

## Apprehensions and problems after laryngectomy: Patients' perspective

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### Abstract

**Objectives:** To evaluate the apprehensions, social, sexual and financial problems in patients with advanced laryngeal cancer after total laryngectomy and the impact of attending laryngeal club on these problems.

**Methods:** The analytical study was conducted at the Dow Medical College and Civil Hospital Karachi from January 1996 to December 2011. Patients with total laryngectomy, operated for advanced laryngeal cancer at various centres of Sindh and Balochistan, attending Laryngeal Club of Pakistan, situated at Civil Hospital Karachi, were included. All the patients were evaluated through a questionnaire covering their apprehensions regarding social, sexual and financial impact on their lives after total laryngectomy. Data was analysed using SPSS 16.

**Result:** Of the 125 patients, 120(96%) were males, and 5(4%) were females; all housewives. The overall mean age was 54.8±0.5 years (range: 31-65 years). Further, 92(74%) participants were worried about financial uncertainty, while 84(67%) had regrets over loss of their voice; patients worried about losing family support and facing social rejection were 23(18%) and 15(12%) respectively. Only 7(5%) patients feared losing sexual relationship with their spouse. All these apprehensions were subdued after attending the Laryngeal Club of Pakistan. Severe financial impact was faced by 55(44%) patients due to loss of job, while 05(4%) had moderate impact due to change of job with lower income and 60(48%) patients had no financial problem. A good 102(82%) participants thought the support from their friends and family was upto their expectations; 98(78%) enjoyed satisfactory sex life although with reduced frequency of 1 to 2 intercourses per month; 21(17%) were having the frequency of 3-10 per month; and 3(2%) had more than 10 per month. Only 16(13%) patients were not involved in sexual relations with their spouses due to various reasons.

**Conclusion:** Majority of laryngectomised patients expressed apprehensions and showed some social problems after laryngectomy, especially in the initial phase which improved either with passage of time or after attending Laryngectomy Club. The main problem was financial constraints; majority had good friends and family support and enjoyed satisfactory sexual relationship with their spouse.

**Keywords:** Total laryngectomy, Apprehensions, Social problems, Financial problem, Sexual relations. (JPMA 65: 1214; 2015)

### Introduction

Psychological trauma in head and neck cancer is more pronounced compared to cancers of other sites. Any treatment modality especially the surgical treatment leads to a significant anatomical, physiological as well as cosmetic disturbances and cause a considerable psychological impact on quality of life of the patients.<sup>1,2</sup>

Relative survival of laryngeal cancer patients varies between 60% - 70% depending on sub-site involved, worst being the supraglottic laryngeal cancer which often requires total laryngectomy.<sup>3</sup>

Total Laryngectomy (TL) not only deprives the patient from breathing through natural channel, but also takes away the basic mean of communication i.e. phonation and verbal speech. However, along with impact on voice,

other domains such as psycho-social, financial and sexual elements should not be under-estimated. All these areas should be taken care of during preoperative assessment, counselling, care during treatment and, most importantly, postoperative rehabilitation.<sup>4</sup>

In our setup, majority of healthcare providers pay attention to voice restoration and speech development. They hardly bother about the psycho-social and financial aspects of life. The word cancer itself and its prolonged treatment phase due to repeated hospital visits and admission considerably interferes with routine work, job, social life and everyday activities of not only the sufferer but his family as well. This hindrance definitely leads to psychological and financial stresses which lead to social disturbances.<sup>5,6</sup> Therefore, unlike some other cancer surgeries, the patients with TL often require a life-time rehabilitation through reasonably adequate friends and family support, provision of trained and skilled rehabilitation staff and also an efficient communication between the patient, his family and healthcare providers as well as other patients with similar status. All these can

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enhance the chances of patient's satisfaction and a successful re-entry into family dynamics along with reasonably acceptable social and sexual activity.<sup>7</sup>

The rationale of the current study was to provide a baseline to formulate guidelines for counselling of laryngectomised patients and their families in order to help them to promote normal family life.

The study was planned to evaluate the apprehensions, social, sexual and financial problems in patients with advanced laryngeal cancer after TL and the impact of attending laryngeal club on these problems.

### Subjects and Methods

The analytical study was carried out at the Department of Ear Nose Throat (ENT)-Head & Neck Surgery, Dow Medical College (DMC) and Civil Hospital Karachi (CHK) from January 1996 to December 2011, and comprised TL patients who regularly attended the Laryngectomy Club of Pakistan. Patients with partial laryngectomy, those who visited the club less than once a month and with whom it was found difficult to develop doctor-patient relationship were excluded.

After becoming a member of the club, the patients started to attend the Laryngeal Club from 06weeks after the surgery, but there was no time bar for induction in the study. Laryngeal Club of Pakistan is situated in the Department of ENT-Head & Neck Surgery, CHK. It provides a platform for laryngectomised patients to discuss their problems and share experiences with other alaryngeal patients of similar status. It also gives an opportunity to learn oesophageal speech by trained speech therapist and also to consult doctors for regular follow-up. The club is supervised by a senior doctor of the department.

A standardised questionnaire was developed to collect the data regarding the problems of alaryngeal patients. The information was acquired regarding anxiety and fears about the problems due to financial uncertainty, loss of

voice, loss of family support, social rejection, loss of sexual relation with spouse and cosmetic disfigurement. Patients were also inquired about their post-operative job status, sexual relationship with spouse and continuation of family support up to their expectation. The level of anxiety was assessed using generalised anxiety disorder 7-item (GAD-7) Scale, from mild to severe.

The information gathered by interviewing the patient and their attendants was according to patient's perspective and recorded on a propforma approved by the institutional ethical and review committee. The comparison in improvement in fear and apprehensions among the same group of patients was made at 6 months and 1 year interval after attending the club. The data was analysed by applying McNemar test for statistical significance.

### Results

Of the 125 patients, 120(96%) were males and 5(4%) were female; the male-to-female ratio of 25:1. The overall mean age was 54.8±0.5 years (range: 31-65 years) (Table-1).

Further, 92(74%) participants were worried about financial uncertainty, while 84(67%) had regrets over loss of their voice; patients worried about losing family support and facing social rejection were 23(18%) and 15(12%) respectively. Seven (5%) patients feared losing

**Table-1:** Demographic Data (n=125).

<b>Gender</b>	
Male	120 (96%)
Female	05 (04%)
<b>Age</b>	
Maximum	65 years
Minimum	31 years
Mean	54.8 years (± 0.5)
<b>Job Status</b>	
Employed before surgery	120 (96%)
Unemployed before surgery	05 (04%)

**Table-2:** Apprehensions.

Types Of Apprehensions / Regrets	Before Attending Laryngeal Club	06 Months After Attending The Club		01 Year After Attending The Club	
	n	n	P-value	n	P-value
Anxiety	125	70	<0.001	10	0.002
Financial uncertainty	92	38	0.635	31	0.91
Loss of voice	84	36	0.649	15	0.001
Loss of family support	23	11	<0.001	02	<0.001
Social rejection	15	Nil	<0.001	Nil	<0.001
Relationship problem with spouse	07	Nil	<0.001	Nil	<0.001
Cosmetic reasons	01	Nil	<0.001	Nil	<0.001

**Table-3:** Job status after total laryngectomy (n=120).

Retain same Job	60	50%
Change of Job	05	4.16%
Jobless	55	45.83%
<b>Financial Impact</b>		
Severe	55	45.83%
Mild to Moderate	05	4.16%
Nil	60	50%
<b>Reason For Loss of Job</b>		
Loss of voice	35	29.16%
Weakness	05	4.16%
Family Support / Retirement	15	12.5%

**Table-4:** Sexual behaviour.

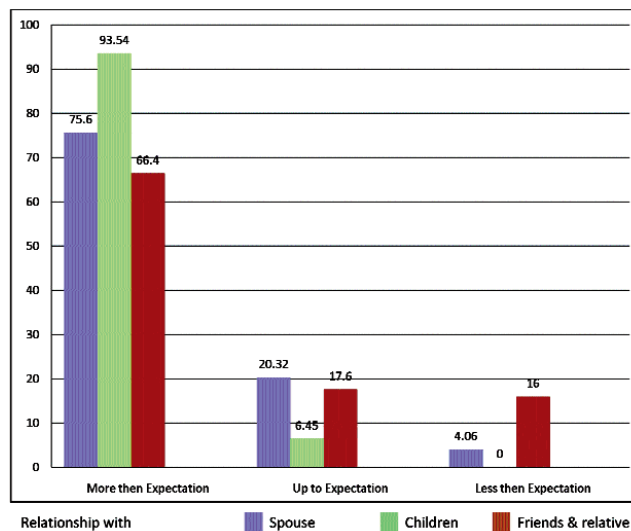
<b>Frequency of Intercourse</b>		
No Inter course	16	12.8%
1-2 months	74	59.2%
3-10 months	21	16.8%
>10 / months	03	2.4%
<b>Main Reasons For Decreased Intercourse</b>		
Old age	53	42.4%
Loss of libido	31	24.8%
Non cooperative spouse	3	2.4%
General weakness	5	4%
Co morbidity	6	4.8%
Breathlessness	3	2.4%
Widow / Widowed / Divorced	11	8%

sexual relationship with their spouse. Only 1(0.8%) patient was worried about post-operative cosmetic disfigurement. The effect of Laryngeal Club was statistically insignificant ( $p>0.05$ ) on sense of financial uncertainty after 06 months and one year, while the change in regrets about the loss of voice was statistically insignificant ( $p>0.05$ ) after the first six months, but it became significant after one year ( $p<0.05$ ). Mostly the apprehensions were diluted to an extent after 06 months of attending the club. The impact of these apprehensions and regrets reduced markedly after one year (Table-2).

All the 120(96%) male patients were either self-employed or employed before surgery while all the 5(4%) females were housewives. Among the males, 60(50%) retained the same job after recovery from surgery, 55(45.8%) became jobless due to various reasons and 5(4.16%) had to change their job due to certain implications (Table-3).

Consequently, severe financial impact was faced in 55(45.8%) cases. Mild to moderate impact was observed in 05(4.2%) cases, while 60(50%) had no financial problem in the post-laryngectomy periods.

A good 102(82%) participants thought the support from

**Figure:** Social Relationship after Laryngectomy (figures displayed in percentages).

their friends and family was upto their expectations. Spouses of 2(1.6%) patients expired before surgery and 1(0.8%) patient did not have children. Out of the remaining 124(99%) cases, 116(93.5%) had excellent to good support from their children (Figure).

Of the total, 98(78%) enjoyed satisfactory sex life although with reduced frequency of 1 to 2 intercourses per month; 21(17%) were having the frequency of 3-10 per month; and 3(2%) had more than 10 per month. Only 16(13%) patients were not involved in sexual relations with their spouses due to various reasons (Table-4).

## Discussion

Laryngeal cancer is a life-threatening disease, and entails highly stressful sequence of events from diagnosis to treatment and then to rehabilitation, especially for patients suffering from head and neck cancer. These patients have to face the immense post-treatment challenges not only in terms of physical disability such as eating, swallowing or speaking problems, but also the cosmetic disfigurement, forcing them to readjust their lifestyle and, hence, leading to a greater degree of distress and social problems as compared to the patients with cancers of other regions.<sup>8,9</sup>

Among other head and neck cancers, laryngeal malignancy has the best overall survival rate, but the prolonged morbidity and associated problems following total laryngectomy puts a negative impact on routine life.<sup>3</sup> Therefore, the need for a comprehensive rehabilitation has become even greater with the increased survival rate of patients

with laryngeal cancer.<sup>2,10</sup>

Rehabilitation following TL is difficult. Most healthcare providers usually perceive loss of voice, disfigurement, altered swallowing and altered energy levels as the most relevant issues in postoperative period, but attention should also be given towards anxiety and depressive symptoms. The patient's social readjustment, participation in recreational activities and return to normal sexual functioning are important but often neglected postoperative issues.<sup>7,8,11,12</sup>

Formal psychological treatment could be of benefit in the management of these patients.<sup>6</sup> Social and medical support are important factors in improving patients self-confidence and satisfaction. Speech rehabilitation and psychological support plays a crucial role in their re-entry in the society with acceptable quality of life.<sup>7</sup>

Anxiety and depression are usual emotional reactions which may arise in patients with the diagnosis of cancer. It is also important to consider the aetiology of head and neck cancer which is primarily related to the use of tobacco and alcohol. Quitting the habits may lead to withdrawal symptoms. These factors further aggravate and interfere with treatment and rehabilitation process. Therefore all healthcare providers must be aware of the potential problems related to such substance abuse and their tendency to develop withdrawal symptoms.<sup>9</sup>

In present study, majority of the participants were worried about a variety of issues related to their disease and post-treatment problems which may lead to anxiety and depression. All these apprehensions were allayed to an extent after 06 months of attending the Laryngectomy Club. These apprehensions were reduced markedly after one year of attending the club. Reported studies also observed improvement in anxiety and depression as greater the time elapsed since treatment.<sup>13,14</sup>

This study also reflects the financial problems faced by patients. Only 50% of the patients were able to retain their jobs with insignificant financial impact, but 48.8% of the patients became jobless after surgery mainly due to loss of voice. Although, loss of voice in laryngectomised patients was the major factor in loss of their job, generally they did not consider it as reason for any hindrance in their day to day routines. Voice handicap is reported to be a problem, but not predictive of overall quality of life.<sup>15</sup>

In the present study, most of our patients had a comprehensive family support and excellent relations with their spouses, children, friends and other relatives. These findings strongly favour combined family dynamics of Muslim community. In contrast a Western study found

that most common social problems encountered by head and neck cancer patients are limited family or social support system, limited financial resource and significant stress level for patients and family as unit.<sup>16</sup>

Another very important social issue is of sexual activities in the post-treatment period. A study highlighted that more than half of the patients reported reduced libido and sexual enjoyment after treatment. They observed that sexual difficulties were unrelated with gender, formal education, alcohol or tobacco consumption, type of surgery, radiotherapy and tumour site. They associated the sexual problem with depression.<sup>12</sup> In our study we found decreased but persistent sexual activity among these patients and main reason for that apart from old age was loss of libido due to a variety of reasons.

Decreased frequency of sexual activity is noted in laryngectomised patients. A pleasurable sexual activity is very much dependent upon the response of both the partners. Lack of sexual desire on the part of patient's spouse may also lead to decreased frequency. A study suggested that intervention should be offered to couples besides individual counselling to achieve better quality of their relationship.<sup>17</sup> Another study also reported the negative affect of laryngectomy on sexual activity.<sup>8</sup>

Rehabilitation of laryngeal cancer patients depends on an integrated effort between the healthcare providers worked as unit, as no single quarter can do it alone.<sup>9,18,19</sup> It is important to establish short-term goals that are easily attainable along with long-term goals according to the disease process, treatment options and the changing needs of patients over the time.

Screening for distress and depression is important at the time of follow-up visits with the surgeons or oncologists to identify patients with psychological, social or sexual concerns along with their physical problems. The identification of psychosocial problems at this stage can provide an opportunity to refer the case for psychological counselling if needed.<sup>2,9,18,19</sup>

In a number of studies, researchers emphasised the need for a comprehensive psycho-social support of cancer patient and their families taking into account the prevalence of psycho social problems and psychiatric disturbances observed among them.<sup>2,10,19-23</sup>

Despite all these facts, the matter of prime concern is that in most of the Third World countries, there is a poor infrastructure and lack of appropriate treatment facilities at most centres, which lead to poor survival rates. Hence, more emphasis is placed in attaining disability adjusted quantity of life years rather than quality of life.<sup>24</sup>

In addition, the priorities of state health department is mainly focused on communicable diseases (e.g. tuberculosis, malaria, dengue, and polio etc.), malnutrition and diarrhoea in children and women health.<sup>23</sup> The priority in laryngeal cancer particularly and in any cancer generally, is just to improve the patients' survival and quantity of years postoperatively. The quality of life and rehabilitation is often ignored. The Laryngeal Club at our set up is an effort to provide useful platform for interaction and sharing the experiences in alaryngeal patients and to provide opportunity for regular follow-up. Close interaction with senior doctors not only help them to solve their routine health problems, but are also beneficial in addressing their apprehensions and social issues.

### Conclusion

Apprehensions, financial and sexual issues in laryngectomised patients have significant impact on their postoperative life in our society. Laryngectomy Club serves as a useful platform to interact and share experiences among the people with similar status. Regular attendance at the club could help the patient recover from depression and lead a better life. Conducive environment, regular meeting and provision of recreational activities would markedly allay the apprehension of laryngectomised patients. The pivotal role of government funding backed by NGO support for smooth functioning of Laryngectomy Club cannot be over-emphasised.

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