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Adherence to Preventive Exercises and Self-Reported Swallowing Outcomes in Post-Radiation Head and Neck Cancer Patients

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Abstract

Background—To reduce the risk of long-term swallowing complications after radiation, swallowing exercises may be helpful. Both the rate of adherence to swallowing exercises and its impact on future swallowing function is unknown.

Methods—109 oropharyngeal cancer patients beginning radiation were tracked for two years to determine adherence to swallowing exercises. Participants completed the M.D. Anderson Dysphagia Inventory (MDADI) 1–2 years after treatment to assess self-reported swallowing function. Adherence, demographics, tumor and treatment variables were multivariably regressed onto the MDADI physical subscale score.

Results—Per speech pathologist documentation, 13% of the participants were fully adherent and 32% were partially adherent. Adherence was associated with the Physical MDADI Subscale score in the multivariate model ($p=.01$).

Conclusions—The majority of head and neck cancer patients are nonadherent to swallowing exercise regimens and may benefit from supportive care strategies to optimize their adherence.

Keywords

Adherence; dysphagia; exercises; oropharyngeal cancer

INTRODUCTION

Long-term swallowing problems affect between 13–30% of all oropharyngeal cancer survivors after nonsurgical cancer treatment.^{1,2} For oropharynx cancer, large-field radiation is almost always used and encompasses the salivary parotid glands and key swallowing structures including the base of tongue, pharyngeal constrictors, strap muscles.³ Unfortunately radiation to these areas can result in long-term complications including

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trismus,⁴ loss of taste and fibrosis of the skin and soft tissue.⁵ In addition, concurrent cisplatin chemotherapy is standard, further increasing the risk for long-term dysphagia.⁶ To diminish these problems, patients can do a series of exercises before and during treatment to promote strength, mobility and endurance of base of tongue, pharyngeal constrictors and suprahyoid strap muscles. These exercises include the Shaker, Mendelsohn, Supraglottic swallow, Pitch glide, Masako, effortful swallow and jaw stretching.^{22,39,40} Recent data point to these exercises as a promising method in preventing dysphagia and are a standard preventive regimen recommended by speech pathologists in many head and neck radiation therapy programs nationwide.⁷⁻⁹ Optimally, oropharyngeal cancer patients should perform these exercises during radiation before fibrosis occurs; however because these exercises can become painful as treatment progresses, patients are encouraged to do what they can until their pain subsides.

At the University of Texas MD Anderson Cancer Center (MDACC), patients are referred to the Speech Pathology service for comprehensive baseline evaluation of swallowing function, which often includes videofluoroscopy, a modified barium swallow, to determine physiology and swallow deficits. Based on examination findings, a targeted preventive swallowing program is designed that frequently includes 11 exercises to improve laryngeal elevation, air protection and supraglottic swallow, depending on each patient's specific needs.¹⁰

Despite the potential benefit to long-term swallowing, the rate of patients' adherence to swallowing exercises during radiation has not been studied extensively.⁸ Therefore we assessed adherence to preventive exercise regimens in oropharyngeal cancer patients both during and after their radiation treatment along with reasons for adherence or nonadherence. As a secondary outcome, we also evaluated patients' perceptions regarding their swallowing function 1–2 years after their treatment was completed.

METHOD

Sample

Following Institutional Review Board approval, we evaluated all speech pathology medical records of 127 newly diagnosed oropharyngeal cancer patients receiving radiation treatment at MDACC. These participants had enrolled into a larger prospective psychosocial study assessing the utility of a depression intervention program between April 2005 and May 2007. Participants who had: a) not been referred to speech pathology, b) were irradiated for recurrent oropharyngeal cancer, or c) had distant metastasis at the time of treatment were excluded from the current study. A total of 109 patients who were taught swallowing exercises met inclusion criteria for this study.

Design

After providing written consent, participants were enrolled at the beginning of radiation treatment, which lasted 6 weeks, and followed until the last available speech pathology record (median length of follow-up is 1.8 years). Adherence to speech pathology exercises was recorded prospectively in the electronic medical record by speech pathologists. Each speech pathology record was abstracted to determine whether the participant had attended his or her initial Speech Pathology appointment to learn swallowing exercises and whether the participant was adherent to his or her exercises as demonstrated to the speech pathologist during subsequent follow-up visits. The initial speech pathology visit occurred either one week before radiation or 3 months before radiation for those patients undergoing induction chemotherapy. During radiation, all participants were scheduled with Speech Pathology for

two follow-up appointments during weeks 3 and 6 to assess adherence and monitor changes in swallowing function.

Six months after completion of radiation, participants were interviewed by telephone to assess reasons for nonadherence. Finally, 1–2 years after completion of radiation treatment, the MDADI was administered to determine participants' self-reported swallowing function (please see Figure 1).

Measures

Definitions of Adherence Adherence was defined categorically as fully adherent to the swallowing exercises, partially adherent, or nonadherent. Participants were considered *fully adherent* if speech pathology follow-up records documented that the patient had demonstrated adequate competency of all assigned swallowing exercises to their speech pathologist (While this measure may be considered more a parameter of skill rather than of adherence to daily practice, it was not possible for participants to demonstrate competency to the speech pathologist at later follow up appointments if they had not practiced regularly at home). Participants were considered *partially adherent* if speech pathology follow-up records documented patients' adequate competency with some but not all assigned exercises. Finally, participants were considered *nonadherent* if a) the speech pathologist's follow-up records documented that the patient was unable to demonstrate the swallowing exercise and needed to be re-taught the exercises, or b) if the speech pathology record documented complete nonadherence to swallowing exercises (e.g., the patient told the speech pathologist that he or she was not performing their swallowing exercises at all).

Reasons for nonadherence were retrospectively assessed by trained research staff via telephone with a structured interview asking participants a series of questions for each of the 11 swallowing exercises commonly prescribed at MDACC. During the interview, a description of each individual exercise was read out loud to the participant and then participants were asked whether a) the exercise was assigned to him or her, b) whether they did the exercise during radiation, and c) for how many weeks during radiation. Participants were then asked the accompanying reasons for nonadherence or adherence, whichever was the case. Patients were not told the reason for this telephone assessment and were not asked about their swallowing functioning.

MD Anderson Dysphagia Inventory (MDADI) The MDADI measures swallowing-related quality of life (QOL) in patients with head and neck cancer. It evaluates the patient's physical (P), emotional (E) and functional (F) perceptions of swallowing dysfunction. This instrument has high internal consistency (.85 to .93), and demonstrated good construct validity with the SF-36 subscales.¹¹

Demographic and medical information were collected at the beginning of radiation therapy. Age, gender, stage of disease, whether or not the participant had received percutaneous endogastric tube feeding, and receipt of induction and concurrent chemotherapy status were abstracted from the medical record.

Statistical Plan

For general categorical adherence, the number of fully, partially or nonadherent participants per speech pathologists' documentation were divided by the number of participants who had been taught their swallowing exercises. For the secondary analyses comparing effect of adherence on MDADI score, adherence was dichotomized into nonadherent versus partial/full adherence. MDADI subscale score means were compared by adherence status using t-tests. Next, a multivariate model was created containing all variables of interest: tumor size

(T3/T4 vs T1/T2), percutaneous endoscopic gastrostomy (PEG) tube use, concurrent chemotherapy (dichotomized into concurrent chemotherapy vs not), age, gender, and adherence. The final model regressed these factors onto the major variable of interest, the MDADI physical subscale score.

RESULTS

Sample characteristics

Of the 127 participants whose records were reviewed, 109 had been taught swallowing exercises by speech pathologists at MDACC (86%) and were included in this study. Of the 18 participants who had not been taught their exercises, 15 had attended the initial speech pathology evaluation but not the follow-up appointment to be taught swallowing exercises, and 3 did not attend their scheduled speech pathology appointments. Eighty-seven percent of the sample were men, the age range was 31 to 79, and 92% of the patients were diagnosed with stage III-IVB disease (see Table 1 for sample characteristics).

Adherence to Swallowing Exercises

Adherence data per speech pathology documentation was available for 98 of the 109 participants (89%) who had been taught swallowing exercises. Of the 11 participants for whom no adherence data was available, 9 did not have adherence data documented in the medical record, 1 participant did not have follow-up speech pathology appointments due to multiple hospitalizations and 1 participant died shortly after enrollment. Of the 98 participants for whom adherence data was available, 55% were nonadherent, 32% were noted to be partially adherent, and 13% fully adherent (See Table 2).

Adherence to Exercise During Radiation

Of the 109 patients who had been taught swallowing exercises, 86 participants were taught the exercises during radiation. The other 23 participants delayed follow-up with speech pathology services until after radiation. When restricting the sample to those who were taught exercises during radiation, adherence data was available for 78 participants. The rate of fully adherent participants was slightly higher during radiation (15%) but the nonadherence rate (49%) and partial adherence rate (36%) were similar (see Table 2).

Self-reported Amount of Exercise Adherence

Sixty-five of the 109 participants who had been taught their exercises were reached by telephone to complete the Adherence Scale to determine the number of exercises performed and for how many weeks during radiation. The resulting descriptive data for the number of exercises performed are provided in Figure 2. For the participants who were partially adherent, the mean number of exercises performed was 7 (Std Dev =2), and the mean number of weeks that the participant did the exercises during radiation was 4.7 (Std Dev= 1.5).

Reasons for nonadherence

Among the participants who were interviewed by telephone, 38 participants (58%) reported that they did not attempt the exercises even one time after being taught by the speech pathologist. When asked for reasons, the 38 nonadherent participants gave one or more reasons for nonadherence (Table 3). The two most common reasons for nonadherence can be characterized by a general lack of understanding about the importance of the swallowing exercises and radiation side effects (such as pain, fatigue and nausea) interfering with their ability or motivation to do the exercises. The third most common reason was forgetting to do the exercises.

Relationship between Adherence and Swallowing-related Quality of Life

In univariate models, adherence per speech pathologist documentation was significantly associated with each of the MDADI subscale scores. For the emotional subscale, which ascertains concepts such as embarrassment and social concerns around eating, partially/fully adherent participants' mean MDADI subscale score was 87 compared to nonadherent group, 78 ($p=.01$). For the functional subscale score, which asks about limitations on work-related and social functioning, partially/fully adherent participants' mean MDADI subscale score was 88 compared to 80 in the nonadherent group ($p=.009$). For the physical subscale, which contains various items such as "I cough when I try to drink liquids," or "Swallowing takes great effort," partially/fully adherent patients mean MDADI subscale score was 79 compared to 70 in the nonadherent group ($p=.03$; See Table 4).

Multivariate results

None of the potential confounding variables were significantly related to the MDADI physical subscale, which was the major outcome of interest. However, gender, age, T size, PEG use and concurrent chemotherapy were included in the model because these variables are known to potentially be related to adherence and/or swallowing function.^{3,12,13} When these variables are included in the model the relationship with MDADI physical and partial/full adherence is basically unaffected indicating minimal confounding. In the final model, adherence was the only variable to remain significantly associated with the MDADI Physical Subscale score ($F=5.5$, $p=.02$, $n=78$; Table 5).

DISCUSSION

The key findings of our study is that patient adherence to swallowing exercise is low, ranging from 13% for full adherence to 32% for partial adherence. Furthermore, adherence to swallowing exercise is associated with self-reported swallowing functioning 1–2 years after radiation treatment. Recent studies suggest that motor exercise before and during radiation may reduce long-term dysphagia in advanced head and neck cancer patients.^{13,14,20} In 2006, Kulbersh et al. reported significant improvement in dysphagia among 37 hypopharynx, larynx, and oropharynx cancer patients who were non-randomly assigned to start four swallowing exercises during radiation.¹⁴ In a randomized study with irradiated head and neck cancer patients, Carnaby-Mann et al. demonstrated that oropharynx cancer patients randomized to a motor swallowing exercise regimen during radiation had less structural deterioration in the genioglossus, mylohyoid and hyoglossus as determined by magnetic resonance imaging at 6 week follow-up.¹⁵ However, while patients randomized to the exercise regimen did report fewer problems in oral feeding on the Functional Oral Intake Scale after the six-week followup, this reduction was nonsignificant, as were weighted change scores on videofluoroscopic assessment ($n=58$).

Other studies have reported adherence rates to exercise regimens during radiation. In a trial of 49 head and neck cancer patients randomized to either standard range of motion exercises or device-based therapy, Van der Molen et al. retrospectively assessed adherence via two self-report items estimating duration of adherence in days and familiarity with exercises 10 weeks after treatment. They found that 14% of the total sample reported doing exercises every day during the entire radiation treatment and follow-up period, and that 57% stopped their exercises after an average of 3.5 weeks. In general, comprehensive evaluation of patient adherence to prescribed exercises is difficult to assess, in part because not all head and neck cancer patients undergoing radiation are prescribed exercises as a preventive measure. Instead, many patients are referred to speech pathologists after swallowing problems have manifested and these referral patterns at comprehensive cancer centers are unknown.

The overall low rates of adherence may be surprising in light of the fact that participants knew they were in a study assessing adherence. However, it should be pointed out that during consent, adherence was explained as just one of several purposes of the study. In light of competing demands during radiation, it is likely that most participants were not actively anticipating that their adherence to swallowing exercises would be assessed. The most prevalent reasons for nonadherence among our participants seemed to be lack of understanding about the importance of the swallowing exercise, the effort involved, and forgetting. Another reason may be that during the time of our study, our clinical collaborators (WM, AG) recalled that they did not reinforce either the importance of attending follow-up speech pathology appointments or adherence to the radiation swallowing exercise protocol, because it was not yet known that a majority of our participants were nonadherent to exercises.

Regarding pain and fatigue, other studies have shown that disease burden is a highly significant barrier to adherence to preventive exercise programs in cancer patients.^{18,19} Our data also show that it is particularly difficult to persuade a patient to engage in a preventive regimen when they are already experiencing pain, fatigue or nausea, particularly when they are not yet experiencing dysphagia and may not recognize its significance. Finally, the problem of patient nonadherence to nearly all types of medical treatment regimens is significant. Depending on the type of health behavior, rates of adherence to medical recommendations range from 15 to 93%.¹⁶ One review found that patients correctly followed physician instructions about 30% of the time, and that 20–50% of all treatment appointments are missed.¹⁷

Limitations

Because our study is a secondary analysis, we did not measure adherence prospectively, but abstracted speech pathologists' documentation of adherence as patients progressed through radiation. Therefore because some information on patient adherence may have not been recorded in the medical record, our statistical power to detect significant differences was reduced and may have resulted in an overly conservative estimate of significant differences.

Conclusion

This is one of the first studies to report patient adherence rates to swallowing exercises based on speech pathologists' observations and its long-term effects on self-reported swallowing function in oropharynx cancer survivors. While likely effective in reducing the risk of long-term swallowing problems, adherence to swallowing exercises is difficult for patients to achieve. Future research should be directed toward effective strategies to ameliorate the barriers associated with nonadherence toward swallowing exercises during radiation.

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Figure 1.
Study Design

Figure 2.
Number of Exercises performed

Table 1**Demographics**

Age (Mean, Std Dev)	57, 9.5	
	No. of Patients	No. of Patients (%)
Male	95	(87)
Female	14	(13)
Race		
Hispanic White	10	(9)
Non Hispanic Black	1	(1)
Non Hispanic White	98	(90)
Education		
No HS diploma	7	(6)
HS /GED or technical/vocational degree	18	(16)
Some college or 2-year college degree	38	(35)
College degree	46	(42)
Marital/ partner status		
Lives alone	12	(11)
Lives with significant other	97	(89)
AJCC Stage		
I-II	9	(8)
III-IVb	100	(92)
T size		
1	32	(29)
2	39	(36)
3	19	(17)
4	19	(17)
Induction Chemo		
Yes	41	(38)
No	68	(62)
Concurrent Chemo		
Yes	56	(51)
No	53	(49)
Both Induction and Concurrent	23	(21)
TOTAL	109	

Abbreviations:

HS= High School

GED= Grade Equivalent Diploma

AJCC= American Joint Committee on Cancer

T size= Tumor size

Table 2

General Adherence Categories

Overall	No. of Patients	No. Patients (%)
Nonadherent	54	(55)
Partially		
Adherent	31	(32)
Fully Adherent	13	(13)
Total	98	(100)
<hr/>		
During Radiation	No. of Patients	No. Patients (%)
Nonadherent	38	(49)
Partially		
Adherent	28	(36)
Fully Adherent	12	(15)
Total	78	(100)

Table 3

Reasons for nonadherence to swallowing exercises

Reason	No. of Patients	No. of Patients (%)
There was no need since I did not have a swallowing problem	8	(22)
The exercises were hard to do, so I didn't do them	8	(22)
Kept forgetting	6	(16)
Pain	6	(16)
Fatigue and Nausea	4	(11)
My mouth had sores (mucositis)	4	(11)
Was too busy	2	(5)
Total Number of Participants (1 primary reason each)	38	

Table 4

Univariate Differences on MDADI Subscale Score

	Mean MDADI Subscale Score (SD)	<i>p-value</i>
Global		
Adherent	85 (25)	.05
Nonadherent	73 (27)	
Physical		
Adherent	79 (16)	.03
Nonadherent	70 (20)	
Emotional		
Adherent	87 (13)	.01
Nonadherent	78 (17)	
Functional		
Adherent	88 (13)	.009
Nonadherent	80 (18)	

Table 5

Multivariate Model For MDADI Physical Subscale Score-

Variable		Regression Coefficient	Standard Error	F Value	P Value
Intercept		60.3	14.6		<.0001
Adherence	Partial/Full Adherence	10.6	4.5	5.5	0.02
Gender	Male	-2.5	5.9	.2	0.68
T Size	T3/T4	7.4	4.5	2.7	0.10
Age at Radiation Treatment		0	0.2	.00	0.99
Concurrent Chemotherapy	Yes	1.1	4.9	.05	0.82
Feeding Tube	Did Not Use	8.9	4.8	3.4	0.07