# THE GHOSTLY PHENOMENON OF PHANTOM LARYNX IN TOTAL LARYNGECTOMY PATIENTS

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#### ABSTRACT

*Objective:* To determine the frequency of the phenomenon of phantom larynx in post total laryngectomy. *Study Design:* Descriptive cross section study.

*Place and Duration of Study:* Department of Otorhinolaryngology Head and Neck Surgery, Combined Military Hospitals Rawalpindi and Lahore from Sep 2015 to Aug 2016.

*Material and Methods:* A total of 51 patients were assessed at six months and 1-year interval of laryngectomy. A questionnaire containing six questions was presented at six months and one year to total laryngectomy patients. More than 4 positive responses indicated presence of phantom larynx phenomenon. The questionnaire assesses nasal airway and breathing, functions of larynx and adaptations after laryngectomy.

*Results:* All the patients were males. The Patients were divided in to two groups depending whether they were assessed at six months or at one year Patients varied in age from 48 years to 74 years. Mean age of patients was 62 years. Thirteen patients (81%) showed positive phantom larynx phenomenon at six months whereas eighteen patients (51%) showed positive phenomenon at one year after operation. Phantom larynx phenomenon was compared between two groups assessed at six months and one year. No significant difference in trends between the two groups was observed except for the question pertaining to straining while lifting (81% vs 68%).

*Conclusion:* In our study we identified phantom larynx phenomenon in post-operative patient's total laryngectomy patients. The phenomenon persisted strongly for six months while it was also found at one year postoperatively. It can result in lot of anxiety and even depression in laryngectomy patients which could greatly hamper rehabilitation process in these patients.

Keywords: Amputation of limb, Cortical reorganization, Laryngeal cancer, Phantom limb, Total laryngectomy.

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#### **INTRODUCTION**

Total laryngectomy (TL) is an important treatment option for advanced laryngeal and hypopharyngeal cancers<sup>1,2</sup>, resulting in a permanent tracheostomy and potential difficulties with a patient's speech, communication, and swallowing<sup>3</sup>. The "Phantom limb" phenomenon has been described after amputation of a limb or other parts of the body. Amputation or removal of any part is usually associated with a global feeling that the missing part is still present<sup>4</sup>. The interruption of the afferent input to the brain from the "external organs" is the cause<sup>5</sup>. Head and neck cancers cause a lot of psychological trauma. The stress starts at the time of diagnosis and affects the daily lives of the patient and the relatives. The anxiety symptoms increase over time<sup>6</sup>. Surgery of such head and neck cancers leads to significant anatomical, physiological, cosmetic, and psychological disturbances which greatly affects the quality of life of such patients7. Phantom phenomenon also adds to the psychological stress of the patients8. The rationale of our study is to establish the phenomenon of 'phantom larynx' in total laryngectomy patients which may cause anxiety and poor rehabilitation post surgically. Presently preoperative counseling does not include educating patients regarding this phenomenon which, if our study shows positive results, may help decrease anxiety and depression following the surgery and improve the quality-of-life of laryngectomy. There has

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been no clinical study locally or a mention in standard text books to include this phenomenon as a part of the pre- and post operative counseling of laryngectomy.

## PATIENTS AND METHODS

This descriptive cross sectional study was conducted at the department of Otorhinolaryngology, Head and Surgery, Combined Military Hospitals, Rawalpindi and Lahore. We used WHO calculator for sample size and included 51 patients that were evaluated at six months to one year after the operation from Sep 2015 to Aug 2016. Non probability consecutive sampling technique was used. Considering the impact of Specific responses proving the phantom phenomenon are written as 'yes' and 'no' for easy response for the patients (table-I). Most patients were followed in the outpatient department while some were contacted over the telephone and questions read from questionnaire and answered taken through near relatives. All patients fulfilling the prerequisite criteria were handed over questionnaire proforma after taking verbal informed consent in the language he/she understands i.e. in English and Urdu. In illiterates, the proforma was described by the doctor in the presence of the patient or over telephone. All patients who had undergone total laryngectomy in the past one year were

S. No.	Questions	Question pertains to	Phantom phenomenon considered if reply is
1	Do you try to speak spontaneously?	Intact larynx perception	Yes
2	Do you inadvertently try to cough out through the mouth?	Intact larynx perception	Yes
3	Do you inadvertently jump in water/take shower and have aspiration?	Intact larynx perception	Yes
4	Do you try to strain (can you strain while lifting heavy objects)?	Valsalva maneuver	Yes
5	Do you realize that you can continue to breath while you eat?	Post laryngectomy habituation	No
6	Can you flex your neck completely?	Post laryngectomy habituation	No

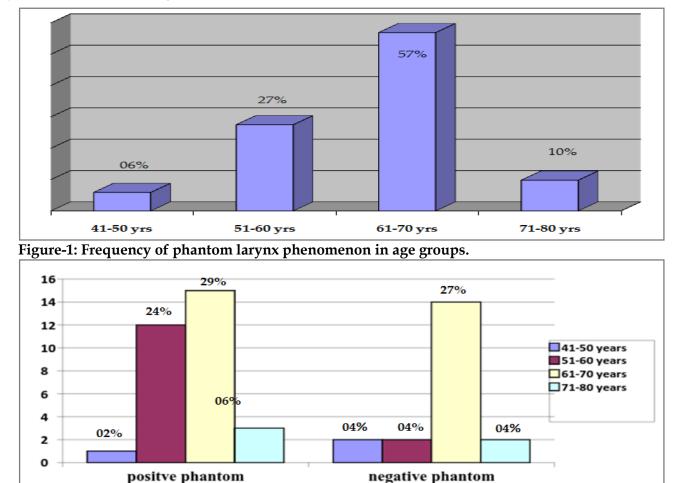
Table-I: Adopted phantom larynx questionnaire with explanation of relevant phantom association.

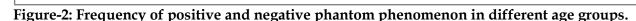
total laryngectomy on speech, communication and swallowing; a questionnaire containing 6 questions were presented to these patients. It pertains to changes in day to day activities like olfaction, coughing, sneezing, lifting, staining and swallowing etc, certain leisure activities like taking a shower or swimming become impossible tasks. The questionnaire therefore relates to nasal airway and breathing, functions of larynx and adaptations after laryngectomy. In the questionnaire first four questions deal with nasal and laryngeal functions and last two questions deal with the adaptation phenomenon so a 'yes 'response on first four questions and a 'no' response on last two questions were considered as positive responses to confirm the presence of phantom larynx phenomenon.

included in the study. Both sexes and age ranging from 30 to 80 years were included. Patients who had undergone voice preservation surgery like hemi-, partial-, near total laryngectomy and patients with mental illnesses like depression were excluded from the study. The data was entered in SPSS (version 21) software. Descriptive statistics were used to calculate qualitative and quantitative variables. For quantitative variable like age, mean ± SD were calculated. For qualitative variable like presence of phantom larynx phenomenon were measured as frequencies and percentages. Qualitative variable were presented as tables and charts. Effect modifiers like age and gender were controlled by stratification of data. Post stratification chi square test were applied.

## RESULTS

In this study, total 51 (all male) patients fulfilling the criteria were selected for survey. We divided 51 patients into two groups depending whether they were assessed at six months or at one year. Sixteen (31%) patients were assessed at six months and 35 (69%) patients were assessed at one year. The maximum age of patients was 74 years while minimum age of presentation was 48 menon at one year after surgery and 17(49%) were found negative for phantom phenomenon. Age wise stratification showed most positive result in age group 61-70 years followed by age group 51-60 years (fig-2). Chi square test was applied and a significant difference was seen in the phantom larynx phenomenon with *p*-value of 0.04 (table-II). The phenomenon of phantom larynx with respect to age was not significant





years. Mean age was 62 years. Age was divided into four groups in which group 61-70 years showed maximum cases 29 (57%) whereas age bracket 41-50 years showed minimum cases 3 (6%) (fig-1). Thirteen (81%) patients were found to have phantom phenomenon at six months where as three (19%) patients showed negative for phantom phenomenon. Eighteen (51%) patients were found positive for phantom phenowith *p*-value of 0.13. Phantom larynx phenomenon was compared between two groups assessed at six months and one year. No significant difference in trends between the two groups was observed except for the question pertaining to straining while lifting (81% vs 68%). Speaking spontaneously without stoma occlusion (100% vs 91%) and coughing through mouth (100% in both) were the most common phantom larynx phenomenon across the two groups. Phantom phenomena in breathing while eating (69% vs 51%) and complete neck flexion (62 vs 51%) were comparatively less appreciated in both groups (table-III).

# DISCUSSION

The "Phantom limb" phenomenon occurs after amputation of limb or any other part of the body<sup>9</sup>. The theory behind the development of a phantom organ is that if a part of the somatosensory cortex has no input, then the cortical map reorganizes itself in such a manner that the unaffected part of the cortex represents a different part of the body surface<sup>4,5</sup>. One study has characterized separate somatotopic represenanxiety, can present as social isolation, irritability, lack of appetite, vegetative symptoms, respiratory problems or sleep disorders<sup>21</sup>. One twenty five TL patients were evaluated in a study and many factors were identified to be the cause of anxiety and depression in TL patients including regret over loss of voice, worry regarding losing job and family support, fear of losing sexual relationship. The role of group therapy was demonstrated in the form of laryngectomy club to alleviate depression<sup>22</sup>. A study by Almonacid also demonstrated anxiety in 40 TL patients study. It was demonstrated that dependency is also a factor contributing in the postoperative anxiety whereas self sufficiency reduces it<sup>23</sup>. A

Table-II: Stratification of phantom larynx phenomenon with respect to time from operation (n=51).

Time from operation		Phantom larynx			Total			
		Yes		No		1 Otd1	<i>p</i> -value	
At 6 months		13 (25%)		03 (6%)		16 (31%)		
6 months to 1 year		18 (36%)		17 (33%)	17 (33%)		0.04	
Total		31 (6	(61%) 20 (39%		)	51 (100%)		
Table-III: Trends in two groups.								
S. No.	Questions		at 6	months	at 1 year		<i>p</i> -value	
1	Speak spontaneo	usly	16 (100%)		32 (91%)		0.227	
2	Cough through n	nouth	16	(100%)	35 (100%)		0.329	
3	Taking shower	14		(87%)		0 (86%)	0.863	
4	Strain while liftir	ıg	13	(81%)	24 (68%)		0.346	
5	Breath while eat		11	(69%)	18 (51%)		0.309	
6	Complete neck fl	exion	10	(62%)	18 (51%)		0.020	

tation of the larynx in the human motor cortex<sup>10</sup>. Patients describe Phantom phenomenon as tingling or painful sensations<sup>11</sup> or burning sensation<sup>12</sup>, illusion of that body part and visual hallucinations<sup>13</sup>. Phantom phenomenon have been seen after orchiectomy14, mastectomy15, tooth's root canal treatment<sup>16</sup>, penis amputation<sup>17</sup>, and ocular evisceration or enucleation<sup>18</sup>. TL is reserved for advanced tumors. It is a traumatic experience for the patient and brings out the feeling of vulnerability, sadness and fear which is a cause of great anxiety<sup>19</sup>. Support care is necessary after every head and neck surgery. Patients face a lot of coping difficulties in absence of supportive care which lead to lot of stress<sup>20</sup>. TL can provoke symptoms of depression and

recent study looked at cutaneous sensations of intact larynx following total laryngectomy. The study concluded that a phantom larynx phenomenon does appear to occur after total laryngectomy and as many as 69% patients either had a subjective sensation of phantom or a positive response to cutaneous stimulation<sup>24</sup>. In another study a questionnaire was used to detect the presence of phantom larynx in laryngectomy patients, as many as 25% patients thought they coughed through their mouth whereas 29% tried to talk spontaneously without stomal occlusion. 27% patients had water contact, 54% strained while lifting heavy objects, 43% breathed and ate simultaneously and 50% had neck flexion<sup>25</sup>. The presence of a phantom larynx phenomenon can

potentially be an important cause of delayed rehabilitation of these patients. It may also cause anxiety and depression among these patients. Current literature has evidence to suggest that phantom phenomenon leads to significant anxiety and depression and hence poor qualityof-life but it is not yet formed a part of our preoperative counseling process<sup>26</sup>. Our survey proves that phantom larynx phenomenon exists and it persists even after six months but it is most strongly felt by most patients within six months of the operation. Phantom phenomenon related to coughing through mouth was the most prevalent. Patients apparently put their hands to cover the mouth while coughing, which is in built reflex and they don't even realize that they are coughing through the stoma. The next most common phantom phenomenon is trying to speak spontaneously which is also an inbuilt reflex. Significant decline in trend was seen in the question pertaining to ability to realize that one cannot strain while lifting heavy objects. It's due to inability to maintain positive intrathoracic pressure. This physical inability causes patients to quickly learn to adapt. We believe that the low response on the last two questions is due to inability of the patient to completely understand these questions. Post laryngectomy habituation had a lower response due to lack of education in patients. Language barrier and various dialects made it difficult even in presence of translator in many cases. Phantom larynx is not completely described in literature. It has not been described in any local study. Recent strong evidences of PS in other organs have lead us to believe that this phenomenon exists in total laryngectomies too. Just as phantom limb phenomenon causes anxiety amongst amputee so we believe that phantom larynx phenomenon may also be a cause of delayed/difficult rehabilitation in total laryngectomies. We also believe that lack of education is a major contributor to phantom larynx in our country along with cortical reorganization. There is also lack of trend of having a proper counseling sessions with the patients. These sessions should be explaining the whole

surgical procedure with helping aids like diagrams and videos to the patients. We believe that educating patients regarding changes in day to day functions after surgery like breathing, coughing, speaking etc can greatly help us with the rehabilitation. The goal of any cancer surgery is not to treat but to effectively rehabilitate as well.

## CONCLUSION

In our study we identified phantom larynx phenomenon in post-operative patient's total laryngectomy patients. The phenomenon persisted strongly for six months while it was also found at one year postoperatively. It can result in lot of anxiety and even depression in laryngectomy patients which could greatly hamper rehabilitation process in these patients

## **CONFLICT OF INTEREST**

This study has no conflict of interest to declare by any author.

## REFERENCES

- Kierzek A, Paprocka-Borowicz M, Pozowski A, Kuciel-Lewandowska J. The first polish total laryngectomy. Contemp Oncol (Pozn) 2013; 17: 473-6.
- 2. Iseh K. Total laryngectomy for laryngeal cancer in a Nigerian tertiary health center: prognosis and outcome. J Surg Tech Case Rep 2011; 3: 23-30.
- 3. Noonan BJ, Hegarty J. The impact of total laryngectomy: the patient's perspective. Oncol Nurs Forum 2010; 37: 293-301.
- Pirokwska A, Wloch T, Nowobilski R, Plaszewski M, Hocini A, Menager D. Phantom phenomena and body scheme after limb amputation: A literature review. Neurol Neurochir Pol 2014; 48: 52-9.
- 5. Pereira JC Jr, Alves RC. The labeled-lines principle of the somatosensory physiology might explain the phantom limb phenomenon. Med Hypotheses 2011; 77: 853-6.
- 6. Aarstad AK, Besiland E, Aarstad HJ. Personality, choice of coping and T stage predict level of distress in head and neck cancer patients during follow-up. Eur Arch Otorhinolaryngol 2012; 269: 2121-8.
- Bussian C, Wollbrück D, Danker H, Herrmann E, Thiele A, Dietz A, et al. Mental health after laryngectomy and partial Laryngectomy: A comparative study. Eur Arch Otorhinolaryngol 2010; 267: 261-6.
- Sahu A, Sagar R, Sarkar S, Sagar S. Psychological effects of amputation: A review of studies from India. Ind Psychiatry J. 2016; 25(1): 4-10.
- 9. Sumitani M, Miyauchi S, Uematsu H, Yozu A, Otake Y, Yamada Y. Phantom limb pain originates from dysfunction of the primary motor cortex. Masui 2010; 59: 1364-9.
- 10. Browm S, Laird AR, Pfordresher PQ, Thelen SM, Turkeltaub P, Liotti M, et al. The somatotopy of speech: Phonation and articulation in the human motor cortex. Brain Cogn 2009; 70: 31-41.

- 11. Buonocore M. Where is hidden the ghost in phantom sensations? World J Clin Cases 2015; 3: 542–4.
- Schley MT, Wilms P, Toepfner S, Schaller HP, Schmelz M, Konrad CJ, et al. Painful and nonpainful phantom and stump sensations in acute traumatic amputees. J Trauma 2008; 65: 858-64.
- de Andrés C, Gil R, López L, Salinero E, Bittini A. Nonpainful phantom sensation, illusory limb movement in a patient with dorsal myelitis. Neuropathological and SPECT findings. J Neurol 2002; 249: 930-32.
- Pühse G, Wachsmuth JU, Kemper S, Husstedt IW, Kliesch S, Evers S. Phantom testis syndrome: prevalence, phenomenology and putative mechanisms. Int J Androl 2010; 33: 216–20.
- 15. Medina Jde M, Fabro EA, Amaral e Silva Bd, Thuler LC, Bergmann A. Frequency and associated factors of phantom breast syndrome in women submitted to mastectomy for breast cancer. Rev Bras Ginecol Obstet 2015; 37(9): 397-401.
- Clark GT. Persistent orodental pain, atypical odontalgia, and phantom tooth pain: when are they neuropathic disorders? J Calif Dent Assoc 2006; 34(8): 599-609.
- 17. Wade NJ, Finger S. Phantom penis: historical dimensions. J Hist Neurosci 2010; 19: 299-312.
- Hope-Stone L, Brown SL, Heimann H, Damato B, Salmon P. Phantom Eye Syndrome: Patient Experiences after Enucleation for Uveal Melanoma. Ophthalmology 2015; 122(8): 1585-90.
- 19. Semple CJ, Dunwoody L, Kernohan WG, McCaughan E. Development and evaluation of a problem-focused psyhosocial intervention for patients with head and neck cancer. Support

Care Cancer 2009; 17: 379-88.

- Moore KA, Ford PJ. I have quality of life but.": Exploring support needs important to quality of life in head and neck cancer. Eur J Oncol Nurs 2014; 18: 192-200.
- 21. Dooks P, McQuestion M, Goldstein D, Molassiotis A. Experiences of patients with laryngectomies as they reintegrate into their community. Support Care Cancer 2012; 20: 489-98.
- 22. Hirani I, Siddiqui AH, Muhammad Khyani IA. Apprehensions and problems after laryngectomy: Patients' perspective. J Pak Med Assoc 2015; 65: 1214-8.
- Almonacid CI, Ramos AJ, Rodríguez-Borrego MA. Level of anxiety versus self-care in the preoperative and postoperative periods of total laryngectomy patients. Rev Lat Am Enfermagem 2016; 24; e2707.
- 24. Mal RK, Baldwin DL. Phantom larynx: a clinical survey. Eur Arch Otorhinolaryngol 2009; 266: 397-401.
- 25. Chaturvedi P, Pawar PV, Syed S, Nair D, Dutta S, Chaukar D, et al. A clinical survey of laryngectomy patients to detect presence of the false perception of an intact larynx or the "phantom larynx" phenomenon. Indian J Med Paediatr Oncol 2013; 34: 3-7.
- 26. Kazemi H, Ghassemi S, Fereshtehnejad SM, Amini A, Kolivand PH, Doroudi T. Anxiety and depression in patients with amputate limbs suffering from phantom pain: A comparative study with non phantom chronic pain. Anxiety and Depression in Patients with Amputated Limbs Suffering from Phantom Pain: A Comparative Study with Non-Phantom Chronic PainInt J Prev Med 2013; 4: 218-25.

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