be referred to a nutritionist for an assessment and treatment. Finally, assisting survivors who have comorbid conditions in managing cancer-related self-management tasks by providing additional support such as a survivorship navigation program may prove beneficial. Overall, this population of survivors may benefit from targeted post-treatment follow-up services.

ACKNOWLEDGEMENTS

We would like to thank the following individuals for their valuable contributions to this project: Carolina Lozada, Lisa Paddock, Alexandria Kulik, Muhammad Farooq Ahmed (NJSCR) and Wendy Huggins (NJSCR). We would like to acknowledge the following for their assistance with recruitment: the Cancer Registry of Greater California (Public Health Institute) and the New Jersey State Cancer Registry (supported by the Cancer Surveillance Research Program [CSR] and the New Jersey State Cancer Registry [NJSCR]) and the US Centers for Disease Control and Prevention's National Program of Cancer Registries. This project was supported by the National Cancer Institute under R01 CA240344-01A1, awarded to Sharon Manne Services, results and/or products in support of the research project were generated by Rutgers Cancer Institute of New Jersey Population Science Research Support Shared Resource. The content is entirely the author's responsibility.

CONFLICT OF INTEREST

The authors have no relevant financial or non-financial interests to disclose.

INFORMED CONSENT STATEMENT

Informed consent was obtained for all participants and this information is in the paper.

DATA AVAILABILITY STATEMENT

The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

ORCID

Sharon L. Manne  <https://orcid.org/0000-0002-9304-7822>

REFERENCES

- Akin, S., Can, G., Durma, Z., & Aydinler, A. (2008). The quality of life and self-efficacy of Turkish breast cancer patients undergoing chemotherapy. *European Journal of Oncology Nursing*, 12(5), 449–456. <https://doi.org/10.1016/j.ejon.2008.07.006>
- Al-Harithy, F. M., & Wazqar, D. Y. (2021). Factors associated with self-management practices and self-efficacy among adults with cancer under treatment in Saudi Arabia. *Journal of Clinical Nursing*, 30(21–22), 3301–3313. <https://doi.org/10.1111/jocn.15843>
- Ali, R., Draman, N., Mohd Yusoff, S. S., & Norsa'adah, B. (2020). Self-efficacy for coping with breast cancer in north-eastern state of peninsular Malaysia. *Asian Pacific Journal of Cancer Prevention*, 21(10), 2971–2978. <https://doi.org/10.31557/apjcp.2020.21.10.2971>
- Ang, K. K., Harris, J., Wheeler, R., Weber, R., Rosenthal, D. I., Nguyen-Tân, P. F., Westra, W. H., Chung, C. H., Jordan, R. C., Lu, C., Kim, H., Axelrod, R., Silverman, C. C., Redmond, K. P., & Gillison, M. L. (2010). Human papillomavirus and survival of patients with oropharyngeal cancer. *The New England Journal of Medicine*, 363(1), 24–35. <https://doi.org/10.1056/NEJMoa0912217>
- Badr, H., Lipnick, D., Gupta, V., & Miles, B. (2017). Survivorship challenges and information needs after radiotherapy for oral cancer. *Journal of Cancer Education*, 32(4), 799–807. <https://doi.org/10.1007/s13187-016-1048-8>
- Baldwin, A. S., Rothman, A. J., Hertel, A. W., Linde, J. A., Jeffery, R. W., Finch, E. A., & Lando, H. A. (2006). Specifying the determinants of the initiation and maintenance of behavior change: An examination of self-efficacy, satisfaction, and smoking cessation. *Health Psychology*, 25(5), 626–634. <https://doi.org/10.1037/0278-6133.25.5.626>
- Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Prentice-Hall, Inc.
- Bandura, A. (1997). *Self-efficacy: The exercise of control*. W H Freeman/Times Books/Henry Holt & Co.
- Boyes, A., Girgis, A., & Lecathelinais, C. (2009). Brief assessment of adult cancer patients' perceived needs: Development and validation of the 34-item Supportive Care Needs Survey (SCNS-SF34). *Journal of Evaluation in Clinical Practice*, 15(4), 602–606. <https://doi.org/10.1111/j.1365-2753.2008.01057.x>
- Bunkarn, O., & Kusol, K. (2021). The relationship between perceived self-efficacy and cervical cancer screening among village health volunteers in Suratthani Province, Thailand. *Asian Pac J Cancer Prev*, 22(1), 179–183. <https://doi.org/10.31557/apjcp.2021.22.1.179>
- Cancer Stats and Figures. (2022). <https://www.cancer.org/research/cancer-facts-statistics/all-cancer-facts-figures/cancer-facts-figures-2022.html>
- Cardoso, R. C., Kamal, M., Zaveri, J., Chambers, M. S., Gunn, G. B., Fuller, C. D., Lai, S. Y., Mott, F. E., McMillan, H., & Hutcheson, K. A. (2021). Self-reported trismus: Prevalence, severity and impact on quality of life in oropharyngeal cancer survivorship: A cross-sectional survey report from a comprehensive cancer center. *Support Care Cancer*, 29(4), 1825–1835. <https://doi.org/10.1007/s00520-020-05630-7>
- Cardoso, R. C., Qazali, A., Zaveri, J., Chambers, M. S., Gunn, G. B., Fuller, C. D., Lai, S. Y., Mott, F. E., & Hutcheson, K. A. (2018). Self-reported oral morbidities in long-term oropharyngeal cancer survivors: A cross-sectional survey of 906 survivors. *Oral Oncology*, 84, 88–94. <https://doi.org/10.1016/j.oraloncology.2018.07.006>
- Carneiro-Neto, J. N., de Menezes, J. D., Moura, L. B., Massucato, E. M., & de Andrade, C. R. (2017). Protocols for management of oral complications of chemotherapy and/or radiotherapy for oral cancer: Systematic review and meta-analysis current. *Medicina Oral, Patología Oral Y Cirugía Bucal*, 22(1), e15–e23. <https://doi.org/10.4317/medoral.21314>
- Casswell, G., Gough, K., Drosdowsky, A., Bressel, M., Coleman, A., Shrestha, S., D'Costa, I., Fua, T., Tiong, A., Liu, C., Rischin, D., & McDowell, L. (2021). Fear of cancer recurrence in survivors of human papillomavirus-associated oropharyngeal carcinoma. *International Journal of Radiation Oncology, Biology, Physics*, 111(4), 890–899. <https://doi.org/10.1016/j.ijrobp.2021.07.006>
- Charlson, M. E., Pompei, P., Ales, K. L., & MacKenzie, C. R. (1987). A new method of classifying prognostic comorbidity in longitudinal studies: Development and validation. *Journal of Chronic Diseases*, 40(5), 373–383. [https://doi.org/10.1016/0021-9681\(87\)90171-8](https://doi.org/10.1016/0021-9681(87)90171-8)
- Chaturvedi, A. K., Engels, E. A., Pfeiffer, R. M., Hernandez, B. Y., Xiao, W., Kim, E., Jiang, B., Goodman, M. T., Sibug-Saber, M., Cozen, W., Liu, L., Lynch, C. F., Wentzensen, N., Jordan, R. C., Altekruze, S., Anderson, W. F., Rosenberg, P. S., & Gillison, M. L. (2011). Human papillomavirus and rising oropharyngeal cancer incidence in the United States. *Journal of Clinical Oncology*, 29(32), 4294–4301. <https://doi.org/10.1200/jco.2011.36.4596>
- Chen, S. C., Lai, Y. H., Liao, C. T., Chang, J. T., Lin, C. Y., Fan, K. H., & Huang, B. S. (2013). Supportive care needs in newly diagnosed oral cavity cancer patients receiving radiation therapy. *Psychooncology*, 22(6), 1220–1228. <https://doi.org/10.1002/pon.3126>
- Cohen, E. E., LaMonte, S. J., Erb, N. L., Beckman, K. L., Sadeghi, N., Hutcheson, K. A., Stubblefield, M. D., Abbott, D. M., Fisher, P. S., Stein, K. D., Lyman, G. H., Pratt-Chapman, M. L., & Pratt-Chapman, M. L. (2016). American Cancer Society head and neck cancer survivorship care guideline. *CA: A Cancer Journal for Clinicians*, 66(3), 203–239. <https://doi.org/10.3322/caac.21343>
- Coroiu, A., Moran, C., Bergeron, C., Drapeau, M., Wang, B., Kezouh, A., Ernst, J., Batist, G., & Körner, A. (2020). Short and long-term barriers and facilitators of skin self-examination among individuals diagnosed with melanoma. *BMC Cancer*, 20(1), 123. <https://doi.org/10.1186/s12885-019-6476-5>
- Denlinger, C. S., Ligibel, J. A., Are, M., Baker, K. S., Broderick, G., Demark-Wahnefried, W., Friedman, D. L., Goldman, M., Jones, L. W., King, A., Ku, G. H., Kvale, E., Langbaum, T.S., McCabe, M. S., Melisko, M., Montoya, J. G., Mooney, K., Morgan, M. A., Moslehi, J. J., ... Freedman-Cass, D. A. (2016). NCCN guidelines insights: Survivorship, version 1.2016. *Journal of the National Comprehensive Cancer Network*, 14(6), 715–724. <https://doi.org/10.6004/jnccn.2016.0073>
- Dingman, C., Hegedus, P. D., Likes, C., McDowell, P., McCarthy, E., & Zwilling, C. (2008). A coordinated, multidisciplinary approach to caring for the patient with head and neck cancer. *The Journal of Supportive Oncology*, 6(3), 125–131.
- Dunne, S., Coffey, L., Sharp, L., Desmond, D., Cullen, C., O'Connor, J., O'Sullivan, E., Timon, C., & Gallagher, P. (2019). Investigating the impact of self-management behaviours on quality of life and fear of recurrence in head and neck cancer survivors: A population-based

- survey. *Psychooncology*, 28(4), 742–749. <https://doi.org/10.1002/pon.5010>
- Durosier Mertilus, D. S., Lengacher, C. A., & Rodriguez, C. S. (2022). A review and conceptual analysis of cancer pain self-management. *Pain Management Nursing*, 23(2), 168–173. <https://doi.org/10.1016/j.pmn.2021.04.005>
- Epstein, J. B., Thariat, J., Bensadoun, R. J., Barasch, A., Murphy, B. A., Kolnick, L., Popplewell, L., & Maghami, E. (2012). Oral complications of cancer and cancer therapy: From cancer treatment to survivorship. *CA: A Cancer Journal for Clinicians*, 62(6), 400–422. <https://doi.org/10.3322/caac.21157>
- Follow-up Care Use Among Survivors (FOCUS) Survey. (2020, September 24). For researchers. <https://cancercontrol.cancer.gov/ocs/resources/researchers/FOCUS>
- Gillison, M. L., D'Souza, G., Westra, W., Sugar, E., Xiao, W., Begum, S., & Viscidi, R. (2008). Distinct risk factor profiles for human papillomavirus type 16-positive and human papillomavirus type 16-negative head and neck cancers. *JNCI: Journal of the National Cancer Institute*, 100(6), 407–420. <https://doi.org/10.1093/jnci/djn025>
- Greene, J., & Hibbard, J. H. (2012). Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *Journal of General Internal Medicine*, 27(5), 520–526. <https://doi.org/10.1007/s11606-011-1931-2>
- Grimmett, C., Haviland, J., Winter, J., Calman, L., Din, A., Richardson, A., Smith, P. W., & Foster, C. (2017). Colorectal cancer patient's self-efficacy for managing illness-related problems in the first 2 years after diagnosis, results from the ColoREctal Well-being (CREW) study. *Journal of Cancer Survivorship*, 11(5), 634–642. <https://doi.org/10.1007/s11764-017-0636-x>
- Hanlon, P., Daines, L., Campbell, C., McKinstry, B., Weller, D., & Pinnock, H. (2017). Telehealth interventions to support self-management of long-term conditions: A systematic meta-review of diabetes, heart failure, asthma, chronic obstructive pulmonary disease, and cancer. *Journal of Medical Internet Research*, 19(5), e172. <https://doi.org/10.2196/jmir.6688>
- Head and Neck Cancers. (2022, February 2022). NCCN guidelines. <https://www.nccn.org/guidelines/guidelines-detail?category=1&id=1437>
- Heitzmann, C. A., Merluzzi, T. V., Jean-Pierre, P., Roscoe, J. A., Kirsh, K. L., & Passik, S. D. (2011). Assessing self-efficacy for coping with cancer: Development and psychometric analysis of the brief version of the Cancer Behavior Inventory (CBI-B). *Psychooncology*, 20(3), 302–312. <https://doi.org/10.1002/pon.1735>
- Hill, R. E., Wakefield, C. E., Cohn, R. J., Fardell, J. E., Brierley, M. E., Kothe, E., Jacobsen, P. B., Hetherington, K., & Mercieca-Bebber, R. (2020). Survivorship care plans in cancer: A meta-analysis and systematic review of care plan outcomes. *The Oncologist*, 25(2), e351–e372. <https://doi.org/10.1634/theoncologist.2019-0184>
- Hinz, A., Mehnert, A., Kocalevent, R. D., Brähler, E., Forkmann, T., Singer, S., & Schulte, T. (2016). Assessment of depression severity with the PHQ-9 in cancer patients and in the general population. *BMC Psychiatry*, 16, 22. <https://doi.org/10.1186/s12888-016-0728-6>
- Hodges, L. J., & Humphris, G. M. (2009). Fear of recurrence and psychological distress in head and neck cancer patients and their carers. *Psychooncology*, 18(8), 841–848. <https://doi.org/10.1002/pon.1346>
- Howell, D., Harth, T., Brown, J., Bennett, C., & Boyko, S. (2017). Self-management education interventions for patients with cancer: A systematic review. *Supportive Care in Cancer*, 25(4), 1323–1355. <https://doi.org/10.1007/s00520-016-3500-z>
- Jones, J. M., Cheng, T., Jackman, M., Walton, T., Haines, S., Rodin, G., & Catton, P. (2013). Getting back on track: Evaluation of a brief group psychoeducation intervention for women completing primary treatment for breast cancer. *Psychooncology*, 22(1), 117–124. <https://doi.org/10.1002/pon.2060>
- Jung, M. E., & Brawley, L. R. (2011). Exercise persistence in the face of varying exercise challenges: A test of self-efficacy theory in working mothers. *Journal of Health Psychology*, 16(5), 728–738. <https://doi.org/10.1177/1359105310388322>
- Keinki, C., Seilacher, E., Ebel, M., Ruetters, D., Kessler, I., Stellamanns, J., Rudolph, I., & Huebner, J. (2016). Information needs of cancer patients and perception of impact of the disease, of self-efficacy, and locus of control. *Journal of Cancer Education*, 31(3), 610–616. <https://doi.org/10.1007/s13187-015-0860-x>
- Kissun, D., Magennis, P., Lowe, D., Brown, J. S., Vaughan, E. D., & Rogers, S. N. (2006). Timing and presentation of recurrent oral and oropharyngeal squamous cell carcinoma and awareness in the outpatient clinic. *The British Journal of Oral & Maxillofacial Surgery*, 44(5), 371–376. <https://doi.org/10.1016/j.bjoms.2005.08.010>
- Kohno, Y., Maruyama, M., Matsuoka, Y., Matsushita, T., Koeda, M., & Matsushima, E. (2010). Relationship of psychological characteristics and self-efficacy in gastrointestinal cancer survivors. *Psychooncology*, 19(1), 71–76. <https://doi.org/10.1002/pon.1531>
- Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine*, 16(9), 606–613. <https://doi.org/10.1046/j.1525-1497.2001.016009606.x>
- Leach, C. R., Troeschel, A. N., Wiatrek, D., Stanton, A. L., Diefenbach, M., Stein, K. D., Sharpe, K., & Portier, K. (2017). Preparedness and cancer-related symptom management among cancer survivors in the first year post-treatment. *Annals of Behavioral Medicine*, 51(4), 587–598. <https://doi.org/10.1007/s12160-017-9880-6>
- Liang, S. Y., Yates, P., Edwards, H., & Tsay, S. L. (2008). Factors influencing opioid-taking self-efficacy and analgesic adherence in Taiwanese outpatients with cancer. *Psychooncology*, 17(11), 1100–1107. <https://doi.org/10.1002/pon.1326>
- Linde, J. A., Rothman, A. J., Baldwin, A. S., & Jeffery, R. W. (2006). The impact of self-efficacy on behavior change and weight change among overweight participants in a weight loss trial. *Health Psychology*, 25(3), 282–291. <https://doi.org/10.1037/0278-6133.25.3.282>
- Logemann, J. A. (2006). Medical and rehabilitative therapy of oral, pharyngeal motor disorders. *GI Motility Online*.
- Lorig, K. R., Sobel, D. S., Stewart, A. L., Brown, B. W. Jr., Bandura, A., Ritter, P., Gonzalez, V. M., Laurent, D. D., & Holman, H. R. (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: A randomized trial. *Medical Care*, 37(1), 5–14. <https://doi.org/10.1097/00005650-199901000-00003>
- Lou, Y., Yates, P., Chan, R. J., Ni, X., Hu, W., Zhuo, S., & Xu, H. (2021). Unmet supportive care needs and associated factors: A cross-sectional survey of Chinese cancer survivors. *Journal of Cancer Education*, 36(6), 1219–1229. <https://doi.org/10.1007/s13187-020-01752-y>
- Luszczynska, A., & Schwarzer, R. (2003). Planning and self-efficacy in the adoption and maintenance of breast self-examination: A longitudinal study on self-regulatory cognitions. *Psychology and Health*, 18(1), 93–108. <https://doi.org/10.1080/0887044021000019358>
- Manne, S., Hudson, S., Frederick, S., Mitarotondo, A., Baredes, S., Kalyoussef, E., Ohman-Strickland, P., & Kashy, D. A. (2020). e-Health self-management intervention for oral and oropharyngeal cancer survivors: Design and single-arm pilot study of empowered survivor. *Head & Neck*, 42(11), 3375–3388. <https://doi.org/10.1002/hed.26403>
- Manne, S., Hudson, S. V., Baredes, S., Stroup, A., Virtue, S. M., Paddock, L., & Kalyoussef, E. (2016). Survivorship care experiences, information, and support needs of patients with oral and oropharyngeal cancer. *Head & Neck*, 38(Suppl 1), E1935–E1946. <https://doi.org/10.1002/hed.24351>
- Manne, S., Kashy, D., Albrecht, T., Wong, Y. N., Flamm, A. L., Benson, A. B., & Meropol, N. J. (2014). Knowledge, attitudes, and self-efficacy as predictors of preparedness for oncology clinical trials: A

- mediational model. *Med Decis Making*, 34(4), 454–463. <https://doi.org/10.1177/0272989x13511704>
- Massa, S. T., Rohde, R. L., McKinstry, C., Gresham, M., Osazuwa-Peters, N., Ward, G. M., & Walker, R. J. (2018). An assessment of patient burdens from head and neck cancer survivorship care. *Oral Oncol*, 82, 115–121. <https://doi.org/10.1016/j.oraloncology.2018.04.024>
- Mathew, B., Sankaranarayanan, R., Wesley, R., & Nair, M. K. (1995). Evaluation of mouth self-examination in the control of oral cancer. *British Journal of Cancer*, 71(2), 397–399. <https://doi.org/10.1038/bjc.1995.81>
- Mayne, S. T., Cartmel, B., Kirsh, V., & Goodwin, W. J. Jr. (2009). Alcohol and tobacco use prediagnosis and postdiagnosis, and survival in a cohort of patients with early stage cancers of the oral cavity, pharynx, and larynx. *Cancer Epidemiology, Biomarkers & Prevention*, 18(12), 3368–3374. <https://doi.org/10.1158/1055-9965.Epi-09-0944>
- Mazanec, S. R., Sattar, A., Delaney, C. P., & Daly, B. J. (2016). Activation for health management in colorectal cancer survivors and their family caregivers. *Western Journal of Nursing Research*, 38(3), 325–344. <https://doi.org/10.1177/0193945915604055>
- McDowell, L., Casswell, G., Bressel, M., Drosdowsky, A., Rischin, D., Coleman, A., Shrestha, S., D'Costa, I., Fua, T., Tiong, A., Liu, C., & Gough, K. (2021). Symptom burden, quality of life, functioning and emotional distress in survivors of human papillomavirus associated oropharyngeal cancer: An Australian cohort. *Oral Oncology*, 122, 105560. <https://doi.org/10.1016/j.oraloncology.2021.105560>
- Melchior, H., Büscher, C., Thorenz, A., Grochocka, A., Koch, U., & Watzke, B. (2013). Self-efficacy and fear of cancer progression during the year following diagnosis of breast cancer. *Psychooncology*, 22(1), 39–45. <https://doi.org/10.1002/pon.2054>
- Mirosevic, S., Thewes, B., van Herpen, C., Kaanders, J., Merckx, T., Humphris, G., Baatenburg de Jong, R. J., Langendijk, J. A., Leemans, C. R., Terhaard, C. H. J., Verdonck-de Leeuw, I. M., Takes, R., & Prins, J. (2019). Prevalence and clinical and psychological correlates of high fear of cancer recurrence in patients newly diagnosed with head and neck cancer. *Head & Neck*, 41(9), 3187–3200. <https://doi.org/10.1002/hed.25812>
- Murphy, B. A., & Gilbert, J. (2009). Dysphagia in head and neck cancer patients treated with radiation: Assessment, sequelae, and rehabilitation. *Seminars in Radiation Oncology*, 19(1), 35–42. <https://doi.org/10.1016/j.semradonc.2008.09.007>
- Mystakidou, K., Parpa, E., Tsilika, E., Gogou, P., Panagiotou, I., Galanos, A., Kouvaris, I., & Gouliamos, A. (2010). Self-efficacy, depression, and physical distress in males and females with cancer. *The American Journal of Hospice & Palliative Care*, 27(8), 518–525. <https://doi.org/10.1177/1049909110376808>
- O'Brien, K. M., Timmons, A., Butow, P., Goberman-Hill, R., O'Sullivan, E., Balfe, M., & Sharp, L. (2017). Associations between neighbourhood support and financial burden with unmet needs of head and neck cancer survivors. *Oral Oncology*, 65, 57–64. <https://doi.org/10.1016/j.oraloncology.2016.12.019>
- O'Connor, A., & Jacobsen, M. (2007). *Decisional conflict: Supporting people experiencing uncertainty about options affecting their health* (p. 41). Ottawa, Hospital Research Institute.
- Papadokos, J., McQuestion, M., Gokhale, A., Damji, A., Trang, A., Abdelmutti, N., & Ringash, J. (2018). Informational needs of head and neck cancer patients. *Journal of Cancer Education*, 33(4), 847–856. <https://doi.org/10.1007/s13187-017-1176-9>
- Papadokos, J. K., Hasan, S. M., Barnsley, J., Berta, W., Fazelzad, R., Papadokos, C. J., Giuliani, M. E., & Howell, D. (2018). Health literacy and cancer self-management behaviors: A scoping review. *Cancer*, 124(21), 4202–4210. <https://doi.org/10.1002/cncr.31733>
- Papadopoulou, C., Kotronoulas, G., Schneider, A., Miller, M. I., McBride, J., Polly, Z., Bettles, S., Whitehouse, A., McCann, L., Kearney, N., & Maguire, R. (2017). Patient-reported self-efficacy, anxiety, and health-related quality of life during chemotherapy: Results from a longitudinal study. *Oncology Nursing Forum*, 44(1), 127–136. <https://doi.org/10.1188/17.Onf.127-136>
- Penner, J. L. (2009). Psychosocial care of patients with head and neck cancer. *Seminars in Oncology Nursing*, 25(3), 231–241. <https://doi.org/10.1016/j.soncn.2009.05.008>
- Perkins, H. Y., Baum, G. P., Taylor, C. L., & Basen-Engquist, K. M. (2009). Effects of treatment factors, comorbidities and health-related quality of life on self-efficacy for physical activity in cancer survivors. *Psychooncology*, 18(4), 405–411. <https://doi.org/10.1002/pon.1535>
- Pfister, D. G., Spencer, S., Adelstein, D., Adkins, D., Anzai, Y., Brizel, D. M., Bruce, J. Y., Busse, P. M., Caudell, J. J., Cmelak, A. J., Colevas, A. D., Eisele, D. W., Fenton, M., Foote, R. L., Galloway, T., Gillison, M. L., Haddad, R. I., Hicks, W. L., Hitchcock, Y. J., ... Darlow, S. D. (2020). Head and neck cancers, version 2.2020, NCCN clinical practice guidelines in oncology. *Journal of the National Comprehensive Cancer Network*, 18(7), 873–898. <https://doi.org/10.6004/jnccn.2020.0031>
- Philip, E. J., Merluzzi, T. V., Zhang, Z., & Heitzmann, C. A. (2013). Depression and cancer survivorship: Importance of coping self-efficacy in post-treatment survivors. *Psychooncology*, 22(5), 987–994. <https://doi.org/10.1002/pon.3088>
- Porter, L. S., Keefe, F. J., Garst, J., McBride, C. M., & Baucom, D. (2008). Self-efficacy for managing pain, symptoms, and function in patients with lung cancer and their informal caregivers: Associations with symptoms and distress. *Pain*, 137(2), 306–315. <https://doi.org/10.1016/j.pain.2007.09.010>
- Rieger, J. M., Zalmanowitz, J. G., & Wolfaardt, J. F. (2006). Functional outcomes after organ preservation treatment in head and neck cancer: A critical review of the literature. *International Journal of Oral and Maxillofacial Surgery*, 35(7), 581–587. <https://doi.org/10.1016/j.ijom.2006.03.026>
- Rogers, H. W., Weinstock, M. A., Feldman, S. R., & Coldiron, B. M. (2015). Incidence estimate of nonmelanoma skin cancer (keratinocyte carcinomas) in the US population, 2012. *JAMA Dermatology*, 151(10), 1081–1086. <https://doi.org/10.1001/jamadermatol.2015.1187>
- Saeidzadeh, S., Gilbertson-White, S., Babaieasl, F., DeBerg, J., & Seaman, A. T. (2021). An integrative review of self-management interventions for treatment sequelae in adult survivors. *Oncology Nursing Forum*, 48(1), 94–111. <https://doi.org/10.1188/21.Onf.94-111>
- Saeidzadeh, S., Gilbertson-White, S., Cherwin, C. H., Reisinger, H. S., Kendell, N., Pagedar, N. A., & Seaman, A. T. (2021). Post-treatment head and neck cancer survivors' approaches to self-management: A qualitative study. *European Journal of Oncology Nursing*, 52, 101944. <https://doi.org/10.1016/j.ejon.2021.101944>
- Schwarzer, R., & Renner, B. (2000). Social-cognitive predictors of health behavior: Action self-efficacy and coping self-efficacy. *Health Psychology*, 19(5), 487–495. <https://doi.org/10.1037/0278-6133.19.5.487>
- Shinn, E. H., Basen-Engquist, K., Baum, G., Steen, S., Bauman, R. F., Morrison, W., Garden, A. S., Sheil, C., Kilgore, K., Hutcheson, K. A., Barringer, D., Yuan, Y., & Lewin, J. S. (2013). Adherence to preventive exercises and self-reported swallowing outcomes in post-radiation head and neck cancer patients. *Head & Neck*, 35(12), 1707–1712. <https://doi.org/10.1002/hed.23255>
- Silverman, S., & Society, A. C. (2003). *Oral cancer* (Vol. 1). BC Decker, Inc.
- Simard, S., & Savard, J. (2009). Fear of cancer recurrence inventory: Development and initial validation of a multidimensional measure of fear of cancer recurrence. *Support Care Cancer*, 17(3), 241–251. <https://doi.org/10.1007/s00520-008-0444-y>
- Smith, E. M., Ritchie, J. M., Summersgill, K. F., Klussmann, J. P., Lee, J. H., Wang, D., Haugen, T. H., & Turek, L. P. (2004). Age, sexual behavior and human papillomavirus infection in oral cavity and oropharyngeal cancers. *International Journal of Cancer*, 108(5), 766–772. <https://doi.org/10.1002/ijc.11633>
- Stacey, D., O'Connor, A. M., DeGrasse, C., & Verma, S. (2003). Development and evaluation of a breast cancer prevention decision aid for

- higher-risk women. *Health Expectations*, 6(1), 3–18. <https://doi.org/10.1046/j.1369-6513.2003.00195.x>
- Stanton, A. L., Ganz, P. A., Kwan, L., Meyerowitz, B. E., Bower, J. E., Krupnick, J. L., Rowland, J. H., Leedham, B., & Belin, T. R. (2005). Outcomes from the moving beyond cancer psychoeducational, randomized, controlled trial with breast cancer patients. *Journal of Clinical Oncology*, 23(25), 6009–6018. <https://doi.org/10.1200/jco.2005.09.101>
- Thariat, J., Ramus, L., Darcourt, V., Marcy, P. Y., Guevara, N., Odin, G., Poissonnet, G., Castillo, L., Ali, A. M., & Righini, C. (2012). Compliance with fluoride custom trays in irradiated head and neck cancer patients. *Support Care Cancer*, 20(8), 1811–1814. <https://doi.org/10.1007/s00520-011-1279-5>
- Tippett, D. C., & Webster, K. T. (2012). Rehabilitation needs of patients with oropharyngeal cancer. *Otolaryngologic Clinics of North America*, 45(4), 863–878. <https://doi.org/10.1016/j.otc.2012.05.005>
- Toljanic, J. A., Heshmati, R. H., & Bedard, J. F. (2002). Dental follow-up compliance in a population of irradiated head and neck cancer patients. *Oral Surgery, Oral Medicine, Oral Pathology, Oral Radiology, and Endodontics*, 93(1), 35–38. <https://doi.org/10.1016/j.moe.2002.11.6599>
- van Dongen, S. I., de Nooijer, K., Cramm, J. M., Francke, A. L., Oldenmenger, W. H., Korfage, I. J., Witkamp, F. E., Stoevelaar, R., van der Heide, A., & Rietjens, J. A. (2020). Self-management of patients with advanced cancer: A systematic review of experiences and attitudes. *Palliative Medicine*, 34(2), 160–178. <https://doi.org/10.1177/0269216319883976>
- van Osch, L., Lechner, L., Reubsat, A., Wigger, S., & de Vries, H. (2008). Relapse prevention in a national smoking cessation contest: Effects of coping planning. *British Journal of Health Psychology*, 13(Pt 3), 525–535. <https://doi.org/10.1348/135910707x224504>
- Vickberg, S. M. (2003). The Concerns About Recurrence Scale (CARS): A systematic measure of women's fears about the possibility of breast cancer recurrence. *Annals of Behavioral Medicine*, 25(1), 16–24. https://doi.org/10.1207/s15324796abm2501_03
- Windon, M. J., D'Souza, G., Faraji, F., Troy, T., Koch, W. M., Gourin, C. G., Kiess, A. P., Pitman, K. T., Eisele, D. W., & Fakhry, C. (2019). Priorities, concerns, and regret among patients with head and neck cancer. *Cancer*, 125(8), 1281–1289. <https://doi.org/10.1002/cncr.31920>
- Wu, F., Howell, D., Fang, Q., Chen, J., & Yuan, C. (2020). Trajectory patterns and factors influencing self-management behaviors in Chinese patients with breast cancer. *Cancer Nursing*, 43(2), E105–e112. <https://doi.org/10.1097/ncc.0000000000000681>
- Yuan, C., Wei, C., Wang, J., Qian, H., Ye, X., Liu, Y., & Hinds, P. S. (2014). Self-efficacy difference among patients with cancer with different socioeconomic status: Application of latent class analysis and standardization and decomposition analysis. *Cancer Epidemiology*, 38(3), 298–306. <https://doi.org/10.1016/j.canep.2014.02.012>
- Ziner, K., Sledge, G., Bell, C., Johns, S., Miller, K., & Champion, V. (2012). Predicting fear of breast cancer recurrence and self-efficacy in survivors by age at diagnosis. *Oncology Nursing*, 39, 287–295.

How to cite this article: Manne, S. L., Hudson, S. V., Kashy, D. A., Imanguli, M., Pesanelli, M., Frederick, S., & Van Cleave, J. (2022). Self-efficacy in managing post-treatment care among oral and oropharyngeal cancer survivors. *European Journal of Cancer Care*, 31(6), e13710. <https://doi.org/10.1111/ecc.13710>