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Voice Disorders and Their Psychosocial Impact on Laryngeal Cancer Patients and Their Families: A Case of Kenyatta National Hospital, Nairobi City County– Kenya

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Abstract: Voice disorders after treatment of laryngeal cancer are usually high ranging from dysphonia to a laryngeal voice. Presence of these disorders not only poses myriad challenges in communication but also contributes to emotional distress which can create psychological problems among patients and their caregivers. The objective of this study was to establish the voice disorders and their psychological impact on the laryngeal cancer patients and their families at the Ear, Nose and Throat clinic; Kenyatta National Hospital – Nairobi City, County-Kenya. This study was anchored on Psychological Impact Theory based on the estimation of the psychological consequences of an action on individual or specific social units. The research used a case study design adopting qualitative research methods. A target population of thirty respondents including fifteen adult laryngeal cancer patients purposively sampled from the ENT clinic of Kenyatta National Hospital, Nairobi County- Kenya and fifteen family members were involved in the study Data was collected using interview schedules administered to the patients, observation checklists administered to both patients and family members and focus group discussions carried out with family members/caregivers. The data was transcribed, organized, edited, coded and sorted for thematic analysis. Patterns across data sets consistent with the theoretical tradition of the study were pinpointed, examined and recorded to answer specific research questions. The key study findings were that the family members were not happy with the patients' condition as they struggled to communicate. Anxiety levels among the patients as well as family members increased as well. There were reduced levels of confidence hence low self-esteem among the patients. In conclusion, voice disorders after laryngeal cancer treatment are a source of psychological challenges thus the need for early intervention involving both patients and family members for effective results. The study recommends increased public awareness on voice disorders and availability of speech therapy services for effective rehabilitation for both patients and family members/caregivers after laryngeal cancer treatment.

Keywords: Voice Disorders, Laryngeal Cancer Patients, Psychological

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INTRODUCTION

1.1Background of the study

Communication disorder is defined as an impairment affecting the reception, sending, processing and even comprehending concepts. The concepts can be presented verbally, non-verbally or in graphic symbol systems. This disorder can manifest in an individual's speech, language and/or hearing. ⁷define speech as the utterance of language verbally and consider it disordered when voice, articulation or fluency is affected. Voice disorders are inappropriate variance in quality, pitch and loudness contrary to the expectations in terms of gender, age, cultural background and geographical location¹. Therefore, individuals suffering voice disorders may be troubled by the sound of their voices sound whereas their listeners may experience difficulty in understanding them. It is important to highlight the fact that voice is not just a tool for communication, but also a feature for identification that allows expression of personality hence the presence of a voice disorder can affect an individual's personality and subject one to negative psychologicaleffect.

According to ⁸, laryngeal cancer which is a variety of Head and Neck Cancer (HNC) forms in tissues of the larynx traditionally referred to as the voice box. This is the area of the throat containing the vocal cords and coordinates voice production, swallowing and breathing. ⁴ confirms the fact that head and neck region supports many fundamental physiologic functions such as voice production among others hence presence of cancer in this area impact critical structures and functions. The patients' psychological, social and physical well-being is generally affected by the severe limitations that various treatment options impact on the functions

of the affected organs. One such impact is alteration in the function of vocal cords necessary for phonation and verbal speech due to (chemo) radiotherapy [(C) RT]² and laryngectomy as modes of treatment. ² express the fact that although there is confirmed improvement in health related quality of life of patients following improved voice function post treatment, there is a limitation on the number of studies specifically on the associated impact of voice disorders on the psychological well-being of patients post laryngeal cancer treatment. This study therefore seeks to fill this gap by focusing on voice disorders and their psychologicalimpact on laryngeal cancer patients and their families.

1.1.1Voice Disorders

Voice means production of recognizable speech sounds through the coordination of the lungs (breathing for speech), larynx, vocal chords and the nasal passage. The abnormal production of these speech sounds or absence of vocal quality, pitch, resonation, loudness and duration which is not suitable for an individual's age or sex indicates presence of a voice disorder. Concur with this view by observing that an individual has a voice disorder when the quality, loudness and pitch of voice have a significant difference or are not appropriate for the gender, age, cultural background or geographical location.

According to⁸, voice disorders can be classified as organic, functional or psychogenic. This study focused on organic voice disorders which are further divided into structural or neurogenic disorders ¹⁷. Focusing on laryngeal cancer patients narrows the scope further to structural voice disorders due to physical changes in the voice mechanism due to the various modes of treatment adopted to cure the laryngeal cancer that can affect vocal fold function or result in total removal of the voice box referred to as total laryngectomy (TL). Development of a voice disorder is secondary to a primary pathology which may be medical as in the case of laryngeal cancer or a change in the structure of laryngeal anatomy. Change in the vocal folds alter their flexibility hence affect the vibratory patterns thus altering vocal quality, pitch and loudness.

There are a few studies on impact of voice disorders on quality of life of patients. A study by ¹⁴ carried out in Ireland-focusing on impact of voice disorders on quality of life of twelvelaryngectomies revealed that various patients face functional difficulties as measured by quality–of–life instruments. These functional difficulties include challenges in voice production and quality, eating, drinking, breathing and kissing ⁶. The challenges thus cause significant changes in the psychological, social and emotional domains for the patient and family. Whereas ¹⁴ have addressed general functional difficulties including challenges in voice production, this study narrowed down and sought in-depth knowledge specifically on the voice disorders and their psychologicalimpact on laryngeal cancer patients and their families.

Another study was done in Sweden by² involving one hundred and sixty three patients with Tis-T4 laryngeal cancer treated with (chemo) radiotherapy at Sahlgrenska University Hospital. The authors used Hospital Anxiety and Depression Scale to confirmthe prevalence of distress after laryngeal cancer treatment specifically regarding voice rehabilitation after laryngeal cancer and the associated effects on psychological well-being of the patient. ² based their findings on a quality of life instrument (Hospital Anxiety and Depression Scale) whereas this study based its findings on qualitative data giving in-depth knowledge and reflection of patients' feelings.⁵ link severity of dysphonia as seen in laryngeal cancer patients who opt for organ preservation modes of treatment such as radiation and chemotherapy without surgery [(C)RT] as candidates of psychological distress hence exhibit emotional disturbance, poor quality of life, inability to express themselves efficiently and unexplained medical symptoms. It is therefore important not to underestimate the impact of voice disorders on the psychological domains of all laryngeal cancer patients in order to provide comprehensive care in post-treatment rehabilitation. 9in a study conducted in China analyzed the effect of voice disorders on everyday activities. The study involved 40 respondents suffering partial voice loss (dysphonia) and 40 respondents with normal voices as control group. It was evident from this study that dysphonic patients significantly demonstrated serious limitations due to the voice problems in their daily activities. The study further proved that the dysphonic subjects' perception of a voice problem positively correlated with their perception of restricted participation and limitation in voice activities. It is therefore clear that patients suffering voice disorders risk social malfunctioning. Such individuals can have both serious psychological and physical complications due to inability to exercise, enjoy a family outing or participate in any social activity without restriction. Nevertheless, ¹⁶ describe such patients as non-assertive, self- restraint and anxious concerning

everyday lifestyle.

19 acknowledges the significance of communication as a human right and raises concern that the needs of people with communication disorders may not be met in low and middle-income countries due to varied limitations and barriers. In East Africa, disability is still linked with stigma. Families with disabled members especially those with communication disorders face serious challenges. Some of these patients are hidden simply because neighbors will not tolerate them. Most families consider communication disorders a curse hence unbearable reflection on them. This state of affairs has been fueled by ignorance and a feeling of helplessness. It is therefore a fact that psychological and emotional stress result from presence of disabilities hence the need for more research in this area.

In Kenya, laryngeal cancer is the third most common cancer at the Ear, Nose and Throat-Head and Neck Surgery Unit of the Kenyatta National Hospital. Alcohol ingestion and cigarette smoking have been identified as strong risk factors for development of not only late stage but also poor differentiation of laryngeal squamous cell carcinoma in Kenyan population¹¹. Kenya Medical Research Institute (KEMRI) report 70% of Kenyan families as alcohol abusers with ages ranging between 15 to 65 years. In addition, 17% of men smoke tobacco with a worrying median age of first use as low as 10years. This means a higher percentage of the active population is at risk of laryngeal cancer exposing them to organic voice disorders.

Although available data on voice disorders in Kenya is sparse, ¹⁰ acknowledges an increase in the number of laryngectomees to a total of 60 by the year 2017. Combined with the steady rise in cancer cases as expressed by ¹⁵ pointing to probable increase in laryngeal cancer cases, many patients continually struggle with voice disorders posing myriad psychological challenges that impact not only on them but their families as well.

Surprisingly, barely any study has been conducted not only in Kenya but the whole of East Africa on psychological impact of voice disorders on patients hence the need for this study on voice disorders and their psychologicalimpact on laryngeal cancer patients and their families at the ENT clinic of Kenyatta National Hospital-Nairobi, Kenya.

1.2Statement of the problem

Voice disorders after treatment of laryngeal cancer are usually high ranging from dysphonia to alaryngeal voice. Laryngeal cancers are listed as the 22nd in incidence of all cancers worldwide with 5.1 percent of the patients surviving with laryngectomy hence alaryngeal voice in communication¹³. ¹³record that a total number of 210,606 new cases of larynx cancer have been diagnosed in 2017 alone translating to 2.76 new cases per 100,000 inhabitants worldwide. This raises concern coupled with the fact that the major risk factors for laryngeal cancer include among others cigarette smoking and alcohol abuse contributing for about 30-60 percent of the overall mortality.

Presence of these voice disorders contributes to the patients' emotional distress which is likely to create psychological problems and personality effects. Emotional distress poses challenges not only to the patient but also to family members who closely interact with the patient on a daily basis. Unfortunately, in Kenya, many people are seemingly ignorant of the impact of the voice disorders on quality of life of laryngeal cancer patients hence some get scared of them, laugh at them or make derogatory comments concerning their condition. In addition, family members may fail to give necessary support such patients need in the process of speaking. Such experiences may cause negative psychological effect.

In consideration of the great need for comprehensive understanding of the impact of voice disorders on patients post laryngeal cancer treatment in Kenya, this study sought to establish the voice disorders and their psychological impact on these patients and their families as an essential guide to effective rehabilitation, optimizing patient psychological health and general function.

1.3Objectives of the study

The objective of the study was to establish the voice disorders and their psychological impact on the laryngeal cancer patients and their families at Kenyatta National Hospital (ENT clinic).

1.4 Significance of the study

The findings of this study on voice disorders and the psychologicalimpacton laryngeal cancer patients and their families at Kenyatta National Hospital (ENT clinic) may: benefit policy makers, speech therapists, psychologists, otolaryngologists, laryngeal cancer patients and their family members; be a source of awareness to the general public on the impact of voice disorders hence need to avoid risk factors.; be an essential guide for optimal and effective rehabilitation; and contribute significant literature for scholarly work in this area of study for global comparison.

METHODOLOGY

2.1 Area of study

This study was carried out at the ENT clinic of Kenyatta National Hospital in Nairobi County, Kenya. It's a referral hospital with equipped Ear, Nose and Throat (ENT) clinic for diagnosis and treatment of laryngeal cancer. This study focused on adult laryngeal cancer patients with voice disorders who come for post-treatment clinical monitoring and support. The researcher found the hospital appropriate for the study being the largest teaching and referral hospital in Kenya. In addition, the hospital has the largest number of laryngeal cancer patients in Kenya.

2.2Research design

This study adopted a case study research design. This design suits this study because it involves study in real life setting in line with ²⁰ recommending case study research designs for real life context studies. Due to reliance on respondents sharing their personal experiences, the researcher used qualitative research methods of direct observation, focus group discussions and interviews to collect data from respondents. Direct observation, focus group discussions and interviews enabled the researcher attain in-depth knowledge on the concept. Qualitative research is recommended especially when collecting data on people's attitudes, opinions, habits or social issues²⁰. This study explored attitudes, personal opinions, habits and consequent impact on both parties, that is, the patient with the voice disorder and the family.

2.3Population and Sampling design

The total target population was sixty (60) comprising fifteen (30) adult laryngeal cancer patients and fifteen (30) family members. The laryngeal cancer patients with voice disorders at least three months post-treatment from KNH – Kenya- ENT clinic were selected. One family member who was a spouse, off-spring or caregiver for each laryngeal cancer patient was included. The patients were targeted as they are the ones directly affected by the voice disorder hence provided relevant data to establish psychological impact of the condition on them. The family members were targeted because they are the closest to the patients interacting on a daily basis.

The study used purposive sampling to enable the researcher get the fifteen laryngeal cancer patients and fifteen family members who provided the relevant data at Kenyatta National Hospital- Kenya – ENT clinic. Inclusion criteria involved laryngeal cancer patients at least three months post treatment and having aphonia, dysphonia or using alaryngeal voice in communication. The patients sampled were adults of 20 years and above. Family members included spouses, off-springs or caregivers of the patients. Exclusion criteria involved other HNC cases that may result in voice disorders. The sample also excluded laryngeal cancer patients with an earlier psychological diagnosis as this may have influenced the findings of the study. The respondents were expected to provide rich data for this study.

2.4 Data collection

Primary data was collected using interview schedules, observation checklist, and focus group discussions and the data was recorded through writing. Interview schedules were used to collect data from key informants (the laryngeal cancer patients) at the ENT clinic at Kenyatta National Hospital. The researcher sought to establish the psychological impact of the voice disorder on the patients. This instrument was used to: facilitate high response quality as it allows the researcher to clarify to the patient the questions for better understanding; and enable the researcher to collect rich data as it allows recording of non-verbal cues such as patients' nervousness, eye contact and posture among others.

Observation checklist was filled as the researcher interacted with the patient and family member or caregiver at the ENT clinic at Kenyatta National Hospital. Observation involves systematic description of events and behaviors in the social setting through watching and recording as they occur. This instrument sought to establish the psychological impact of the voice disorders on the patient and family. This instrument was used: to enhance collection of richly detailed data through viewing and recording relevant unscheduled events; and to enable the researcher explain existing situations using senses³.

Focus group discussions were used to collect data from family members (spouses, off-springs or caregivers). The researcher divided the 15 family members into two groups; one having 7 and the other 8 members. The researcher believed that a group of 7-10 participants was effective for efficient communication. This instrument was used to establishparticipant's views on the psychological impact of the voice disorders onthe patients and family members at the KNH (ENT clinic). It enabled the researcher to solicit in-depth information from personal and group feelings of family members; and encouraged interactions with participants. It also allowed multiple narratives to be voiced in one session.

2.5 Data analysis

³ refer to the process of data analysis as systematic searching and arrangement of data collected in a study. Data was analyzed qualitatively in this study. The data collected from observation check lists, interview schedules and focus group discussions was transcribed, organized, edited, coded and sorted for thematic analysis. Patterns across data sets consistent with the theoretical tradition of the study were pinpointed, examined and recorded to answer specific research questions.

Data Analysis and Discussions

3.1Background characteristics of the laryngeal cancer patients

The patient's background characteristics included sex, age, marital status and occupation. Out of the 15 patients interviewed and observed 13 (86.67%) were males while only two (13.33%) were females. Thus most of the patients were males. In regard to the age of the patients, the mean age of the patients was 62 years, with the youngest being 46 years and the oldest 71 years. Hence, all the patients interviewed and observed were adults. On the marital status of the patients, 14 (93.33%) of the patients were married while only one (6.67%) was widowed. Thus majority of the patients are married. The occupation of the patients shows that the patients who were into peasant farming were five (33.33%), while four (26.67%) were into farming only with three (20.00%) practicing business and farming. Hence, most 12 (80.00%) of the patients were into farming either in isolation or with other activities irrespective of the extent of their farming activities be it peasant or large scale.

3.2Types of voice disorders among the patients

The different voice disorders among the interviewed patients at KNH ENT department, shows that six (40.00%) of the patients had alaryngeal, five (33.33%) had dysphonia, while four (26.67%) had aphonia.

3.3Psychological impact of the voice disorders on the laryngeal cancer patients and families

In an attempt to establish the psychological impact of the voice disorders, table 3.1 isolates the researchers' findings from observation on the psychological impact of voice disorders on the patients and their families. The table shows that 80% (mean of 0.8) of the patients and families experienced sadness, concurring with findings by²¹ in Brazil that showed that a patient requiring special care such as those with voice disorders have a higher probability of influencing the environmental and emotional aspects of others in the family. It was further noted from the FGD that family members were not happy with the patients' voice condition and wished it was reversible or would get better with time. In addition, 60% of the patients were tense as a result of the voice disorder especially at initiating verbal communication.

Table 3.1: Psychological impact of voice disorders on patients and families

Variable	Obs	Mean	Std. Dev.	Min	Max
Sad	15	0.8	0.414039	0	1
Calm	15	0.6667	0.48795	0	1
Tense	15	0.6	0.507093	0	1
Restless	15	0.3333	0.48795	0	1
Relaxed	15	0.2	0.414039	0	1
Нарру	15	0.1333	0.351866	0	1

The researcher observed that most of the patients when faced with the challenge of initiating verbal communication fidgeted on chair, had a tense facial expression, avoided eye contact, over-manipulated the lips, had dilation of pupils, frowned and kept rubbing hands together. These are key indicators of the patient struggling to communicate verbally hence a source of stress. Freported earlier that the presence of voice disorders such as severe dysphonic voices increased the patients inability to express themselves. This leads to considerable functional restrictions triggering stress to the patient. The above restrictions can therefore be linked to psychological distress.

From the FGD, it was revealed that the family members get stressed too in the case of misunderstanding the patient's attempts at verbal communication. A caregiver confessed that:

"Stress levels have increased especially when one fails to understand the patient in the process of verbal communication".

The findings conform to those in a study done in Sweden by² which confirmed prevalence of distress after laryngeal cancer treatment specifically regarding voice rehabilitation after laryngeal cancer. In addition, from the Focus Group Discussions, it was clear that worry and fear affected the family members more when the patient was out unaccompanied. The family members got worried of the patient's safety whereas the patients in most cases relied on caregiver for safety. Worry and fear are strong indicators of anxiety hence justifying the fact that anxiety levels went up when the patients were out unaccompanied. Anxiety was also noted among some patients based on how people reacted when they spoke. This seemed to hinder their confidence in participating in many outdoor activities as stated by one of the patients:

"My condition has interfered with my participation in church activities since many people frown at the quality of my voice causing me a lot of anxiety."

One respondent, a matatu driver admitted his limitations at work due to the voice condition. He admitted that he could not shout nor engage with colleagues well in a noisy environment hence feeling like quitting the job. He further says that sometimes he feels others want to exploit him due to his voice condition. Similar findings were reported by 18 who stated that the direct effect of the voice disorder on speech puts the patients at risk of being ignored, laughed at or exploited at place of work. Consequently, such a patient may become depressed, anxious and develop low-self-esteem. 16 also agree that such patients are usually selfrestrained and anxious in everyday lifestyle.

The interviews revealed that some cultural perspectives considered patients with voice disorders as cursed, which supports the findings by¹² who established that most families consider communication disorders a curse hence unbearable reflection on them. Similar perspectives included patients or their families believing that they are paying for a wrong thing they had done or viewing the condition as a punishment from God. Such beliefs affect not only the patient but the family as well exposing them to distress and negative psychological effects.

CONCLUSIONS AND RECOMMENDATIONS

4.1Conclusions

The study resulted in the following three major conclusions: Firstly, presence of voice disorders made the patients have limited verbal interactions, lose many friends and the families became unusually quiet in the effort to provide a conducive atmosphere for them. It was also concluded that there was an over-reliance of the patient on family member/caregiver. In addition, it was noted that the patients depended on family members for assistance in verbal communication; their goals in life changed and standard of life lowered; the family expectations also dropped in some cases. The family members also admitted reduced levels of daily social interactions as the patient is limited in verbal communication. This brings to light the fact that severity in voice disorders as seen in laryngeal cancer patients makes them candidates of psychological distress ⁵. Furthermore, the patients were generally sad as well as family members confessing being unhappy about the patients' conditions. Moreover, the patients' struggle at initiating verbal communicational led to functional restrictions triggering psychological distress.

Looking at ⁹ analysis of the effect of voice disorders on everyday activities, they concluded that such patients risk social malfunctioning just as seen in heightened anxiety levels due to people's reactions to the patients' voice in this study. This leads to lack of confidence among the patients and family members in engaging in verbal communication in social settings. In addition, this led to lower self-esteem among the patients. Avoidance of such engagements by family members led to withdrawal of the patients and stress.

Thirdly, it came out clearly that both family members and the patients had many aspects of negative coping strategies. For instance, failure to engage the patients in verbal communication in social settings caused the patients to withdraw brewing stress. This finding provides a link to Jochmann and Ossietzky (2005) finding that in East Africa, some patients with communication disorders are even hidden because neighbors will not tolerate them. 12 also recorded the high levels of stigma that is linked to disability in the same region. Some of the patients totally avoided social settings and meeting new people among other negative coping strategies. Tension exhibited by most patients at initiating verbal communication caused them both physical and psychological strain. In addition, venting of anger on family members when the patient is frustrated caused a rift in the family affecting relationships.

4.2 Recommendations

By investigating the voice disorders and their psychological impact on the laryngeal cancer patients and their families the study seeks to enlighten the clinicians of the myriad sources of patient challenges hence the need for a multidisciplinary approach in treatment and rehabilitation plan for these patients. Moreover, finding out the coping behavior developed by the laryngeal cancer patient and family in verbal communication provides an important platform upon which speech therapists can focus as they draft their various intervention plans.

The following recommendations are based on the findings of the study.

- Need for increased public awareness on voice disorders after laryngeal cancer treatment, functional limitations and the psychological effect it has on the patient and family.
- Inclusion of stakeholders in recommending, financing and following up on multi-disciplinary approach in the support and intervention needs of laryngeal cancer patients and families.
- Need for the Ministry of Health to engage more speech therapists in hospitals to facilitate effective early intervention for laryngeal cancer patients and families in regard to communication and elimination of negative psychological effect for both patient and family members.

Taking the limitations and delimitations of the study, the following areas were suggested for further research

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- i). Further research should be done focusing on willingness of family members to be involved in the intervention plan for rehabilitation of laryngeal cancer patients with voice disorders. The speech therapists may be willing to work with the family members/caregivers but they may not be consistent, serious and willing to engage in the rehabilitation process.
- ii). Further research should also be done using other designs other than a case study design.

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