

Permanent Tracheostomy Care and social Stigma in Nigeria

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Abstract- Lifesaving therapies may sometimes require the surgical removal or interference with a normal body structure that is obvious to the people in the immediate social environment. These may elicit some unsavory reaction, from people around, causing adverse psychological effects on the patients concerned. Permanent tracheostomy is one of such surgical procedures; though intended to be life-saving, may end up being a permanent disability. Permanent tracheostomy is done for patients with permanent recurrent laryngeal nerve damage post-thyroidectomy, post-laryngectomy (due to oropharyngeal cancer), head and neck trauma and some neck cancers. Due to the small percentage of surgical, hospital attending patients needing tracheostomy, the special concerns of these patients have been easily overlooked. These group of patients have peculiar problems managing the tracheostomy, starting from prolonged hospital stay, and multiple hospital admission both contributing to their cost burden. Few publications have been done in our environment on the psychological impact on adults and children who end up with this surgery as in other climes. Outside the initial Problems of negative attitude of immediate family, speech difficulty and nonavailability of tracheostomy tube parts to enhance speech; Social stigmatization is a source of grave concern, which requires concerted efforts at rehabilitation and social re-integration. The travails of the permanent tracheostomy patient is mitigated, not only by highly skilled and specialized medical care; but also by advocacy groups for such a minority ailment: unlike sickle cell, hypertension, and diabetes that over time have become familiar to the populace. Advocacy groups can help in ensuring availability of tracheostomy accessories to aid speech, thereby making the tracheostomy patient attractive in the community and aiding meaningful social integration. This would make them a voice for the “voiceless”; to mitigate the effects of stigmatization and discrimination in the Nigerian society.

Keywords: Permanent Tracheostomy, post tracheostomy care, Stigmatisation, Social integration

Introduction

Lifesaving therapies may sometimes require the surgical removal or interference with normal body structure that is obvious to the people in the immediate social environment. These may elicit some unsavory reaction, from people around, causing adverse psychological effects on the patients concerned. Permanent tracheostomy or limb amputation or permanent colostomy are examples of such surgical therapies. Tracheostomy is done in people with difficult breathing due to obstruction of the upper part of the respiratory system which may necessitate a bypass lower down in the respiratory tract for air to get to the lungs. Though this is largely a temporary and lifesaving procedure, it may become permanent in some medical conditions. These include permanent recurrent laryngeal nerve damage post-thyroidectomy, post-laryngectomy (due to oropharyngeal cancer), head and neck trauma and some neck cancers.¹

In New Zealand and Australia about 7000 people require tracheostomy annually Some of which may end up with permanent tracheostomy.² In the United States, the figures may be up to 1000.³ The number that end up with permanent tracheostomy is unknown because patients are categorized by medical diagnosis and not as tracheostomies Besides tracheostomies are done as emergencies without the consent of the individuals concerned; but from relations. In Nigeria, there is paucity of figures.⁴ Because most of the existing literature address the clinical scenario surrounding urgent lifesaving tracheostomies, little attention has been given to the peculiar challenges of patients with long standing tracheostomies.^{5,6,7} At best, attention has been given to challenges encountered by patients and relations when transitioning

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from hospital to home environments.⁸ Few publications have been done in our environment on the psychological impact on adults and children who end up with this surgery as in other climes.⁹ Problems encountered may include negative attitude of immediate family, speech difficulty and nonavailability of tracheostomy tube parts to enhance speech. It is important the products are designed to meet the special needs of this group of persons. Social stigmatization as a result of these problems also requires concerted efforts at rehabilitation and social re-integration. This article seeks to address these concerns as it relates to a Nigerian patient on permanent tracheostomy.

Discussion

Tracheostomy is a lifesaving surgical procedure done for upper airway obstruction described as far back as the first century¹⁰This was done when other ways like endotracheal intubation has failed. Current approaches like cricothyrotomy and percutaneous dilatation tracheostomy which can be done at bedside are preferred options in acute airway obstruction, while surgical tracheostomy is taken as a last resort.^{11,12,13}Tracheostomy is immense benefit to tracheobronchial toileting and prolonged mechanical ventilation.^{11,12,14,15}

In the past the commonest causes of upper airway obstruction were infections of the airway in children; though this is no longer so with improved clinical care and production of effective newer generation antibiotics.^{11,12,16} The change in trend heralded the emergence of trauma related causes in the adult population in the 21st century.¹⁷ Head and neck trauma increases the risk of upper airway obstruction especially in high velocity injuries like RTA and gunshot.

Head and neck tumors, and surgeries like laryngectomy are other common requirements for permanent tracheostomy. Of these post thyroidectomy nerve injuries seem to feature less commonly due to improved modalities of treatment and care.¹⁸ ¹⁹ Because tracheostomy is mostly a lifesaving surgery, most relations of patients are not averse to it. Besides patient who have problems requiring tracheostomy wake up see themselves in the state literally unprepared for, hoping it would be for a short time. The problems with phonation creates initial anxieties that can be assuaged with speaking aides like temporary blockers or valves. In patients with total laryngectomy, external devices, oesophageal speech and internal voice prostheses and surgically created tracheo-oesophageal fistula are some of the methods used to overcome this disability.²⁰ For others, some types of tracheostomy tubes with speaking valves have been tried with a degree of success, thereby easing anxiety in this group of patients.

The reality of tracheostomy being permanent creates new sets of emotions in patients and relations as it is seen to surely attract stigmatization and discrimination in their immediate community. This makes patients not desire early discharge from the hospital, thereby incurring more hospital bills which they may find difficult to pay, in the absence of comprehensive health insurance in our environment. Management of the tracheostomy with suction machine, both manual and electric is cumbersome and difficult for the patients and care givers to learn. Also of great concern is the expectoration of mucus from the site in which may be a source of embarrassment, making patients and relations desire to live in isolation.²¹ Frequent visits to the hospital may be necessary until care givers are able to manage the care of the tubes on their own for longer periods of time, thereby reducing frequent hospital visits

Stigmatization in Nigerian culture

Nigeria has over 250 ethnic groups with divergent cultures with two major religions Christianity and Islam; a third being traditional religion among other minor ones.²² Among the different tribes, physical and health challenges are associated with myths and taboos that are not restricted to rural dwellers; but find expression among the average urban dwellers.

The presence of tracheostomy tube in the neck of a patient attracts a negative response from the society, limiting social interaction and causing embarrassment. Stigma is negative attitudes and beliefs about people living in a community. It is the prejudice that comes with labeling an individual as part of a group that is believed to be socially unacceptable. While stigma refers to an attitude or belief, discrimination is the behaviors that result from those attitudes or beliefs; treating people with permanent tracheostomy with pity or being seen as abnormal and unacceptable to society. These may affect the individual concerned, affecting their emotional and mental wellbeing. People living with permanent tracheostomy may internalize the stigma they experience and begin to develop a negative self-image. And a feeling of being discriminated against, feeling of shame and isolation by patients and relations.²³

Stigmatization and discrimination against people with specific ailments is well established in different community settings creating a negative impact on quality of life. These lead to prejudicial actions from family, colleagues, health care providers, employers, communities and sometimes government

Economic elements

Prolonged hospital stay and repeated hospital visits has economic consequences in our environment where patients pay out of pocket. The economic impact may even be more significant; as some with jobs may lose them and those seeking jobs suffer some disadvantage on very obvious health grounds. Employers sometimes are afraid of litigation in the event of an adverse health incident. Due to the practice of alms giving common to both religions tracheostomy patients may sometimes take advantage of this to collect alms in the streets, as they become an object of public pity.^{24, 25}

Legislation and legal elements

World Health organisation 2011 disability report suggest that at least 25million Nigerians have a disability. These persons face stigmatization and discriminatory challenges, for which the law enacted in 2017 by the Nigerian government imposes sanctions for those who contravene it. By this law, a commission set up by government ensures access to housing, education and healthcare

Presently in Nigeria, there are no laws, addressing the needs of tracheostomy patients in particular. This may be due to the sheer low number of these group of persons in our society. The right to live a good quality life, where the norm is the survival of the fittest. The laws that protect the physically challenged may be applicable but does not specifically address the peculiar rights of permanent tracheostomy patients.²⁶

Solution

To prevent the embarrassment created by the sight of tracheostomy, a number of costumes can be designed to cover both the tape and the tube. These could be made of different colours to match the dressing of the individual. Golden or silver neck laces could also be used in place of usual silk tapes.¹ Different brands of tubes ranging from silver, plastic or silicone are available for long term adult use. They usually come as double lumen tubes for ease of cleaning and disinfection. Daily physical activities like speech, can be helped by finger occlusion and speech valves. Swallowing may occasionally be a challenge, but can be overcome by appropriate choice of meals suitable to the individual.²¹ Other accessories useful to the patient are humidifiers and nebulisers.

There are restriction to activities like swimming, riding on motorbikes and other activities that can obstruct the stoma or provoke coughing. Tracheostomies are also easier to manage in warm humid weather than dry cold weather due to easy crust formation and blockage in dry, cold and windy environment.²¹

Psychotherapy

Self- appreciation and the state, and accepting to live with the tracheostomy the disease causing it. The services of a clinical psychologist or Psychiatrist can be employed to help improve the self- image of both family and relations.

Public enlightenment

Low level of public enlightenment which may be responsible for the negative societal perception and response to such patients. Public enlightenment on radio, television, and other media tools, could create a positive attitude and acceptance of these group of persons

Formation of dedicated support group.

Hospital can form support groups, and provide a safe environment and forum for social interaction among tracheostomy patients, encouraging them to improve their self-image

Internet groups. These days internet groups help patients and relations cope with stress of stigmatization. It provides a wide forum for patients and relation to identification and re-integration in society

Non-governmental organisations(NGOs) .NGOs play a vital role in helping to express their personal challenges and solicit government support, finance, legislation and laws to improve their quality of life through TV and radio programmes.

Employment. Issues of employment, though easily resolved, can be handled well when they come together in groups. This can be further aided by the intervention of NGOs and advocacy groups, for employment in government and private institutions

Summary

The travails of the permanent tracheostomy patient is mitigated, not only by highly skilled and specialized medical care; but also by advocacy groups for such a minority ailment: unlike sickle cell, hypertension, and diabetes that over time have become familiar to the populace. Advocacy groups can help in ensuring availability of tracheostomy accessories to aid speech, thereby making the tracheostomy patient attractive in the community and aiding meaningful social integration. This would make them a voice for the “voiceless”; to mitigate the effects of stigmatization and discrimination in the Nigerian society.

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