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Research

Managing Lymphedema and Fibrosis in Head and Neck Cancer Survivors: A Data Analysis on Self-Care Behaviors

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ABSTRACT

Objectives: Head and neck cancer survivors (HNCS) often face lymphedema and fibrosis (LEF) post-treatment, which require long-term self-management to minimize LEF progression and its negative impact on quality of life. This secondary data analysis aims to evaluate self-care, LEF status, and symptom burden among HNCS, and to examine the associations among self-care status, LEF status, and symptom burden in HNCS.

Methods: Descriptive statistics summarized the sample and variable distributions. Bivariate analysis assessed associations between variables. Multiple linear regression tested for associations, incorporating moderators including health literacy, self-efficacy, anxiety, and depression.

Results: Most participants ($N = 59$) were non-Hispanic (98.3%), White (89.8%), and males (83.1%). On average, participants had 2.68 anatomical sites affected by LEF in the head and neck region and spent 20.29 minutes daily on self-care. Participants spent more time (minutes per day) on self-care when their LEF was more severe ($P < .05$). Participants with worse symptom burden spent more time (minutes per day) conducting self-care activities ($P < .05$). Self-efficacy moderated the relationship between time spent on self-care and the number of sites involved with LEF. Furthermore, anxiety and depression moderated the relationship between time spent on self-care and symptom burden.

Conclusions: HNCS with more severe LEF and worse symptom burden spent more time on self-care. Self-efficacy, anxiety, and depression may moderate self-care behaviors. Findings highlight the importance of self-care management strategies to address self-efficacy and psychological factors to maximize engagement and LEF outcomes. Further investigation is warranted.

Implications for Nursing Practice: Nurses play a critical role in supporting HNCS with LEF. This study highlights the importance of assessing both the physical and psychological aspects of survivorship care. Nurses should routinely evaluate LEF severity, symptom burden, and psychological well-being (anxiety, depression, and self-efficacy) to personalize self-care guidance.

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The incidence of head and neck cancer (HNC) has risen significantly, largely driven by the surge in human papillomavirus (HPV)-related oropharyngeal carcinoma.¹ HPV-associated HNC now affects a broader age range, including younger and middle-aged adults. Unlike traditional forms of HNC, this HPV-related subtype is not linked to smoking and generally responds better to treatment, resulting in HNC survivors (HNCS) with longer life expectancies.^{2,3} Consequently, the population of HNCS continues to grow, with over half a million survivors currently in the United States.^{4,5} The treatment for locally advanced HNC often requires multimodal approaches and is associated with significant acute and long-term toxicities. Among these, soft-tissue damage leading to secondary lymphedema and

fibrosis (LEF) is a common late effect affecting three-quarters of HNCS more than 3 months post-treatment.^{6,7}

LEF is a transtissue process manifesting as soft tissue swelling and fibrosis. It involves both internal (e.g., tongue and epiglottis) and external structures (e.g., face and neck),^{6,8,9} leading to discomfort and altered sensation. Survivors may notice diminished range of motion (ROM) and function when LEF affects the underlying connective tissue and muscle.^{8,10} Additionally, survivors may suffer from dysphagia, altered speech, airway compromise, anxiety, and negative body image. These substantial symptoms and functional deficits often profoundly diminish survivors' quality of life (QOL).^{8,10}

Complete decongestive therapy is the standard treatment practice for lymphedema and involves two distinct phases.¹¹ Phase I consists of intensive lymphedema therapy provided by a certified lymphedema therapist, while Phase II focuses on long-term self-management, carried out by the patient or a caregiver.^{12,13} For patients

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Layperson Summary

What we investigated and why

People who survive head and neck cancer often develop lymphedema and fibrosis (LEF), which can be painful and affect their quality of life. Managing LEF requires long-term daily self-care, but there is limited information on how survivors manage it and how that affects their symptoms.

How we did our research

This study looks at how self-care activities relate to the severity of LEF in head and neck cancer survivors. The study explores the link between how much time survivors spend on self-care, the severity of their LEF, and how burdensome their symptoms are. It also looks at how psychological factors (anxiety and depression) and self-efficacy affect these relationships.

What we have found

The results show that survivors with more severe LEF and worse symptoms spent more time on self-care. Self-efficacy, anxiety, and depression influenced these behaviors.

What it means

Helping survivors build confidence and manage psychological health may improve how they care for themselves and reduce LEF-related problems.

experiencing more severe soft tissue complications, routine follow-up evaluations by lymphedema therapists during the self-care phase are considered ideal. During follow-up, patients are assessed for adherence to self-care behaviors and any changes in their condition that may require a change in the care regimen. This follow-up routine is not standard practice in the United States and is often not covered by insurance. This presents a challenge because (1) soft tissue changes may progressively worsen, necessitating adjustments to the care plan; and (2) adherence to self-care routines can decline over time without consistent follow-up. Research is needed to investigate the importance of follow-up care and its impact on addressing this gap in therapy.

Although self-care is widely recognized as essential for the long-term management of LEF, a standardized approach to self-care for HNC-associated LEF has yet to be established. Currently, there are no evidence-based self-care programs (SCP) specifically addressing LEF for HNCS, leading to significant variability in clinical practice based on the training and experience of individual lymphedema therapists.^{8,14,15} As a result, some HNCS may not receive sufficient self-care education. The lack of a standardized approach to self-care reflects a critical gap in the current clinical guidelines for LEF self-management among HNCS. This highlights the need for a baseline understanding of self-care behaviors in the HNCS population. Before structured programs can be developed, we must first understand how HNCS engage in self-care and the factors that influence their behaviors.

Previous research has highlighted significant challenges in long-term self-care among HNCS with LEF, with over half of participants reporting poor adherence to self-care regimens due to low motivation, lack of confidence, and insufficient ongoing support.^{14,16,17} On the other hand, higher self-efficacy is shown to be associated with greater self-care behaviors among heart failure and diabetic patients.^{18,19} In other chronic conditions, psychological factors such as increased depression and anxiety are associated with less optimal self-care behaviors.^{18,19} Furthermore, greater health literacy is

associated with optimal self-care among diabetic patients.²⁰ Research has yet to explore the impact of psychological factors, self-efficacy, and health literacy on self-care among HNCS with LEF. Identifying these baseline factors is essential in establishing clinical guidelines for self-care interventions to ensure these programs are practical and meet the needs of HNCS.

The objective of this data analysis is to evaluate LEF self-care practices before any interventional support, with the goal of understanding how evidence-based interventions can be structured to support HNCS in the future. The aims of this study are as follows:

1. Aim 1: to evaluate self-care, LEF status, symptom burden, and jaw ROM (JROM) among HNCS.
2. Aim 2: to examine the associations among self-care status, LEF status, symptom burden, and JROM in HNCS.

Materials and Methods

Design

A secondary data analysis was conducted to examine HNCS' self-care behaviors for guiding intervention development and delivery. All data were collected as part of a pilot randomized clinical trial (parent study).²¹ The parent study aimed to evaluate the feasibility of an LEF-SCP in the HNC population by comparing three groups: (1) Usual care, (2) usual care plus LEF-SCP, and (3) usual care plus LEF-SCP plus follow-up. Additionally, it assessed the SCP's impact on self-efficacy and the benefit of routine follow-up on adherence. The parent study was approved by the Institutional Review Board (IRB) of the University of Pennsylvania. The study was conducted from June 2018 to May 2020. Detailed information about the parent study is available in previous publications.^{15,21} Secondary data analysis was approved by the IRB at the University of Pennsylvania. Only the baseline data were used and analyzed for the purpose of this report.

Sample

Participants were recruited for the parent study at the Head and Neck Cancer Clinics in the University of Pennsylvania Health System. Individuals who met the following eligibility criteria were included in the study: (1) post-HNC primary treatment; (2) no active cancer; (3) within 12 months following the completion of initial lymphedema therapy for head and neck lymphedema; (4) > 18 years of age; (5) the capacity to comprehend written English; (6) capability to participate in study activities; and (7) the capacity to provide informed consent. Individuals who had recurrent or metastatic cancer; any other active cancer; acute infection; congestive heart failure; renal failure; cardiac or pulmonary edema; sensitive carotid sinus; severe carotid blockage; or uncontrolled hypertension were excluded due to the risk of unsafe implementation of self-care of LEF. After recruitment and data cleaning, 59 participants completed the appropriate baseline data needed for the data analysis (Fig. 1). For the purpose of this report, we examined participant characteristics, self-care activities, LEF status, symptom burden, JROM, anxiety and depression, health literacy, and self-efficacy.

Measures

The primary outcome variables in this analysis were the LEF self-care activities participants reported at baseline. We utilized the LEF Self-Care Checklist, a study-specific tool, where participants record the self-care activities they performed within the last 7 days.¹⁵ This included measuring the frequency of various self-care activities, including self-manual lymph drainage, neck exercises, maintaining skin care, and wearing compression garments on a scale from 0 to

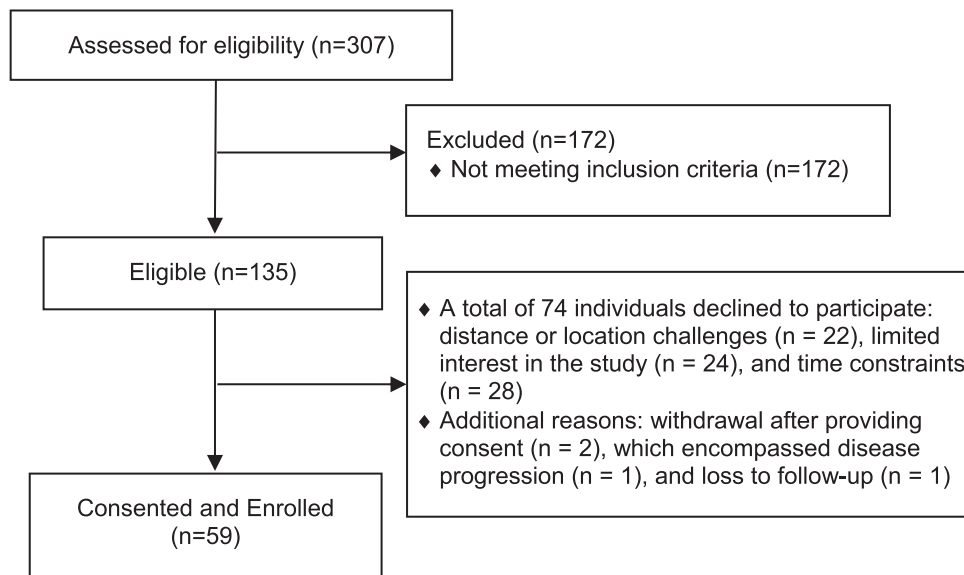


FIG 1. Study recruitment.

7 days per week. Additionally, this checklist collected data on the average number of minutes participants spent on self-care each day.

The predictors in the model were the number of sites with LEF and the total severity of LEF. These were measured with the validated tool with inter-rater reliability ($\kappa = 0.75$, $P < .001$), Head and Neck External LEF (HN-LEF) Assessment Criteria.^{22,23} The trained study staff used this tool to assess participants' head and neck external LEF status through a physical examination.²² The number of sites with LEF was defined by the number of head and neck regions where the participant developed LEF. Per the tool, the anatomical sites of LEF include the left and right peri-orbital region, left and right cheeks, left and right neck, left and right supraclavicular region, and the submental area. For each site, the severity of LEF includes no LEF (=0), mild (=1), moderate (=2), and severe (=3). The total severity of LEF was quantified by summing the severity scores for each affected site.

Symptom burden was assessed using the Head and Neck Lymphedema and Fibrosis Symptom Inventory, a validated tool for assessing LEF-related symptom burden in HNCS. The tool asks participants about the presence and burden associated with specific symptoms over the past 7 days. There are 7 symptom subscales (soft tissue and neurologic toxicity, systemic symptoms and social functioning, jaw and oral dysfunction, swallowing and taste changes, body image and sexuality, communication, and mucosal irritation) measured independently on a 5-point scale to quantify symptom intensity (1 = slight, 5 = severe). Each subscale demonstrates good reliability with a Cronbach's alpha close to 0.70.^{9,24} A higher score indicates greater symptom burden. Furthermore, we measured JROM using a validated JROM Scale.^{25,26} This measured the maximum interincisal distance (in millimeters) between the central incisors when the mouth is fully open.

The psychological factors, anxiety and depression, were assessed as potential moderators in the relationship between self-care behaviors and LEF-related outcomes. These were measured using the Hospital Anxiety and Depression Scale (HADS), a validated tool for assessing anxiety and depression symptoms in nonpsychiatric populations. The HADS has good reliability, with Cronbach's alpha values ranging from 0.84 to 0.91.²⁷ Although a score between 0 and 7 was considered within the normal range, higher scores indicate greater anxiety and/or depressive symptom burden.

In addition, we examined health literacy and self-efficacy as moderators of the self-care and LEF-related outcomes. Health literacy was measured using the Brief Health Literacy Screen, a 3-item scale with a 5-point response format. To follow the tool's user instructions, this

tool was read aloud by the trained study staff to participants. The Brief Health Literacy Screen has a Cronbach's alpha of 0.79, indicating good reliability.²⁸ Scores range from 3 to 15, with scores below 9 indicating inadequate health literacy, and higher scores reflecting greater perceived health literacy.

Self-efficacy was assessed using the 8-item Perceived Medical Condition Self-Management Scale, which evaluates how individuals perceive their ability to manage their medical condition on a 5-point scale (1 = strongly disagree, 5 = strongly agree). The total score ranges from 8 to 40, with a higher score indicating stronger belief of perceived self-management competence. The Perceived Medical Condition Self-Management Scale has demonstrated good reliability, with a Cronbach's alpha of 0.84.^{29–31}

Data Analysis

Data were analyzed using the statistical software package SAS version 9.4 by a statistician. The research team discussed all results. Missing data was omitted from the study sample. Descriptive statistics were conducted to describe the sample and the variable distributions. Bivariate analysis was conducted to explore pairwise relationships using simple regression that regresses each of self-care activities (frequency of self-manual lymph drainage, neck exercises, skin care, and wearing compression garments, and the average number of minutes on self-care each day) on each of LEF and related variables (the number of sites with LEF, the total severity of LEF, JROM, and 7 symptom burden subscale variables). We then used multiple linear regression to explore whether anxiety, depression, health literacy, or self-efficacy separately moderated the significant relationships between self-care activities and the LEF and related variables demonstrated in the simple regression models. Residual diagnostics were performed to assess the normality and homoscedasticity of residuals. All data analyses were conducted using complete cases. Statistical significance was considered to be P values below .05.

Results

Sample Characteristics

Table 1 summarizes participants' demographic and clinical characteristics. The majority of participants ($N = 59$) were non-Hispanic (98.3%), White (89.8%), and males (83.1%). The mean age of participants was 59.8 years of age. Most participants (69.5%) resided in

TABLE 1
Demographic and Clinical Characteristics (N = 59)

Characteristic		Total (N = 59)
Age	Mean (SD)	59.8 (9.8)
Sex at birth	Female	10 (16.9%)
	Male	49 (83.1%)
Race	White	53 (89.8%)
	Black or African American	5 (8.5%)
	Other	1 (1.7%)
Ethnicity	Not Hispanic	58 (98.3%)
	Hispanic	1 (1.7%)
Education	High School	18 (30.5%)
	Undergraduate	25 (42.4%)
	Graduate	16 (27.1%)
Marital status	Single/windowed/other	9 (15.3%)
	Married or single, living with a partner	50 (84.7%)
Employment	Employed	39 (66.1%)
	Unemployed/other (homemaker, retirement)	20 (33.9%)
Annual household income	Up to \$30,000	2 (3.4%)
	\$30,001-\$60,000	11 (18.6%)
	Over \$60,000	39 (66.1%)
	Do not care to respond	7 (11.9%)
Residence	City	12 (20.3%)
	Country	6 (10.2%)
	Suburb	41 (69.5%)
HNC primary location	Nasal cavity	2 (3.4%)
	Oral cavity	4 (6.8%)
	Nasopharynx	2 (3.4%)
	Oropharynx	45 (76.3%)
	Hypopharynx	1 (1.7%)
	Larynx	2 (3.4%)
	Salivary gland	2 (3.4%)
	Unknown	1 (1.7%)
HNC stage	X/unknown	3 (5.1%)
	I	23 (39.0%)
	II	16 (27.1%)
	III	8 (13.6%)
	IVa	4 (6.8%)
	IVb	5 (8.5%)
Virus	Not tested	5 (8.5%)
	No known virus	11 (18.6%)
	HPV	41 (69.5%)
	EBV	1 (1.7%)
	Other	1 (1.7%)
Surgery	No	10 (16.9%)
	Yes	49 (83.1%)
ChemoXRT (CCR)	No	25 (42.4%)
	Yes	34 (57.6%)
Radiation therapy (XRT)	No	1 (1.7%)
	Yes	58 (98.3%)

EBV, Epstein–Barr virus; HPV, human papillomavirus; SD, standard deviation.

suburbs. Most participants (69.5%) had a HPV-positive tumor and received multimodality cancer treatment (Table 1).

Aim 1: Self-Care Activities, LEF Status, Symptom Burden, and JROM

Self-Care Status

On average, participants conducted 20.29 minutes of LEF self-care daily. Self-manual lymph drainage (MLD) was conducted on average for 4.14 out of 7 days of the week. Furthermore, on average, participants completed neck exercises for 4.95 days, wore compression garments for 2.72 days, and conducted skin care for 6.66 days per week. Most (72.9%) participants wore compression garments (Table 2).

LEF Status

Participants had 2.68 anatomical sites with LEF in the head and neck region. The average total severity of LEF was 4.22 (Table 2).

TABLE 2
Self-Care Activities

Self-care activities	Overall (N = 59)
Conducting self-MLD	
<i>n</i>	49 (83.1%)
Number of days conducting self-MLD per week	
Mean	4.14
SD	2.78
Median	5
Q1, Q3	2, 7
Min, Max	0, 7
Performing neck exercise	
<i>n</i>	55 (93.2%)
Number of days performing neck exercises per week	
Mean	4.95
SD	2.13
Median	5
Q1, Q3	4, 7
Min, Max	0, 7
Conducting skin care	
<i>n</i>	56 (94.9%)
Number of days performing skin care per week	
Mean	6.66
SD	1.05
Median	7
Q1, Q3	7, 7
Min, Max	2, 7
Used compression garments	
<i>n</i>	43 (72.9%)
Number of days using compression garments per week	
Mean	2.72
SD	2.84
Median	2.00
Q1, Q3	0, 6
Min, Max	0, 7
Wore compression garments	
Yes	43 (72.9%)
No	16 (27.1%)
Total of minutes per day (of taking care of lymphedema)	
<i>n</i>	56 (94.9%)
Mean	20.29
SD	14.81
Median	15.00
Q1, Q3	10, 30
Min, Max	0, 60
Missing	3

Symptom Burden

On a 5-point scale, the HN-LEF Symptom Inventory's seven subscales: average soft tissues and neurologic toxicity was 1.32, average swallowing and taste changes was 1.14, average body image and sexuality was 0.75, average communication was 0.95, average mucosal irritation was 0.56, average systemic symptoms and social functioning was 0.86, and average jaw and oral dysfunction was 0.83 among participants. Each of the 7-subscale average and maximum scores at baseline are displayed in Fig. 2.

JROM

Participants' average JROM at baseline was 44.35 millimeters (mm). Participants' JROM average and maximum scores at baseline are displayed in Fig. 3.

Aim 2: Associations of Self-Care Activities with LEF Status, Symptom Burden, and JROM

Association Between Severity of LEF and Self-Care Activities

Bivariate analysis showed that participants spent more time (minutes per day) on self-care when their LEF was more severe. Specifically, increased self-care correlated with higher total severity of LEF ($b = 2.50$, $P = .003$, $CI = [0.91, 4.10]$) and more sites of soft tissue involved with LEF ($b = 3.81$, $P = .016$, $CI = [0.74, 6.88]$).

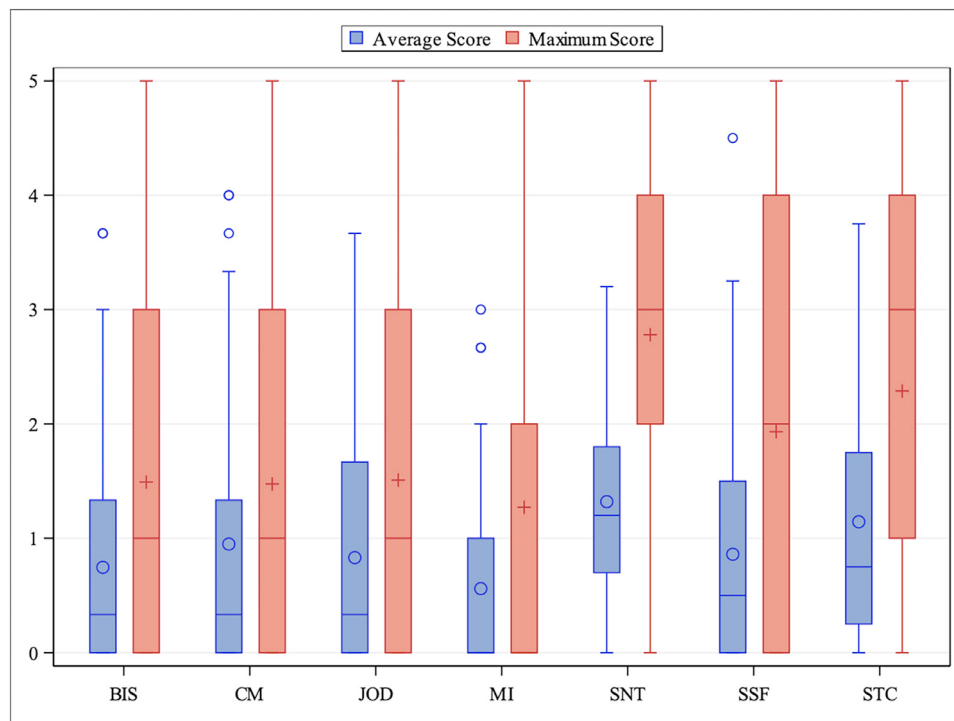


FIG 2. Interquartile range (IQR) of respective data distributions. The dark line in the box indicates the median value, and the circle or the plus sign inside the box indicates the mean value. If there are no outliers in the distribution, the upper and lower ends of the lines extending from each box represent the maximum and minimum values, respectively. If there are outliers, the end of the line represents values nearest to, but within, 1.5 times the IQR, with the circles representing values beyond 1.5 times the IQR. BIS, body image and sexuality; CM, communication; JOD, jaw and oral dysfunction; MI, mucosal irritation; SNT, soft tissue and neurologic toxicity; SSF, systemic symptoms and social functioning; STC, swallowing and taste changes.

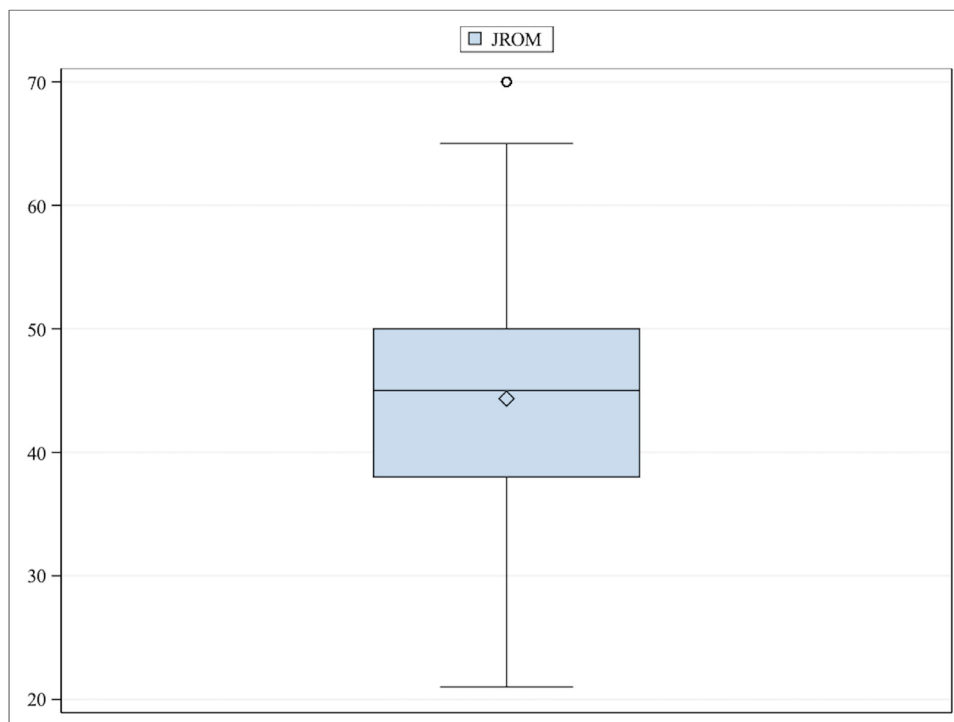


FIG 3. Interquartile range (IQR) of the JROM distribution. The dark line inside the box indicates the median, while the diamond indicates the mean. The upper and lower ends of the lines extend to the maximum and minimum values within 1.5 times the IQR from the quartiles. A single upper outlier, shown as a circle, lies beyond this range. JROM, jaw range of motion.

Association Between Severity of Symptom Burden and Self-Care Activities

Patients with worse symptom burden spent more time (minutes per day) conducting self-care activities. Specifically, increased self-care correlated with increased swallowing and taste changes ($b = 4.72, P = .010, CI = [1.16, 8.28]$), worse systemic symptoms and social functioning ($b = 5.85, P = .002, CI = [2.33, 9.36]$), and worse body image and sexuality ($b = 5.69, P = .01, CI = [1.40, 9.98]$).

Association Between Symptom Burden and Use of Compression Garment

Patients with worse body image and sexuality used compression garments more frequently ($b = 0.92, P = .02, CI = [0.15, 1.70]$).

Assessment of Moderators

For each of the simple linear regression models noted above, we then explored the moderating effect of anxiety, depression, health literacy, and self-efficacy.

The average anxiety level in the sample was 3.31, with scores ranging from a minimum of 0 to a maximum of 13. For depression, the average score was 2.29, with participants' scores ranging from 0 to 10. The average health literacy score was 13.22, with a minimum of 5 and a maximum of 15. Lastly, the self-efficacy score averaged 29.78, with scores ranging from 11 to 40.

Although the scores for anxiety and depression as measured by the HADS were generally low, the analysis showed that anxiety and depression moderated the relationships between time spent on self-care and swallowing and taste changes. Patients with lower levels of symptom burden and anxiety were less likely to perform self-care. As symptom burden increased, anxiety and depression were noted to be higher, and self-care was more frequent.

Specifically, for patients with HADS anxiety scores less than or equal to 2, the relationship between time on self-care and swallowing and taste changes was not significant ($P > .2$, e.g., when the HADS anxiety score is equal to 2, $b = 2.22, P = .22, CI = [-1.36, 5.80]$). For patients with HADS anxiety scores greater than 2, the relationship between self-care and swallowing and taste changes was statistically significant (b for interaction = 2.16, $P = .001, CI = [0.93, 3.40]$) (Fig. 4). Moderating effects were not noted with other symptom subscales.

Results for depression were similar to those observed for anxiety. For patients with HADS depression scores less than or equal to 2, the relationship between time on self-care per day and swallowing and taste changes was not significant ($P > .1$, e.g., when the HADS depression score is equal to 2, $b = 2.58, P = .12, CI = [-0.70, 5.86]$). For patients with HADS depression scores greater than 2, the relationship between self-care and swallowing and taste changes was statically significant (b for interaction = 2.74, $P < .0001, CI = [1.46, 4.02]$) (Fig. 5). Moderating effects were not noted with other symptom subscales.

Self-efficacy moderated the relationship between time spent on self-care and the number of sites with external LEF. Specifically, for patients with self-efficacy scores less than or equal to 26 (low self-efficacy), time on self-care increased with more LEF sites (b for interaction = $-0.38, P = .02, CI = [-0.70, -0.07]$). For patients with self-efficacy scores greater than 26 (high self-efficacy), the association between time on self-care and the number of LEF sites was not significant ($P > .05$, e.g., when the self-efficacy score is equal to 27, $b = 2.74, P = .06, CI = [-0.10, 5.58]$) (Fig. 6).

Discussion

Previous research has highlighted the challenges HNCS face with LEF self-care and emphasized the need for improved support for these essential efforts.^{8,14,16,17} However, no studies to date have evaluated HNCS' self-care behaviors at baseline. It is important to understand

these behaviors to tailor effective self-care management strategies to meet the needs of survivors. This study investigated self-care behaviors alongside LEF status, symptom burden, JROM, self-efficacy, health literacy, anxiety, and depression among HNCS. The results of this data analysis suggest participants spent more time on daily self-care when they had worse symptom burden and more severe LEF.

Self-Care and Symptom Burden

Our findings are consistent with other reports in that patients with higher symptom burden are more likely to engage in self-care to manage their chronic conditions.^{32,33} HNCS with higher symptom burden may be more aware of the need for self-care efforts. Of note, our results have highlighted the importance of several symptom domains that prompt self-care behaviors. These symptom domains are swallowing dysfunction and taste changes, systemic symptoms and social functioning, as well as body image and sexuality, many of which are critical functions that significantly contribute to HNCS' overall QOL.

Patients' self-care behaviors may be motivated by symptom burden. For example, the use of compression garments is one of the critical components of self-care activities. Our study observed increased engagement in the use of compression garments when participants reported worse body image and sexuality. Past results have revealed that individuals who experienced poor body image had more motivation for exercise, a form of self-care.³⁴ Our results build upon this and suggest that worsening body image and sexuality may motivate individuals to engage in self-care.

These results highlight the potential for symptom burden to drive self-care engagement, but they also suggest that patients without noticeable symptom burden may undervalue the importance of self-care. It is essential to encourage all HNCS with chronic LEF to consistently engage in preventive self-care, regardless of symptom presence, to mitigate future complications such as discomfort, altered sensations, and decreased ROM in the jaw, neck, and shoulders.^{8,10,21} The health care provider is in the critical position of highlighting the importance and benefits of self-management of LEF and providing HNCS with educational resources to encourage self-care.

Moderating Effects of Psychological Factors

A majority of participants in this study had low-level anxiety and depression scores. Our moderation analysis indicated that anxiety and depression moderate the relationship between time spent on self-care and swallowing and taste changes. Participants with increased anxiety and depression (HADS > 2) spent more time on self-care as swallowing and taste changes worsened. However, when anxiety and depression scores were low (HADS ≤ 2), the relationship was not significant. Low levels of emotional distress may drive increased engagement in self-care. Our results may indicate that low-level anxiety and depressive symptoms are critical motivators for self-care. Current literature suggests that individuals with low levels of anxiety and depression may exhibit higher levels of motivation, which in turn could improve engagement in self-care behaviors. On the other hand, individuals with higher levels of anxiety and depression may become less motivated for activities such as self-care. Moreover, these individuals may struggle with health goals because they might anticipate lower payoffs from self-care behaviors.³⁵⁻³⁹ The findings from this report emphasize the importance of integrating psychological support into self-care management for individuals with LEF to improve engagement in such behaviors. Prior research has shown that psychological factors significantly impact engagement in behavior change interventions, including SCP. Integrating psychological support, such as cognitive behavioral therapy

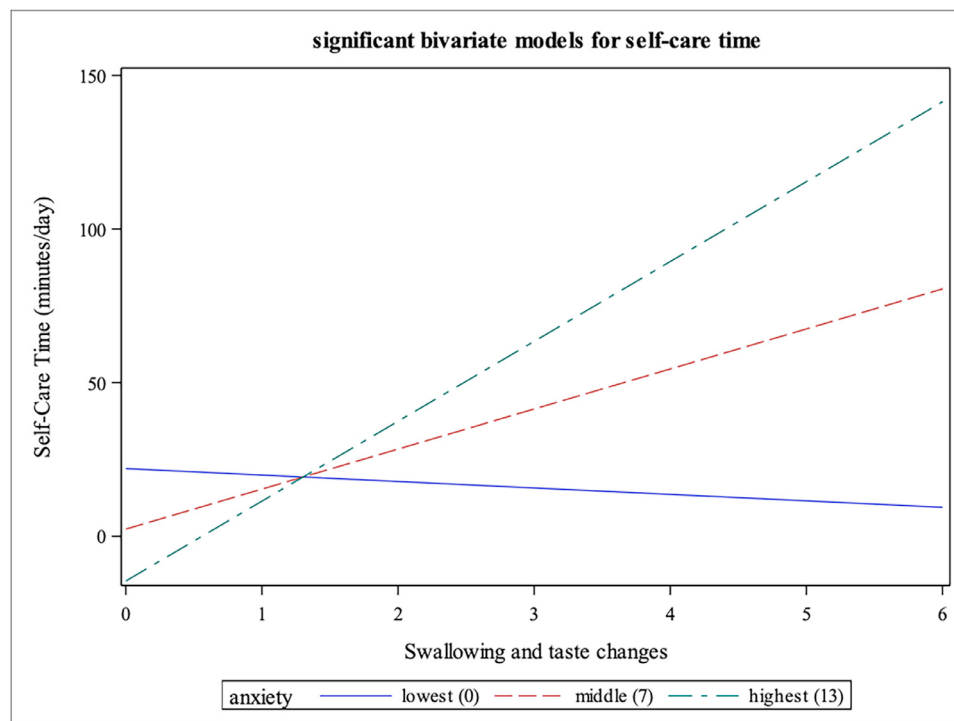


FIG 4. Relationship between self-care and swallowing and taste changes for anxiety.

or education, has been associated with self-care outcomes in chronic conditions.^{40,41}

Additionally, our moderation analysis revealed that self-efficacy moderates the relationship between time spent on self-care and the number of sites affected by LEF. Participants with low levels of self-efficacy (scores less than or equal to 26) engaged more frequently with self-care as the number of LEF sites increased; however, when

participants with high levels of self-efficacy (scores greater than 26), this relationship was no longer significant ($P > .05$). This may suggest that individuals with greater confidence in managing their condition may achieve the same benefits from self-care with reduced time and effort. Past research has shown that individuals with higher self-efficacy are better equipped to utilize self-care resources available to them, hence better managing their condition.⁴² Our findings are

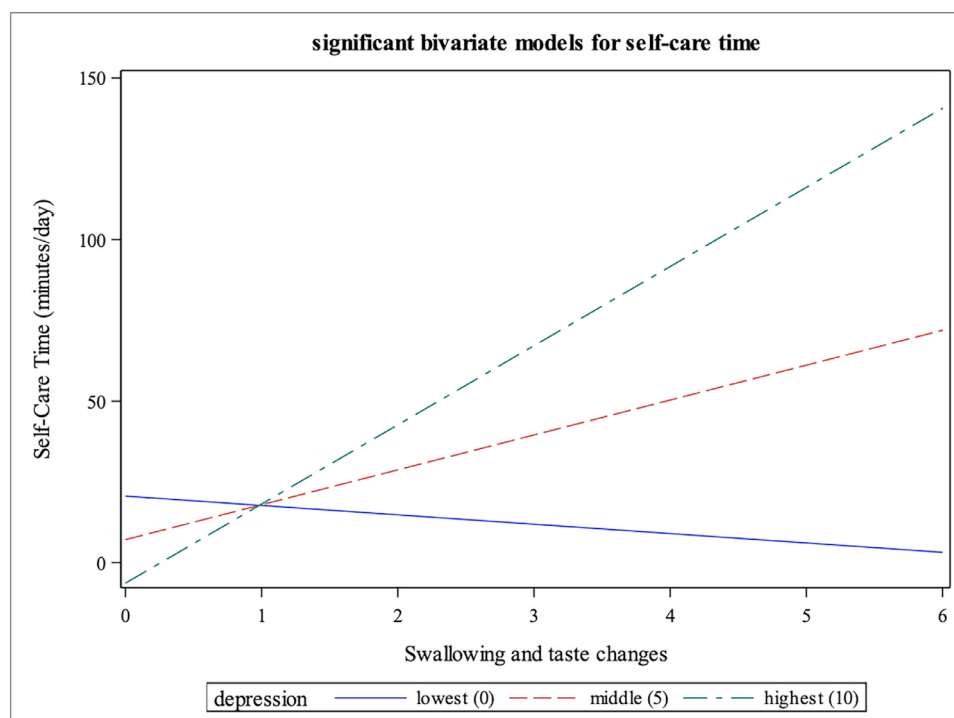


FIG 5. Relationship between self-care and swallowing and taste changes for depression.

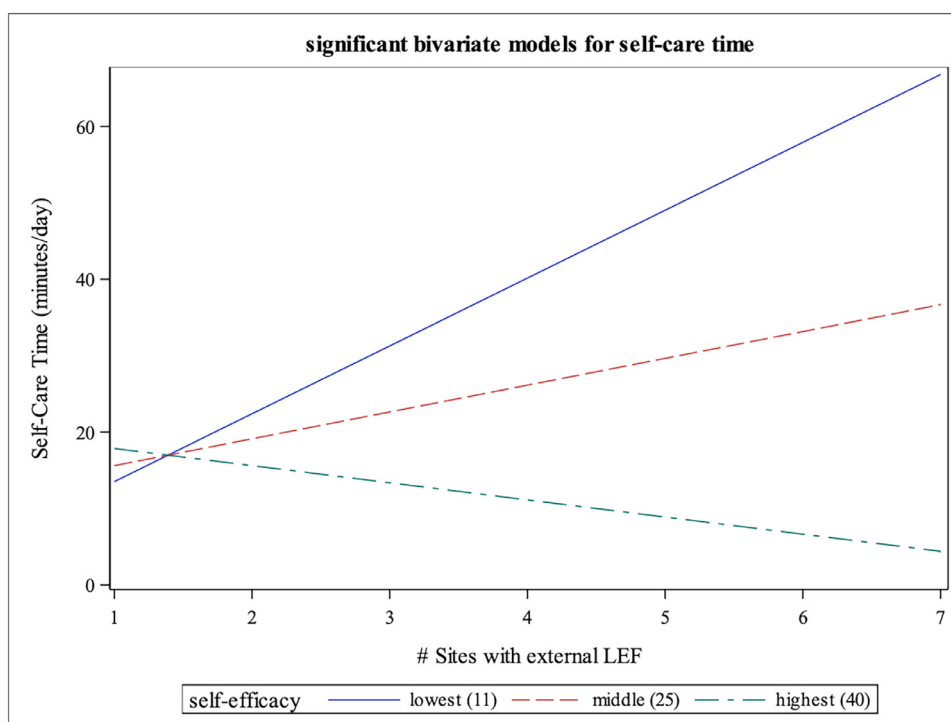


FIG 6. Association between time on self-care and the number of LEF sites for self-efficacy.

significant because they reinforce that enhancing self-efficacy should be a key focus of self-care management strategies.^{18,19} Patients may be able to manage LEF more efficiently with improved self-efficacy, minimizing disruptions to their daily routines.

Study Strengths

There are several strengths of this study. Self-care in HNC-associated LEF is understudied in the literature. This is one of the first studies to examine baseline self-care behavior in HNCS with LEF. With this data analysis, we were able to identify possible associations among LEF severity, affected sites, greater symptom burden, and time spent on self-care. We also identified possible moderation among the conditions, anxiety, depression, lower self-efficacy, and self-care behaviors. Including these moderators adds valuable nuance to survivorship care literature by highlighting how psychological health can influence self-care behaviors. These results emphasize the need to integrate these factors into self-care interventions. Furthermore, the found associations can provide a foundation for further descriptive and interventional studies evaluating self-care for LEF among HNCS.

Study Limitations

This study is not without limitations. First, this was a single-center study, which limits the generalizability of the findings to other settings. The participants in this study were demographically homogeneous in characteristics such as race/ethnicity and income, further limiting the findings' generalizability. The small sample size and non-normal distribution may have introduced skewed results. The modeling involving anxiety and health literacy should be interpreted with caution, as they both contain a very small subgroup with anxiety and low health literacy. Moreover, participants with more severe/mild symptoms may have been more or less likely to participate and motivated for self-care than nonparticipants, creating selection bias. The use of self-reported scales also introduced self-report bias into the self-care behavior reporting within the study. Lastly, our models

tested for associations, not causal relationships, and cannot predict the underlying relationships between the variables.

Implications for Nursing Practice

Nurses play a critical role in supporting HNCS with LEF. This study highlights the importance of assessing both the physical and psychological aspects of survivorship care. Nurses should routinely evaluate LEF severity, symptom burden, and psychological well-being (anxiety, depression, and self-efficacy) to personalize self-care guidance. Nursing education and training should place greater attention on survivorship care and SCP. As the number of cancer survivors continues to rise, there remains a gap in standardized guidelines for educating nurses in survivorship care. Developing a survivorship education program would enhance nurses' ability to address the physical and psychological needs of survivors, including LEF management.^{43,44}

Conclusions

HNCS with higher total LEF severity, more affected sites, and worse symptom subscales such as swallowing and taste changes, body image and sexuality, systemic symptoms, and social functioning spent more time on self-care. Compared to those with higher self-efficacy, those with lower self-efficacy were more likely to spend more time on self-care when necessary. This suggests that self-efficacy plays a key role in self-care efficacy. Furthermore, anxiety and depression show to moderate self-care behaviors. The results suggest that low levels of anxiety and depression can serve as important motivators for self-care. Hence, our analysis can inform clinical interventions and nurse-led survivorship care planning by highlighting the importance of self-care management strategies to address self-efficacy and psychological factors to maximize engagement and LEF outcomes. By incorporating these elements, nurses can better support HNCS in managing LEF and its associated challenges, improving survivors' QOL.

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Ethics Approval

The study was approved by the Institutional Review Board at the study site.

Consent to Participate

All participants signed informed consent forms.

Declaration of competing interest

The authors have no relevant relationships, patents, and intellectual property, or other activities to disclose.

CRediT authorship contribution statement

Jessica Abene: Writing – review & editing, Writing – original draft, Visualization, Validation, Project administration, Methodology, Conceptualization. **Liming Huang:** Writing – review & editing, Software, Formal analysis. **Barbara A. Murphy:** Writing – review & editing, Investigation, Conceptualization. **Jie Deng:** Writing – review & editing, Visualization, Validation, Supervision, Project administration, Methodology, Investigation, Data curation, Conceptualization.

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